West Virginia University – Center for Excellence in Disabilities (WVU-CED) December Grand Grounds Tuesday, December 1, 2017 2:00 p.m. – 3:00 p.m.

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- >> Lesley Cottrell: All right. Can everyone hear me?
- >> Yes.
- >> Lesley Cottrell: All right. So, thanks, everyone, for joining us on our December Ability Grand Rounds for the CED. Just before we introduce our speaker today, I wanted to do some housekeeping really quickly. So, on the top right of your screen you should have things like participants, chat, notes, closed captioning -- we do have closed captioning available today. And that will be going. So, if you want to click that, you'll be able to follow along with the presentation if you want.

You're able to take notes and save them to your private desktop without anyone seeing. That's the other piece. Chats come in handy if -- we usually save questions until it the last few 15 minutes of the hour. And so, if you want to ask those questions during Dr. Ellison's presentation, then we will go back to those and use that as another way to look at the questions. And then finally, if you're curious and you want to know who else is joining us today, you can go to the

participants.

I do encourage everyone to mute your phones if you have the ability just to avoid some background noise during the presentation.

And like I said, the first 45 minutes we'll ask Dr. Ellison to present and then save questions to the end. Okay?

So, with that, I want to introduce Dr. Ellison. And I'm really happy that he joined us today because he's the executive director of the West Virginia Autism Training Center at Marshall University. We worked closely with him, Marshall University, the autism training Center and the University. And it's great to hear about the collaboration today and the work being done down there. I'm also a little biased because it's one of my alma maters. So, I think it's a great place.

So just a little bit more about Dr. Ellison. He's a licensed professional counselor who has worked nearly 35 years to provide person-centered support, and advocacy to those living with autism spectrum disorder, their families and those who support them. A member of the autism society of America's panel of professional advisers and a member of the board of autism for West Virginia. He was in effective -- with autism spectrum disorder and authored or co-authored several publications specific to the support of those diagnosed with ASD. So, we're lucky. We're lucky to have him presenting his work and telling us a little bit about the center and then his research. With that, I'll turn it over to you, Dr. Ellison, and let me know if you need anything.

>> Marc Ellison: I want to make sure, first, everyone can hear

me okay. I presume, Lesley, you'll tell me if you can't. I want to turn my volume down just a little bit, I'm getting some feedback. I appreciate we only have an hour. And that we want to save the last 15 minutes for questions. So, I'm going to probably end up rushing through some things. I carved out information for today's presentation from a three-hour presentation that I do.

I'm really interested, right now, in sex-based presentation differences. In large part because I think that women with autism are often misdiagnosed. And those women who are pretty highly independent who have autism, diagnosed or not, often go to talk therapists for support as opposed to title 19 waiver providers or things like that And I think that talk therapist, counselors or psychologists really sometimes are -- sometimes may miss some of the more subtle aspects of autism as they experience it.

So, this is in part from a training I did for licensed professional counselors a few months ago. Very quickly, I want to make sure we talk just a little bit about what to expect. Because we have folks from all over the state, I want to make sure we talk a little bit about the autism training center and our scope of service and the process for referral. We've changed a lot in the last two or three years, and I'm going to highlight some of those. We want to talk about the DSM five diagnostic criteria to see how women may be experiencing that differently. We have to understand some of the basic aspects that have diagnostic criteria. So, we'll touch on that before we get into the women-specific information.

I also want to talk a little bit about some emerging theories that

might explain the differences. And I'm partial to one in particular I'm going to have some videos that will hopefully highlight or illustrate some of the points I'm trying to make. And you should know that in each of these videos, the individual that is talking is diagnosed with autism. And to note, as you can see on the screen there, I cobbled this presentation together with some help from other licensed professional counselors or provisionally licensed counselors who I work with at the autism Training Center. The Autism Training Center is a statewide autism services and direct services center. I want to highlight a few things you may not be aware of.

The first is we're, in the technical assistance aspect of our work, we maintain and house the autism spectrum disorders registry. You may not know that autism is a mandatory reportable condition in the state. So, any clinical psychologist or medical doctor that makes a diagnosis is obligated by law to report that to the registry. If you didn't know that, the form for how to do that is on the training center for the West Virginia Autism Training Center website. And you can simply go there, download the one-page form, and the instructions are there and how to do those. It's a very simple process.

But we do house that. Another thing I want to mention is that, on the technical assistance piece, we do a significant amount, these days, of school consultations. And we started this past year with our first of what will be annual autism across the life span conference. I've had a dream for years of having a life span conference that's patterned in large part after the Teach conference in North Carolina which I participated in several times and we did that this past year and

I think it was really successful.

We do a significant amount of work in collaboration with the Department of Education. We do teacher academies across the state. Multi-day intense trainings on evidence-based teaching strategies for kids with autism. And we carry out schoolwide and early childhood positive intervention and supports programs across the state. And we're really proud of that. That just started being built about four years ago. And we've worked pretty intensely with about 185 schools through the schoolwide PBIS, and we've done training for over 400 early childhood professionals in a couple of years. So, we're very proud of that program.

The direct services is probably the portion of our agency that's changed quite a bit. In the last year we've developed a multidisciplinary diagnostic and assessment clinic on campus. We can only do that part-time. It's a very insignificant amount of time that we can devote to that because we have pulled in OTs and PTs and speech folks and psychology people from across different aspects of the university. And everybody's time is limited.

And the first year we simply could only do that one day a month. I'm hoping that in 2018 we can increase that somewhat. We have the college program for students with autism spectrum disorder. We were the first university in the country to develop a program specifically on campus for students with autism. And we've since -- since 2002 when we started -- we've since helped about 20, 25 universities across the country develop similar programs. And we support on campus anywhere between 50 and 60 students each

semester who are diagnosed with autism and getting traditional, typical degrees. They're just getting tremendous supports from us. A lot of mentoring.

Really proud of that program. Since 2002, between 93 and 94% of all the students who have been enrolled in our program have graduated. And some of you who are familiar with us may know a program that we used to do called Family-Focused Positive Behavior Support. That doesn't exist as a program anymore. We spent the last year and a half, two years, trying to figure out how to get rid of a wait list, frankly. What the program did, and did well, was take about 100 families a year through a 10-month process. So, if you were the 101st family, you immediately had a 10-month wait to get services. And over 25 years, that wait grew and grew. And we had quite a long wait list.

So, what we've done over the last year and a half is developed services in tier--based services. So, level 1 services would involve a lot of educational things, identification cards, access to our lending library and training videos. Level 2, regional coaching sessions. Which we're really -- we did -- we reached about 1500 people in 2017 through -- in 25 counties -- doing different coaching sessions and skills groups. And parent cohorts. One of the things we started was a co-heart in different regions for parents of newly diagnosed children.

And then level 3 is really what people may know as our family-focused peer support. That would be a level where folks would, based on assessments, need behavior support plans and more intensive services. The referral process for us can be fairly simple

now. You must be a West Virginia resident. One of the misconceptions about us is that -- is that you have to be a child. But we serve any age. We had someone just in his 60s who was recently diagnosed who signed up for some supports from us.

You must have a clinical diagnosis. And that's one area where a lot of folks misunderstand what we need. We get a lot of folks -- a lot of evaluations from different people besides a clinical psychologist or a medical doctor. And our state mandate requires it be a clinical evaluation. Services are free except the college program, which is a fee-based program, and some specific school-base consultations. And hope you can write down the contact information for Kelley Preston, who is our intake coordinator. Email or telephone there would start the referral process.

And when we're talking about individuals with autism, I want to make sure that I say that although there are diagnostic aspects and characteristics that are — that everyone with autism must share as part of the diagnosis, how they share it may be different. And there's an adage in the autism community that gets spoken quite a bit that if you have met one person with autism, you have met one person with autism. And I need you to be thoughtful of that as we discuss things. I want to make sure that I don't make sweeping generalizations. And I want to make sure that I highlight several times here that individuals' experience characteristics and symptoms sometimes in didn't ways and varying ways.

So, I think that, in terms of talking about autism, one of the things I like to talk to teachers about -- and I'm often surprised that it's

a -- that it's an issue that we talk about -- is that autism spectrum disorder is a neural developmental disorder. It's not a behavior disorder like oppositional behavior or things that are willful kinds of disruptive behavior. And neurodevelopmental, of course, are associated with the brain and the neurological system. And those disorders, and autism, of course, is one, affects a person's emotions, memory, ability to learn, socialize, and maintain some self-control.

We go through the diagnostic criteria from the DSM-5. It's pretty controversial for the last few years about whether the -- whether DSM made things better or made things worse. And I'll leave that up to individual diagnostician. I like it better. But that may be me. Can requires a persistent across -- and can be manifested in a variety of ways and the DSM gives lots of examples. But those are consistent deficits that must be there.

And restricted repetitive patterns of behavior or activities. And, again, that can be manifested in lots of different ways. One of the best examples that audiences always get is that if I give a person with what used to be described as PDDNOS or autistic disorder ten match boxcars and tell them to go play, very often that person's going to go to someplace on the periphery and line up the cars. And just keep lining them up. Making sure they're symmetrical. Give the kid with what used to be called Asperger's disorder, the same ten match boxcars, what you might end up with is a 30-minute monologue about Matchbox cars. Or an essay about the cars or they get online and read about them. Those are the same kind of things, just expressed differently in different people.

Symptoms have to be present in the early developmental period. You don't wake up on a Tuesday when you're 8 and suddenly have the diagnostic symptoms of autism. And they have to cause clinically significant impairment in social occupational, other important areas of functioning. And I may say this a couple of times, but I'm going to say it here. There is no such thing as a mild form of autism. I hear that phrase a lot. And I think it does a real disservice to people with autism. Because what it then becomes is, well, he's got a mild form of autism. But to have a diagnosis of autism, you must have a significant impairment in those areas. So, there's a minimal threshold that someone must meet in order to do it. And the most independent person with autism that I know has significant impairment in those areas.

And I recognize that people use those terms to try to draw a distinction between individuals that are more challenges or more independent, I get that. But I think the use of the word "Mild form of" sometimes lends itself to folks who are more independent being ridiculed or they believe that they can do better if they tried harder. And this is the slide I often use to make the point that I just made. Which is that the concept of a spectrum, and the autism spectrum disorder, isn't a left or right linear kind of spectrum. It is that the -- the concept is individual. That folks who have a diagnosis of autism have persistent significant deficits in all the same areas.

But how those characteristics or symptoms are expressed or lived with are different for each people and sometimes different on different days perhaps. But they all must meet a minimum threshold.

And then, individually, they may be experienced in different ways over time.

And as you probably know now, severity levels for autism have been developed. Level 3 is the -- it requires the most substantial report. Really severe deficits in social communication and very inflexible kind of interests and repetitive behavior. The most substantial report is level 3. And then level 2 is market deficits and flexibility mostly. Frequently enough that it's -- that it's of concern. But to a lesser degree than 3. And then level 1 is requiring support in those areas. And I think level 1 would be more along the lines what have used to be called Asperger's disorder.

I pulled some red flags off a circular that's often sent to pediatricians and threw this up here because these are the common published red flags that are often considered by diagnosticians.

Reduced interest in social interaction, a lack of eye contact, unusual prosody near the bottom. But I have some real differences of opinion about some of those. I have put those in bold italics there to the right.

For instance, I think that instead of reduced interest in social interaction, what might be more appropriate is that there's an impairment in social interaction. Many people with autism I know have an interest in social interaction. And sometimes they have a heightened interest in social interaction. But there's always an impairment. Whether that is somebody being incredibly isolated or spending too much time with someone. I used to work with her in our college days, in our program, we had a young man from Alabama what came to summer classes. In those days, it was almost bar baric.

Summer school was four days long and there were four to five hour classes at a time. They were awful.

And he met a woman and they struck up a friendship that morning. And he spent -- he spent literally the next three days with her. In a platonic way. But he ate every meal with her, he slept on the floor of her dorm room, he went to -- he went to every class with her. Every single aspect of this was -- social interaction -- was with her. Until she couldn't take it anymore. And called her boyfriend and had him come and tell the guy to leave her alone. But the point is, he didn't have a reduced interest, but he certainly did have an impairment in social interaction. And the same goes for lack of eye contact. I see that lots of folks actually have eye contact even that is -- that is too much. And especially, I think, kids who are going through skill-building programs who learn eye contact still often have socially inappropriate eye gaze.

And to me, that's much more along the lines of whether -- it's not a lack of eye contact, but socially appropriate eye gaze is, I think, more accurate. The use of communication rather than the development of is probably something that, instead of an impairment in communication, I think they're often ought to be a distinction to make sure that people understand that sometimes incredibly articulate people are often using scripts that they've filed away somewhere to pull out in a certain time. Even though they sound very, very articulate and even impromptu, they're often scripts that have been pulled out for use in that moment.

And to further dissect some of these red flags, I think that not --

that some of those are not necessarily accurate for females especially. And we'll talk a lot about those as we move forward. Especially the reduced interest in social interaction, the eye contact, the lack of showing gestures, repetitive behavior and restricted interests. We're going to talk about all of those as we go forward. But those, I think, are becoming much more recognized as not always being accurate with women.

And this is -- the next couple of pictures are pictures that I chose that I often use just to very quickly kind of illustrate kind of what I'm talking about. I say that with full knowledge that these are snapshots of a second in the lives of these folks. But I think they make the point, at least for me. These are three young boys who are diagnosed with autism. And if you look very closely at that picture, you see that each child is kind of focused in on his own thing. There's not a lot of social interaction. There's almost -- at least in that picture -- just a complete absence of thought of the next person. Even the body postures are kind of odd.

You see the kid on the far left in the blue shirt has his arm kind of torqued up odd, you know, which is often something that you -- you don't normally sit that way. And usually it suggests some kind of sensory issue. And the child in the middle, his -- always reminds me of the concept of theory of mind, which we'll talk about in a second, where he's really just focused on his own comfort. That's not the typical posture of a 10-year-old kid who is fully aware that other people are making judgments about them.

And the other aspect is, they're all sitting on the left side of the

bench. There's an entire half of a bench to the right side that nobody's focused on. And in our world -- in our culture -- the hidden curriculum that is that you don't sit close to people on a bench. About nine out of every ten people find that to be really taboo. And there's a striking distance -- striking difference, I think, in affect between those boys and these girls. All of whom, again, are diagnosed with autism. You see much more of a difference in affect. You see significant difference in social connection.

I get a sense that some of these girls are trying really hard to demonstrate something that may not be intuitive or may not feel very natural to them. But they recognize the need to do that. And they've -- they've seen how selfies are perhaps done and they're doing those things. So, a real difference of -- I think in that presentation.

We'll talk for a few minutes about some of the characteristics I think that boys' and girls' kind of share challenges with. And these are the things that I think are of significant issue to -- for people to understand about autism. Significant problems with executive functions, with challenges of social communication, social skill deficits, communication itself and challenges related to theory of mind. And I think those things individually and combined create lots of -- lots of issues in day-to-day life. They alienate people sometimes who might be part of a social network. Lead to day-to-day stress and daily challenges regardless of what your abilities are. They often lead to behavior difficulties.

And they cause a lot of misunderstandings and even legal

issues for some people. And the first thing I want to talk about a little bit is executive functions. And, of course, if you know executive functions, you know, those are cognitions that help us do these things. They help us organize our time and manage it, they help us with reflection and meta cognition. They -- these are the things that help us self-regulate and be flexible and have some type of self-monitoring aspect of our lives. And folks with attention deficit disorder, for example, and individuals are autism are often very challenged in executive functions.

I think lots of times this is one of the reasons that you see kids with autism in school who -- who are level 1 or Asperger's disorder, maybe they're in middle school and they go to school with their homework in their bag, and the teacher calls up for homework to be turned in and the student just kind of freezes and doesn't turn in the homework.

Perhaps it's the transition of doing something and then doing something else, or perhaps it's the anxiety that comes with, oh, my gosh, they're going to review my homework. But often they just kind of become frozen and don't turn it in. I know lots of people who experience that. Those issues, to me, are really about -- really getting down to executive functions.

And I have a couple of videos that I want to suggest are really about executive function. This is a young boy who, you know, for years in the 30-plus years I've spent working with people with autism, I have often asked people, tell me what it's like to live with autism. And through the '80s, '90s, 2000s, it was hard to hear from people. What

that's like. This young man, at 5 or 6, is describing how he is living with autism in ways that are just magical. He has a speech impediment. So, he's talking about his brain when he says "bwain.". He's been at a birthday party. You will hear the noises in the background. And he's trying very hard to stay in control.

- >> My brain started it. My brain always starts it first. All the time. So that's why me and -- don't get along too good.
 - >> What's your brain do?
- >> He don't -- my brain won't -- my brain does not let me say the words I always need to tell you and daddy. That's why me and my brain -- that's why I have a bad day with my brain.
 - >> You do?
 - >> Yes.
- >> And this happens at -- if that happens at party, whenever we leave party, then it's going to be bad. You know? I'm going to punch it like 100 times and kick him 100 times. You know, like keep on -- one in between. Yeah, I'm going to do those on my brain.
- >> Marc Ellison: Now, just for -- because we don't have a lot of time, I'm going to cut that short. He goes on to describe it. It's remarkable that he's able to describe what he feels like doing -- or in his word, his brain is telling him to do -- and that he's struggling to not do those things. Also, I think that this self-regulation issue is really affected by executive functions. I think lots of people recognize this experience. And I'm going to cut it short too. But it'll go for a few seconds.

[crying and screaming]

>> Mom! No.

>> Marc Ellison: Now, that's not a young girl who is angry or didn't get what she wanted or who's having a meltdown because she's spoiled. That's a young girl who can't regulate the stress or the sensory problems or whatever it is that she's feeling internally. And as the video goes further, she ends up pulling her mother into her tighter because that -- that compression helps her recover and helps her calm down.

Another really important thing I think, especially with women, is understanding what theory of mind is. And theory of mind is essentially the recognition and understanding that people have beliefs and intentions and knowledge that I don't have. And to understand that people are making judgments about us. They're constantly assessing us, making judgments about us. Able to project into the mind of other people. Understanding that other people are having different intentions.

And in typical theory of mind development, young children -- and I think people go -- tend to go through theory of mind milestones or development around the age of 3 or so. But here's a typical -- neurotypical young man who still has not yet gone through theory of mind. And you can see how that plays out with the researcher.

>> So here was our idea. Suppose you take something very basic about what you like and I like. Food we like. Something even babies know about. So, we set up a situation in which the other person is expressing, telling the child, their desires, likes and wants are different from those of the child. And the question is, can the child

use that information to make an inference about what my mental state is, even when that mental state is different from their own. Watch. Watch. Look. Ewww! Yuck. Ewww. I tasted the crackers. Ewww! Yuck! I tasted the crackers. Mm. Broccoli.

Mm. Looks good. I tasted the broccoli. Now, Simon, could you give me some? Can I have some?

>> Very good. Thank you.

>> Marc Ellison: Yeah. Every time. Every time he's going to give her the goldfish because he likes the goldfish. And if he likes the goldfish, everyone must like the goldfish. And I think individuals with autism who struggle with theory of mind experience -- experience the world sometimes in very similar ways. If I have information that I know, and you must know it too, and therefore I don't have to share that with you.

And I think it plays out in lots of different ways. And it helps us predict and assess the intentions of other people. It helps us connect socially. It helps with the demonstration of empathy. And, again, understanding that we're being judged by others. I always put the "Rain Man" poster in there because that poster is the perfect example of theory of mind. The Tom Cruise character is very much aware that other people are watching him. His posture, his clothe, how he looks, the sunglasses, the haircut, everything is saying," I'm the man."

Because he knows you're watching. He's sending that message to you.

And Raymond is dressed for Raymond. Taking care of his own needs. He seems unaware that other people are making judgments of

him. And I think one of the other issues that affect people with autism, both sexes, is the hidden curriculum. Understanding those hidden rules that we learn in our daily lives that -- and the cartoon there sums it up pretty well for me. I assumed he'd know to eat the cone last because he's holding a dollop of ice cream in his hand. Nobody teaches you it eat the cone last. You just watch other people and you figure out from what they're doing how to eat ice cream.

And individuals with autism are not absorbing the hidden curriculums in our day-to-day world. Things like classroom etiquette Most folks who go into a new classroom or a new setting of some kind, if you're uncertain of what to do, you watch other people. And most people with autism, including -- especially boys with autism -- are really challenged in that aspect.

For purposes of time, I won't show you that video. So, in getting specifically to the sex differences, although, you know, prevalence right now is being studied in multi-states among 8-year-old children. Of course, autism is diagnosed four and a halftimes more in boys than it is in girls. And the diagnostic criteria is met in boys about 1 in think, and girls, 1 in 189. That's a significant difference, of course.

There are neuroimaging is being done these days to try to look at differences in the brain. One of the things that is being at least talked about more openly these days is that -- is that the -- perhaps the female brain is designed more along the lines of typically developing males in their social abilities than they are with typical girls. In other words, girls with autism may be more in line or their brains are more in line socially with neurotypical males than they are with typical

girls.

But regardless, girls with autism may be harder to diagnose for lots of reasons. Historically, the criteria is made around boys and they may not fit into the diagnostic criteria. There's some real overlapping symptoms and aspects of a diagnosis with things like OCD and anorexia and certainly social anxiety disorder. And I think how internalized symptoms are experienced is a significant reason for the -- for fewer diagnosis.

In the historical perspective has been that through the '80s and early '90s it was thought that females were -- that were diagnosed with autism had more significant symptoms. They were typically more challenged. If you read a lot of literature in the '80s and '90s about women with autism, girls with autism, they would talk about almost exclusively non-verbal, much more self-injurious behavior, perhaps more aggressive kind of behavior.

And then in '94, when the Asperger's disorder was added to the diagnostic manual, of course, there was that explosion of children diagnosed with autism around that time. And I think that sex differences started looking different. Especially in terms of what I have highlighted in green there. "Fewer restricted and repetitive patterns and externalizing behavior problems" may occur in females. Here's a woman with autism talking about how she can spot women with autism very quickly.

>> Autism looks different in girls. Because we internalize. I can see a girl with autism and think that she blends in fine. But I can pick it straight away. Usually it's subtle movements in the body. It's

intense eye contact rather than no or lack of eye contact. It's the way we articulate. We speak very well.

>> Marc Ellison: Now, research on the topic of sex differences especially in communication and social communication and social skills are really all over the place, frankly. If you look at a lot of the research from 2007 to 2013, lots of studies showed that there are no significant differences in communication and conversation and language levels between the sexes.

But other studies found that males are autism had greater expressive and receptive language than females. And the females have more impaired social communication. And then in 2012 Parker found that females had stronger non-verbal communication abilities than males. So, there's a significant amount of differences sometimes of opinion in research, but I think most of the research is coming to the conclusion that more women diagnosed with autism have fewer social communication challenges than do boys with autism.

Research is much more consistent in had terms of how women and men are different and restricted, repetitive patterns of behavior in activities. The studies from 2007 to 2011 or '12 show that males with autism have much more restricted repetitive patterns of behavior than females. And males have more repetitive motor movements than females. There was no difference in the self-injury section.

Simone in 2009, I'm going to mention this later -- women have obsessive interest. But they are not as obscure or unusual than the interests of males. They tend to be, perhaps, more in line with what a stereo typical young girl will play with. Dolls and those kinds of things.

Jewelry. We will see a video of a woman talking about jewelry. In fact, this is it.

This is David Lindsey. Dave is a meteorologist. By the way, if you have not seen the movie, "Autism and Love," please go home today and watch it. It's a brilliant movie that talks about different people, each with different abilities and levels of independence.

Talking about and showing how they experience intimacy and love and affection. This is Dave and Lindsey. And they both are diagnosed with autism. Dave is a meteorologist. He lives in Tennessee and does -- crunches all the data for information that goes out about the weather to TV and radios -- radio, weather stations. And Lindsey is there, his girlfriend, live-in girlfriend, and now they're married. Lindsey is diagnosed with autism. Lindsey didn't speak until she was 4 or 5.

She went through a lot of ABA trial programs. But this is a really good representation of how people are experiencing their fixed interests in different ways.

Dave is watching TV. Lindsey wants to talk to him about jewelry. Dave suddenly hears the weather being mentioned on TV near the end and watch how he behaves.

>> You know, did I ever tell you one reason I love jewelry, so much is because it gives me a -- a sort of a -- a shield to sort of protect myself from sort of vulnerable elements.

- >> That's news to me. I --
- >> Oh, really?
- >> Vulnerable elements.
- >> Yeah. I kind of discovered that after wearing necklaces for

the past several -- the past -- especially the last ten years, I have really been into wearing heavy jewelry and I discovered the reason why is that it kind of makes me -- because I feel so vulnerable and feel so shy and, you know, introverted, that wearing the jewelry kind of makes me feel that sort of false sense of confidence. And it kind of makes me feel less vulnerable. It makes me feel like it's sort of a shield. So, sort of protect myself from feeling more vulnerable.

- >> Well, looks like the weather just came on. Catch a glimpse here and see what he says about me.
 - >> I can't ever interrupt you and the weather.
 - >> You can stay near me. I just might not talk to you as much.
 - >> Yeah.
 - >> Northwest at 16 --
 - >> I'll be right back.
 - >> Tomorrow night. Satellite picture radar.
- >> Marc Ellison: Makes me smile every time I see it. I'm going to -- I'm very -- I'm really thoughtful -- trying to be thoughtful of time. Breeze through these and we'll still have some time for questions in a moment. But in terms of a hypothesis as to why fewer girls are diagnosed, there has been a real historical bias in the conventional male presentation of autism. And there are theories that are genetic of

Based or other kinds of reasons that people believe that women are not diagnosed as much. One is that an early theory was that women are just as apt as -- prevalent with autism as men, but the genetic threshold nor impairment is higher for females than males.

This hypothesis hasn't been supported by studies. Greater variability model. Talks about how men with autism display more variation and women less variation of symptoms. greater impairments are required to produce the symptoms that meet the criteria. There is a brain difference model which talks about the -- I put in parentheses, some argue that male brains are designed for understanding and building systems while women's brains are designed for empathy and compassion. And the theory is really that females are less acceptable to autism because they're more sophisticated in social competencies.

But the theory gaining traction and that I subscribe to is the camouflage hypothesis. Talked about from Gould and Smith and several other researchers. And that really is simply about women are able to mask, whether it's intentionally or unconsciously, mask their social communication limitations. And avoid autism diagnosis that way.

For instance, it's believed through this theory that girls are more able to follow social actions through observation. Like I said earlier, young children in a classroom, boys with autism are often not going to watch classmates to see how to behave. But that theory says, and I certainly would agree with it, that many girls will follow social actions through observation.

Perhaps it's because of how women are socialized, but they tend to be quicker to apologize and make appeasement when they make an error. They're more socially aware and socially-driven. So, they're going to seek out opportunities. And they might fixate on one special friend with whom they want to share things with. And

sometimes become in a very dependent relationship. But they will seek out that person.

And as they grow in self-awareness and insight, girls may take greater pains to avoid drawing attention to themselves. And we all know that if a -- in our society -- if a boy is -- if an 8-year-old boy is very quiet and withdrawn, we tend to think something may be up. But if a girl is kind of quiet and withdrawn, then she's probably just well-behaved and perhaps shy, it's thought. When really it could be autism. And here's a woman talking about that. She has a British accent. So, may take a second.

>> I was watching Connie do girl play. She had the Barbies and she was making a story and set up the pool and put them in a pool in a position so they're ready to talk. And then she went and left the game. And I came up to her and said, what are they doing? Are they talking to each other? No. They're in the pool. And it suddenly struck me that although it looked like she was doing imaginative pay, at the very surface of it, it wasn't.

>> Some of the -- are made to fit in is quite often this masking thing and pretending to be somebody else. This chameleon factor.

We want to fit in with everybody and I'm a bright and bubbly person. I will try to be funny. The more information we have, the more we can change those around us, the more we are accepted because we know how to communicate with someone.

She looks like she's managing and looks happy and social. But it's all on the surface. You scratch the veneer, it's based on mimicry.

And that's the thing that distinguished the girls from the boys.

>> Marc Ellison: Yeah. And I think the woman who spoke, the blond lady who spoke right before that, really describes how she experiences it and it's what I'm trying to suggest here is that she may not understand going into a situation what the rules -- the social rules are in that environment. But she knows to watch other people and to -- and to kind of conform to what's going on.

I'm not going to show this video for time, but masking often results in improper diagnosis and treatment. I know a significant amount of people I believe are -- women with autism who are diagnosed with borderline personality or other kinds of personality mental health disorders. Sometimes labeled "Overly dramatic," those kinds of things, when really, it's perhaps autism.

And I left this slide in even though it's about talk therapy clients for autism. This is what I think the profile of a typical female talk therapy client is. And for this group, I would say this is probably a highly independent profile -- profile of a highly independent woman with autism that you may see. Desires friendships and enjoys social environments, but is hyper or hypo social. Quality of friendships are not fully understood. Typically, she believes that relationships are deeper than they are really in reality. Experiences frequent conflict due to misunderstandings in relationships on the job. Shuts down, becomes kind of emotionally paralyze when had conflict occurs.

Uses other women as role models to learn interpersonal protocols. Can be highly vulnerable in social situations. Has significantly impaired executive functions particularly with self-regulation and cognitive organization. Struggles to fit in. Has a

strong desire to do so, but has extreme problems in terms of relationship-building.

Has an impaired theory of mind, especially in interpreting the intentions of others. Know lots of people with autism, for instance, that can't tell if you are smiling at them. Whether you're actually angry at them or whether you're happy with them. And they have fixed, obsessive interests that may look typical on the surface, but which take up an extreme amount of time.

Finally, I'll mention that there are lots of resources if you're interested in looking more at this topic. Some media and books, "Sisterhood on the Spectrum," a really good book by Jennifer O'Toole. Please watch autism in love. It's wonderful. The chameleons: women with autism and changing the face of autism: autism in families are on YouTube and can be accessed easily. And TED talks. How to I learned to communicate my inner life with Asperger's. Rosie king, and all of these have something to do with women who are experiencing autism.

You have been very kind and patient. And I appreciate that. If anybody has questions, I'll try my best to answer them.

- Dr. Cottrell, I guess there are no questions.
- >> Lesley Cottrell: Can you hear me? Can you hear me? I was just rambling, and no one can hear me.
 - >> Marc Ellison: I can hear you now.
- >> Lesley Cottrell: Okay. I'm sorry. So, we do have some questions via the chat that I'll ask that are coming in. But before I do that, does anyone else have any questions? All lines unmuted at this

time. Hey, Jeff, mute your phone. Okay. That's okay. The one question that came in through the chat is this: is it common in teenage males with autism to have sexual obsessions with females? The reader says, I know they have obsessions, but are they more times than not harmless, or do sexual obsessions occur? And if so, what would be a pathway to help treat these behaviors?

>> Marc Ellison: Well, that's a loaded question. Because the first thing I thought of was, it's common for every teenage boy to have sexual obsessions with women. And I'm trying to figure out from the question what -- I presume that the person means that it is -- I'm going to presume by the question that it's the amount of time and the amount of effort and thought into -- that's put into the thought. And I don't know the answer to how prominent it is other than it's biology and it does happen. But my suggestion would be that -- and, again, forgive, I don't know the person, obviously. But perhaps it's not the sexual aspect that the person is obsessed with, but, instead, the social misunderstandings about what -- and the inability to kind of organize things.

You know, lots of times young boys are obsessed with sexual kinds of things, but they know when to pay attention to that and when to hide that and when to not talk about it. Or they do it in some kind of moderation because they can predict when they can pay more attention to it. And I tend to think if somebody tells me that somebody is obsessed with relationships or obsessed with stalking or obsessed with sexuality, to me, that's more of an issue about learning how to -- how to self-regulate and learning how to predict and learning how to

plan. Does that make sense?

>> Lesley Cottrell: It does. It does. Okay. Another question is -- and anyone can ask the question. But one that came through the chat, is there any reason, based on the number of West Virginia persons diagnosed with autism, has there been an increase?

>> Marc Ellison: I want to make sure I heard you correctly. In West Virginia, has there been an increase?

>> Lesley Cottrell: Yes.

>> Marc Ellison: No. West Virginia has stayed pretty much at the 1 in 68. It's stayed right along the lines of the prevalence. The reason we pay attention to that is West Virginia was one of the first nine states that was involved in that first original prevalence study. And then, after the first round of two years, West Virginia dropped out. But we paid really close attention to it and we're right at 1 in 68 as well.

>> Lesley Cottrell: Okay. Any other questions? People might have? Oh. So, another question is, is there a way to access the data that is on your IASD registry?

>> Marc Ellison: No, there is not.

>> Lesley Cottrell: Okay.

>> Marc Ellison: It's a very confidential bit of information and we don't use it for anything other than the registration.

>> Lesley Cottrell: Okay. Is autism often misdiagnosed as ADD or ADHD? That's another question.

>> Marc Ellison: I think so. And in terms of -- in terms of folks who are at that level 1 or more independent phase, I think, in my

experience, kind of a typical diagnostic history is ADHD early and sometimes oppositional defiant disorder early. Through the teen years, kind of becomes depression of some sort, and then usually as they're older and things don't change, it becomes more autism. And I think -- I think if you think about -- who are that more independent kid with autism in those stages of his life, that makes a lot of sense. You know, you're struggling with self-regulation and all those things and you seem kind of hyperactive and inattentive.

And then in your teen years you may not be as, you know, making friends as much as everybody else or at all, perhaps. So, it feels like you perhaps are more isolated and depressed. In my experience, looking through thousands of evaluations over 30 years, that's a really common diagnostic history. Yes.

- >> Lesley Cottrell: Okay. All right. Well, with that I will -- I will close this out. We're right at 3:00. So, Dr. Ellison, I appreciate your time and expertise. It was really interesting, and the videos just make it, I think.
 - >> Marc Ellison: Awesome.
- >> Lesley Cottrell: There are comments. I don't know if you have had a chance because you're speaking, but in the chat, people are saying they like it. Enjoyed the presentation.
- >> Marc Ellison: I appreciate it. I can only see the slides, I can't see anything else, sorry.
 - >> Lesley Cottrell: I can send some of those to you.
 - >> Marc Ellison: Thanks a bunch. Thanks, folks.
 - >> Lesley Cottrell: Thank you, everyone. Thank you and happy

holidays.