

UNC Chapel Hill CEDI Lecture Series: Kim Tizzard

February 28, 2019

Understanding Autism and Planning for Community Members

>> In addition to her personal experience as a mother of a son with autism, Ms. Tizzard currently serves as the Director of Family Support for the Autism Society of North Carolina. And in her current role, she supports autism research, resource specialists and chapters across the state. She advocates for a blended approach in teaching individuals with autism and understands the importance of structure for learning, attending, and independent skills. Ms. Tizzard has also worked as a classroom teacher in a self-contained classroom as well as in regular classrooms where children with disabilities were mainstreamed successfully. Thank you.

>> Thank you. Alright, we're going to go ahead and jump right in. Hi to our folks who are not here in the room with us. In addition to what, you know, Dr. Gibson just mentioned, I also want to let you all know a little bit more about my son, and I'll use him as examples as we talk through this a bit, as well as some other close friends' children who also are on the spectrum. So Trevor is now 22 years old. He graduated from high school with what's called the occupational course of study, I see heads, you know, bobbing. So that means that he does have a high school diploma. But he is it's not a college ready diploma. And trust me, the second he graduated, he was done with school. That was it, he had no interest in going back. So he's currently volunteering and we're working towards him finding some employment to help his you know, life get more enriched. So I do want you all, as long as you have me here, not only here, as a professional, I'm here as a parent with a very personal experience. So at any point in time, you're not, don't worry that you're going to offend or anything. This is the time right now, in the cone of silence right here. What happens in Dr. Gibson's class stays here.

>> After the video stops, what happens in Dr. Gibson's class stays here.

>> Yes, this is true. Good. Yes. Thank you for that. So but if there are questions, now's the time to ask me. I'm more than happy to help answer that. I want you all, because let me I'm going to even ask you right now. How many of you have a loved one or know somebody who's on the autism spectrum? I would expect, wow! You too, Emily? I didn't know if your hand was raised. Yeah. So everybody here actually has had some experience. So now just taking a little step back. Why don't you tell me a little bit about what you know about autism. Just some things, just blurt out just a couple things that you know about autism.

>> It truly is a spectrum.

>> Yes.

>> If you know, one child was autism or one person with autism, you know one person with autism.

>> That's right. It's very much like a snowflake oftentimes, we say. Yes. Anything else? So how many that raise their hand, have a family member who's actually? Two. Okay, three. All right,

wonderful. So you all will have some very first hand experiences as well with this. So what I wanted to talk today, though, is in specifically about just inclusive opportunities that you all have this amazing, just you're in an amazing place to offer this through library systems that I heard that most of you all, that's what you're working towards. We have found that families who have a difficult time understanding the diagnosis or for cultural reasons, or what have you, a lot of times won't seek help, but they are going to come into the library. And a lot of times, they're going to go to their faith-based ministries. So I love doing these and trying to help educate that we have folks like you all, that now can help represent those that are on the spectrum in whatever path that you actually end up in. So we're going to go ahead and jump right in. Some of these slides, I'm going to go through very quickly, I'm not going to read them, they're there. We have the presentation to be available to right, Dr. Gibon for those that are online, we made it a PDF.

>> We're sending it right now.

>> Okay. So if anybody did want a copy mailed to them? Sure, that's fine. That's why I made it as a PDF. So you all are welcome to have that. And then those of you that are here, so you can take a look at some of these slides later if you'd like. But we've been around for almost a little over 40 years now, the Autism Society. And it did start as a group of parents whose children at that time were getting the diagnosis. And I don't know if you've ever heard the expression "refrigerator moms?" They were saying that autism was caused from the mothers not giving them love and affection, that that's what was causing, you know, autism. And so they got together, they knew that wasn't true. And they worked with the TEACCH folk in Chapel Hill here in this area, part of your community here. And they started a small group of parents. And now we're going almost 45 years later, and the Autism Society has now grown close to 1500 employees across the state. So for parents that actually help and serve, we have 19 autism resource specialists across the state that cover all 100 counties. So if you all are getting calls are in a place where you're like, oh, I know there's that Autism Society thing, go on our website, it says get help, and you can actually help connect yourself if you want to ask questions or family members, or even self advocates, to to us, and we can help them kind of navigate all this. Today, we're going to be doing this in two parts. The first part for those that are on Zoom, we're going to be covering just kind of the basics of what autism is and talking about those core features. And then we're going to also identify some of those characteristics that you may see or manifest in a library setting. But what it's not like, my son would go into a library and act one way and then go into another community and act differently. It's I'm using that here for both library and community context. So we're going to talk about that today. And then in part two, we're actually going to talk about some strategies that you may find yourself in this situation where you're like, oh, gosh, I want to help this person, I can tell their feeling anxious, I can tell that they're having some difficulty, I really want to do more than just sit and think and throw my hands up. So we're going to spend a little bit of time talking about that. And then we're actually going to, we'll see how much time we have left. But we have three different scenarios that we may have you all break up in smaller groups, depending on the time that you can work on the scenarios. And we'll come all back together and brainstorm together. So that's what this time is going to look like. So when you look at these two pictures, what do you see? Don't make me call on you, I know your names. What do you see? Rachel?

>> Diversity.

>> You see diversity? Excellent. What else do you notice about this? Is there anything that looks different about anyone you see here? Do they look like you all here, right? People, they look like people. This is what somebody with autism oftentimes looks like. It's not like they walk around, and they've got something about them. Until sometimes when they they talk or my son has some odd motor movement. But if I were to show you just a picture of them, there's nothing that would distinguish him as being any different from you or I, which makes it challenging, oftentimes, and especially in the environments that you may be in. Okay, great. So when we think about autism spectrum disorder, this is what we're thinking of. So it is a neurological development of how the brain develops at a very young age. And you kind of think of it as how those neurons or the synapses are shooting off when they're young children. And one, and this is actually Dr. Pivens does anybody he is because he's with... And his research is here through which you guys, there's so much that goes on here. So of course, you're not going to know it all. But he actually has done some very fantastic research and brain studies on individuals on the spectrum. And one thing that has more or less been proven, is that sometimes the head circumference grows quicker than how those brain synapses are actually shooting. So they kind of misfire. So when you actually brain map and watch somebody who's on the spectrum, like, I may show my son a picture of a cat. And what would trigger in my brain, when they watch which parts of the brain actually come on when I see a cat may be very, very different than what it looks like for him or other individuals on the spectrum. And there are so many great things. And I'm not going to get on my soapbox about early intervention. But those of you who have or if anybody's in here saying other education, or have a loved one, then you know very well that early intervention is so imperative because you can actually help reform that -- that their brain and never can cure autism, there is no cure. But you definitely can really help them get more tools and strengths and develop some of the skills they need to function to their to their best ability. So their support areas are listed here. But because I'm going to go into those in some of the additional slides, I'm not going to talk about this, right this second, but you all can see them. So when we think about the spectrum, which Nicole said it is a spectrum disorder, and we said, you know one, you know just that one. There's a full range, when we're looking at somebody who actually, you know, is on the spectrum. Are any of you familiar with the DSM-5? Oh, I see lots of heads nodding. So that is the tool that's used when we actually are trying, we're not trying but we are diagnosing Autism Spectrum Disorder, and I'm going to refer to it moving past this as ASD. But we have, because our loved ones and those that, that you will come in contact with, they're going to run this gamut. They, from mild to more significant issues to being very verbal, or maybe nonverbal, social seeking, they want to talk, they want to be very social or social avoidant, very oversensitive to sounds and sights and textures and smells to very under sensitive, may have a very, very high IQ, or may have a developmental delay. One thing I want to make sure that you all know is that not every individual who's on the spectrum, does not mean that they had an intellectual developmental disability. Okay, so we're looking at Bill Gates, we're looking at... trying to think of all the people that we now know, you know, have ASD so we've got like Bill Gates. Gosh, Hannah what's her... with the blond hair she was, she played the mermaid. She's...

>> Music and listening to her Walkman.

>> Daryl Hannah.

>> Daryl Hannah. She's on the spectrum. They're thinking Albert Einstein, now they've got some stories that have really pointed that possibility. And there are some other great literature that you can get your hands on, if you find this interesting or are curious. But that does not mean that they have an intellectual disability. My son has very good functional language, he is not conversational. So oftentimes, when people need him, they think that he's not understand what they're saying, because he can't then have that back-and-forth conversation. And that's not true, he falls in the average IQ range, and does not kind of have, he has some developmental delay, but not an intellectual disability. And we just kind of look at it like this, this is just in case anybody's curious. And in when we look at the DSM-5, and how folks are actually getting services, another conversation for another day, contact me if you want to talk about this some more. But they actually do the testing, they, the individuals on, on the spectrum are going to fall into one of these three levels. And the first one, the way I like to look at it, is depending on how much support somebody needs. From needing very little support, they may actually be here needing some minor support extra time on things, what have you, staying in the community, to needing a very substantial level of support where somebody has to be with them all the time to help keep them safe, and help them navigate their world. So and then everything in between. So who has autism? So right now, this information actually is very new, it came out in 2018. It didn't change much over, they do it every three years. It was one in 59. But prior to that the numbers were very, very different. And when people ask why, why does it look like the numbers have grown so much? And it's because we've done a such a better job of diagnosing. And then TEACCH Chapel Hill center actually was one of the forerunners in, in working on that, you know, for the entire state of North Carolina. So, when we look at North Carolina, it's one in every 57 for whatever reason, they still haven't been able to identify why it's usually more boys than girls. And you can see the numbers. So let me tell you right now, those of you that are going to be in those community settings, and if you are going to be working in wherever you go from here you are in going to have people on the spectrum. You're going to come encounter with them, they are the ones who are coming into libraries. And we're going to talk about why even though I have a feeling you all probably have a good idea why they love going to the library. So if a child is highly verbal, these are some very common misconceptions. And if you all take a look at this, you'd be surprised some things that you may even have thought before we started this. So thinking about them being very, very verbal, so they must not have autism. They must be a savant, they're a genius. You know, in certain areas, there's actually 13 know, known savant in, in United States. And but I'd say half of them are probably on the spectrum. But that doesn't mean that they, that they all are. If you have ASD, then you don't want to be around other people and you don't want to interact. That's not true either. And there may be some other misconceptions. Not affectionate, poor eye contact, can you all think of anything else that may come to mind that you thought, remember were a safe place? Is there anything, I remember our next door neighbor, he was just a little guy and I, we were young, but he was... stripped his clothes off and run in the neighborhood. Now he was just a little guy. But that's what I thought it was. And when my son got diagnosed, that was my only experience, I didn't know anyone or realize that, what if all the different ways it could look like. So I remember my son first got diagnosed, I thought, oh my gosh. It was scary. So when you all are going to come in contact as well with parents and caregivers, and loved ones and we're going to talk about that more, as well. So how about here in this room, and you all on Zoom, you can raise your hand or not, but... Raise your hand if you like to be in control? How many of you like to be in control? Everybody pretty much likes to be in control. How many of you like to be controlled? Yeah. So this is

oftentimes when we think about somebody with autism, they don't want somebody that's always telling them what to do, how to do it, they need to have their own voice, their own desires, their own interests, they need to have those opportunities that they can be in control. So just kind of think about that as we go, go through this. All right, we're going to unpack the four core features of autism. So this is kind of basic. So if any of you really would like to have more information, just let me know, we can, you know, jump in even further. So we're actually going to tear down each one. Have you all heard of the term joint attention before? I see a few heads nodding, some not. I actually didn't either, before I got into this kind of world, I didn't think about it. Joint attention is something that we take for granted. It's the back-and-forth. It's the interest in what the other person, or even being able to feign interest in what somebody else is saying. That's joint attention. And so often this is one of the very first things that we noticed with individuals who are on the spectrum is having an issue with that back-and-forth. You know, of understanding and that's where these kids, a little girl who wants to show, you know, oranges and happy the same thing with you know, some folks like saw a picture could be right outside the door here. Somebody who's on the spectrum may not have that. So I remember when Trevor was very little that he was very engaged in a toy. And one tests that they did was make noises and rattle things. Trevor never looked toward that. And one of my other things that we kind of noticed is he loved Blue's Clues. He was only 15 months old, loved Blue's Clues. Whenever Blue's Clues, you know, was on, he was right there in front of the TV. He loved it. Laughing, really enjoyed it. He was, and I thought he was deaf because he didn't answer to his name, that there must be something going on. There was nothing when I called his name. So he was all the way the other end of the house and Blue's Clues was, came on in the living room. And it was low. It wasn't loud. He came running from the other side of the house, because he heard Blue's Clues. I thought to myself, I don't think he's deaf. And that's when I started to realize something is going on. That's when he lost his eye contact, started to toe walk, hand flap. And I thought, okay, I think we're dealing with something a little bit more than that. And as it turns out, when he went through his hearing test, because that is part of the full testing that they like to do is, is to still check, you know, the hearing, he almost is that they were having so much fun. It was these couple young guys, that you're in a booth, I don't know that any of you have ever experienced. So you're in this dark booth, and they're doing noises and they're looking to say, say look towards the noise. And when they're testing little ones, it'll you know, it's, it's seeing a they'll look. And I saw Trevor's head snapping around, mine was too, because I could hear them too. And then I'm sitting there, and Trevor's still going like this, they come out of the booth, they're like, oh my gosh, he hears like a dog! We were playing sounds he never should have been able to hear. So even today, if Trevor walks into certain situations, he'll actually hold his ears, and what he's trying to do. It's not because it's too loud, he wants to first take it in just with his eyes, because it's too much to take in with the sound too, because of his sense of hearing is so acute. Remember, I'm just talking about Trevor, I've got other friends whose kiddos had to turn their shirts inside out because even the seams bother them, their socks inside out. All kinds of just, it just depends. They're all very, very different. Because there may be some differences in early forms of expression. And these are some things that we notice. I've got a really good friend whose son graduated from Guilford College, 140 IQ, he's absolutely brilliant. And when he was just a little guy, of course, you know, he's, I don't want to give away too much, because you could figure out if you wanted to where you know where he was. But he would study and memorize books on birds. He loved that. And he was hyperlexic, so he taught himself how to read by the age of four, and was reading books on birds. And so there would be people that would come over to the house. And he would stand

in front of them because it was one of his obsessions, which we'll talk about. And he would go on and on and on about birds. And his mom would ask them, you know, would you like to have some juice? Or are you hungry? He didn't know how to answer that. So he had all this language that looked like oh, my gosh, this kid is amazing. And he's still, he's very amazing. But for him, he learned all that language very early, learned to read very early. But it wasn't meaningful. He couldn't use it functionally. And it took him some time to actually learn to use it functionally. And that's when we mean, when we talk about functional I'm talking about that reciprocity that we talked about with joint attention and asking for his basic needs, you know, bathroom juice, milk, whatever it was. If I say something, by the way, just let me know, if you're like, wait a minute, Kim, what is? What does that mean? Just stop me. So what does that look like in an adult now? So you have some of those things that are going on when they're very, very young. But as an adult, these are some things you may see whether it's even in your fellow students here on campus, or in the workplace, or what have you, you may notice that they aren't initiating that conversation that that can be very, very difficult and making their needs or problems known. That that may be something that you know is doesn't come easy. May not clearly direct their communication, like may mumble and look down. We hear from individuals who are on the spectrum who are very verbal say it is so difficult to look at your face and listen to what you're saying because I I'm so taken with how your face moves and what you're doing that now I can't hear what you're saying. So I can either look at you or listen to you. So don't always think someone's being rude if they're not able to look at you while they're talking. Just think to yourself, alright, this person may need to just process information a little differently. That ping ponging, that back-and-forth conversation and just understanding complex communication that may need to happen and go on just trying to figure all that out. Degree of pain and difficulty in elaborating. We work very closely with dentists and doctors, doctors offices as well to develop some visual supports for them, so that they can help work better with their patients who may be on the spectrum. Receptive communications. You have expressive, that's the talking and then the receptive is how you're able to understand and then follow through on it. So, and here's the whole thing, I can look at you but I can't do both at the same time. Reading behind, between the lines, some of that sarcasm can fly right over their head, it can be really difficult. To just thinking about things in, in this context as well, because when we, I'm going to show you some samples and other things. But for the group that's here, we're going to be working on some activities. So let's see if you guys can put some of these things in place. There's my kiddos at the, over there, there's that picture's a little old. But here, I put it in here. There's a couple things I love about the three pictures here. We're talking about the differences in social interactions. We were does anybody recognize where we are by chance? In Disney, that's in the Toy Story ride. Well, Buzz Lightyear is doing his thing, hello, space rangers. Trevor, I couldn't get him to look at the camera at all because he was so taken with, with Buzz Lightyear. This picture here is something for whatever reason, a lot of individuals on the spectrum really like trains. You know, it's one of their favorite things like the Spencer Museum, we had to do a whole training for them. Because they had so many individuals on the spectrum that you know, we're coming and visiting. But even, I could be sitting here, if this were Trevor, he thing wasn't actually trains, it's Disney World, anything Disney. But trying to get the attention and you're not going to get it, you know this, this little boy is watching how the wheels are moving. He's just very entrenched in what's happening there. And nothing's going to pull this attention away. You can't see this picture good. But what I loved about it was this guy's face, because he's trying to interact with the group. But you can say, see that he's like, I don't know what you all are talking about right now. But I've

learned this skills to actually look like I may, and then I'll work on that later kind of thing. So I really like that. But these are some of the things that may be very difficult when we look at social interaction. We talked about this very weakened reading social cues. So you may even be done with that obsessive conversation. Okay? But they don't care, they're not seeing that you're rolling your eyes, you want to move away, they're not reading those cues. So that's something that, that we noticed a lot. And we have to actually really help work on, on that skill with a lot of the individuals, we have a clinical department and spend time working on things like that as well. And it's hard. And even for those of you that want to possibly work this summer, what have you, that's going to be one of the big things that individuals, you know, have a hard time with. And then just that poorly integrated non verbal skills and regulating that with communicate, and what have you. And let me tell you something, I don't know about you all, but have you even while I'm going through this, have any of you said, gosh I'm a little like that... if you ever, or does that, has that crossed your mind even while we're talking? I, will think about when you shower, do you do everything in the exact same order? When you wake up in the morning, we all have a little bit of the 'tism. But unless you have something in all four quadrants, then it's not. But especially when I do this with teachers, it's like really putting yourself in their shoes, because don't mess up my morning routine. There's a certain order I like to do things in and don't get in my way. That especially Monday through Friday when I'm trying to get ready for work. So it's just some things like that, that I think if you all even for a minute, take a step back, you can see well how would you feel if that happened? Or you know, so... Jump off that soapbox. This, of course is geared towards young children. I don't know how many of you may end up actually working with the little ones in like trying to pull together sensory friendly activities or story times or what have you. But you may see you know how we like to do pretend stuff, oh, let's pretend the scarves are beautiful fairies flying, they're going to be like, that's a scarf that is not a fairy. It's very, very difficult to even like imaginative play and what have you can be hard for some folks that are on the spectrum and it starts very young. Lining the toys up instead of actually using them to maybe battle each other. Even if you, with my daughter who was very imaginative you know, if you take a banana, whatever when their little, and you're pretending it's a phone, you wouldn't do that with Trevor, he would have no idea what you were doing. Bananas are for eating not for talking into. So thinking about that even with some of your adult friends and people that you may come in contact with. Restricted patterns of interest. Okay, who here who said they know somebody who is on the spectrum or have a loved one that's willing to tell me what your loved one or friends or whomever's restricted interests might be? Anybody have?

>> Okay, so that's and certain kind of music?

>> Yes.

Yes. Yeah.

>> Piano and the history of the construction of piano.

>> That's awesome. So cool. It is, isn't it cool? It really is.

>> Harry Potter for my son and mountain biking for my husband. Oh, yeah. Yeah.

>> So that's you know, that's we're right there with you all. For Trevor is anything Disney. He can tell you when the ride opened, who the voices are in any Disney movies, movie, it's, I've had to learn way more about Disney than I ever thought I'd ever have to learn. I've got other friends who was it's maps, and seeing where things are. Some people is space, trains, and then you heard some other, you know, neat examples in here. When they get on their topic of interest, sometimes it's very hard to get them off. Hours. So let's pretend for a second, I'm going to even cheat here for a minute, let's pretend you have a patron that comes in, they're looking for books on pianos, you know, this is their interest, and then they want to stand there and talk to you about that. So I can see you all trying to think, I want to be nice, I want to be kind, but I can't do this right now. So there's some tricks to the trade. And one of the things is, is and I'm just gonna throw this out here, when thinking about special interests is even on a post it said, say on there. It's let's say it's three o'clock, say why don't you come back here at 3:25, we can talk for 10 minutes about pianos. And then right when it's 3:35, the conversation needs to be finished. It's just being very, very clear like that, and you're respecting them, you're letting them kind of get they want you know that that captive audience to talk about their special interests. But then it's also giving you kind of like, there's has to be a madness to the you know, the constant talking about this particular topic. So we see this a lot. Actually, I'm not aware of too many individuals on the spectrum who don't have special interest areas, to be honest. They all, there's something. So, and so some key concepts to keep in mind, that is difficult for somebody who's on the spectrum, is that other people may have a thought that's different than their's. So you can see where a group activity may be very hard for somebody who's on the spectrum, because they're going to attack it this way. It's kind of a rigid way of thinking, and not being able to think pass that or take others, other ideas in mind as well. That can be really, really hard. But they can have thoughts about other people that, you know, as they're interacting can be very difficult. My behavior may even affect what others may think about me. They're like, no, why would how I'm acting, this is normal. You know, it's very much almost, we look at our, you know, you talk about kiddos who think that the world kind of revolves, oftentimes somebody who's on the spectrum, that's how, how they're feeling like, this is it they're not, they're not picking up on those social cues, we kind of call that the hidden curriculum. There's so much that you all, when you developed as a young one, that you were picking up from your environment and you realized when to be quiet or when not to do something. You were picking up and watching cues. That is so difficult for somebody who's on the spectrum, to pick up from cues around them. We talk about it like take yourself and put yourself in a country where you don't know the language, you don't know the food, you don't know the culture and what would that be like for you? That's a little feeling of what it could be like if you had autism. So and it takes time, they're actually molding and changing themselves to fit in in our world and the way that we think. So we hear that awesome. Thinking and learning remember we talked about the four core areas. So this is our last, well there's also the behavior piece, which I saved the best for last. So this is one of the third, the third area. And it's just that uneven... It's the most important thing is just that uneven way of developing. Like I told you about the friend's son at 4 could learn, learn to read and could talk about birds, but couldn't talk about his own functional wants and needs. Just very uneven. Some kiddos, like he was six years old before he actually was fully potty trained. But yet, here's this brilliant kid who was already able to jump from kindergarten to first grade. bypassing kindergarten because he was so smart. We've learned it with Trevor too. There's so many things that he picked up very naturally and other things that were very, very difficult for him. Sensory Processing. How many of you know who Temple Grandin is? Yeah, I'm seeing all these. There

was a great movie. What did you say? [Off microphone] Yeah. Doing what it needs to do. Well my whole, this is what she said. When my hormones hit at puberty, my touch sensitivity worsened. Noise was like a dentist drill hitting a nerve and scratch clothes. I can't see passed that, but you all can see it in your... But let me tell you a story about Temple which is going to give an example of this, what she's talking about here. So those of you, you raised your hand you know she grew up on a farm, she's a farm girl. She, I heard her speak so I heard this right out of her mouth. She was telling a story about Levi jeans that she loves Levi jeans that's what she, well, if she could only wear Levi jeans ever, that's the only thing she'd ever wear. She can tell when she was talking about how she goes to Kmart to get her jeans. And she can tell from which plant in China the Levis come from because there's something slightly different in the fabric of both. So she knows the second she puts them on, she's like, nope, can't, these aren't the right ones. So and this is it, she really talks a lot about this. For her, this was her big sensory, most difficult thing was just the way stuff felt on her skin. We've talked to adults because they help give a window into some of our kiddos who aren't as verbal. When they go to get a haircut. We hear, those you have to loved ones, I see their heads nodding. It was like feeling like you needed to be in a papoose to try to get their hair cut, I've got one friend at work, she'll show me a picture of her son's haircut and it's like all thick and choppy. She said he needs a haircut and I'm only can do it when he's sleeping. But we, they've actually said that it feels, they can actually feel each strand being cut. Like it's that sensory painful for them. So remember, we talked about just how those neurons are hitting and how different parts of the brain are going, kind of firing off. That's why some of these things can be so so difficult for somebody who's on the spectrum. And especially when we think about some of the sensory issues. The first sentence, well, even short sentence, my son ever said, we were at Grove Park Inn, it was the big gingerbread cookie thing. And I thought he loves that. But I didn't realize how crowded it was going to be. So seeing my heads nodding in here, again, those who know. We walk in, and he's already with the ears, just a little guy. And I, he starts to dry heave, and I'm like, oh my gosh, fancy Grove Park, you know, so I run him out the door, and he proceeds to get sick. And the first thing he ever said in a sentence was "too much people." I just thought it was just other things going on, Never did I associate with, because it's like, you're a detective as a parent trying to figure out what it is, it was about too many people. So just they're all different, different things kind of trigger. So what I want to kind of cover with you all now is to think about some things that you may actually see, for those that... And I'm going to talk about a library, but you guys know I'm talking about any environment. So these are some things that you may actually see, or you may not. There's there, especially those that are really high functioning, they can learn to hide and mask. And a lot of times you won't see it out in the community. They wait until they get home. One of the gals that I'm asked, that I work with, her son will, when he gets home, he has to a lot of jumping and kind of running back and forth and jumping. But he doesn't do it all day at school. And he says oh, I sometimes I just feel like I need to jump out of my skin. When it gets home, he's trying to get all of that out. So you may not see some of these things. But just in case I wanted to put this up here. So you may notice even some things like the poor grooming habits. That's one that I've actually gotten a lot of calls on lately, and we're working with some transition specialists. And this is like, I don't know how to get my client to understand the importance of good grooming. So these are some real challenges. Some of those arguing you may see some of that... What do you mean the book on the piano from such and such is not available? Heaven forbid that anybody else would need to check out that particular book. We see this. I've seen, I've done quite a few presentations to different library systems, in Mecklenburg and in Wake. And this is something that the current

librarians are saying that they're seeing and they're like, what do we do? So this is stuff that they are seeing those verbal outbursts, some of that yelling, because they, either they can't get their computer to work, they can't get, they came in looking for a certain magazine that should be out and heaven forbid somebody else is looking at it. There's a lot of these challenges that are happening in, in those settings. So one of my very favorite people that that I love on autism, his name is Jed Baker. There's a few. But Jed Baker's amazing. And I heard him speak a couple years ago. And I already knew this. But he said that the majority of behavior, and he said as high as 95% of behavior, is rooted in fear and anxiety. For people who are on the spectrum. Even you all, how do you feel when you're when you feel fearful or you're anxious about something, you just have developed good tools to, to either just say I just need to get up and walk, walk out for a minute. Whatever it is. That is very, very difficult. And when they're in that moment, and they go from one to 10 I guarantee you the majority of the time it's around fear or feeling very anxious about something. I, this young man that's here, his name is DJ, and I don't know if anybody's ever had the opportunity here to speak. He's great. And he talks about how he was bullied as, as a young man, and he's done this whole... It's called Imaga-friends, you can actually look it up, he's got a website, and he does this whole thing on bullying, and he draws called the Imaga-friends. But if you notice over his shoulder, he has a towel, you will never see DJ without his towel. He needs that towel. That's what he uses. And like he'll be at our conference. And I know when the towel starts to do some flicking, that he needs to step out and do some pacing to pull himself back together. So that's like a towel, you don't always know what somebody's tell is going to be, what's starting to ramp them up. But he's also a greeter at his church, he's, he's very, you know, friendly, that way. You can see like lining up cars, you know, before they can actually play with them, they have to be in a certain order, they all need to be there the whole thing. So you're going to see some of those compulsive looking behaviors and need for things to be very much very certain way. Maybe very, very rigid in, in how they want things to go. Especially let's say they are like, I want to I want to come to library when I know Rachel-Anne is going to be here. And you're like, okay, buddy, I work here Monday, Wednesday, Friday. You go on vacation for a week. And this individual, you know, looking for you. You're not there, you're part of his Friday routine, or what have you. That kind of stuff can be very, very difficult. It's not your fault, you should go on vacation. Oh, gosh. I'm not going to go over this. And a lot of time, take time to look at if you can see it, the way this PowerPoint is... But I, what I do want you to think about here is this is what you see on the surface. Think about that iceberg where you're seeing this is what you're seeing above the water. And you know how you see the picture, this is what's going on underneath the water. That's, think about that. So you may be seeing these behaviors that are happening up here. But all these things could be contributing factors, kind of that iceberg what's going on under me. So if you're, it's a really great slide, I like that one. These are some major contributors that we have found. So these are some things that I'm going to want you all to think about when you're working on some of your group activity in just a little bit, may not be able to communicate what they want. You know it's because the book's gone. But they're not able to maybe verbalize that, because they've already gone from one to 10. Does not communicate what they does not want. No I don't want the one on, you know, whoever else, I want that one. Does not understand what you're trying to communicate. All right. Need help, real quick. How are we doing on time? Yes, I love this video clip. I'm not sure how many of you may or may not have seen it. I love what's coming out of the UK. And that's where this one is. I'll be good. I told, I don't know what it is about this video clip, but it always gets me teared up. But this is an

example of what somebody who's on the spectrum goes through when they get too much stimuli coming in. I did want you all to see this

>> [Very loud ambient sounds] 1, 2, 3, 4, 5, 6, 7, 9. Take my hand. It's fine. I'm not naughty, I'm autistic, and I just get too much information

>> I tried not to cry, but I'm sorry. But when you have a personal experienced and you remember those days, I... Gosh, anyway, sorry about that guys. Alrighty. Right? We're close to a break. So I really loved that clip. And they've got some other great clips that are available as well for you all if you want to just get an idea. It's from that they call them the Autistic Society, which is a weird great, not really people-friendly here in America. Sorry for that. But it's the UK video series. But you get, it's called TMI, Too Much Information. So if you go to that, you'll find a whole bunch more, they've got some really great things. So these are some cool things about people who are actually on the spectrum, they've got some really great strengths that are really, really neat, and can use visual information very meaningfully. Oh my gosh, I can't tell you how many things my son has that keep him, and it helps make him very independent. But he's able to take in that visual information. Understand and use concrete rules, like I said, if we, if you all have this is the rules for the library, this is when we can talk about your special interest area. They're like, oh, okay, it's almost like that anxiety about what's going to happen, while they're there, just kind of, you know, flows out. They can concentrate on the special topics of interest. When you hear Temple Grandin speak, she's very much about this, this is what they can be doing their lifetime work on. You look at Bill Gates, who is obsessed with electronics and computers and you can see what he was able to do with that. So the trains, I've actually got a friend who said, oh my gosh, higher, high functioning actually got their train conducting license and was, is hired. And doing that. And another one actually works at the Spencer Museum. So able to take their special interests really and turn it into, we say taking their power and using it for good. And that the little ones do learn best through play. These are some things and this is especially important for those of you who aren't going to be here for the second half. So all our Zoom friends. When you're thinking about how you're going to support individuals on the spectrum, these are some things to really keep in mind. Make your directions and expectations very clear. Don't be too wordy. Don't think oh, I've gotta say it nicer so you're adding a lot of more words, be just more very clear and concise in how you're providing that information. Provide information visually, not just spoken. Allow that time for processing. Trevor, you can ask him a question, he's not going to answer you in the first five seconds, it usually takes him about 15 seconds. And if he repeats back to you what you've asked him, that means he didn't understand what he was just asked. So that's kind of our tell that we've got to think about a different way of presenting this to him. Provide follow up and be consistent, flexible and patient. Visual supports, move us towards our success and independence. Neuro – , my friend, I won't mention, I almost mentioned his name, that 140 IQ, he would call you all "typies", you're typies for neurotypical. He would call you typies.

>> A librarian, Charlie Remy, is on the schedule, that's also his term for us.

>> Typically non-ASD or...?

>> For him, it's yeah. For him it's specifically non ASD. People who he thinks are just neurotypical, you're all a group of typies. So we may not, we assume that sharing information

verbally like this is the best way. And, you know, that's an assumption us typies make. But people with ASD may also get part of each of these things because of everything we just went through. So and it just depends, like they're all individual again. So some may be able to take in more. But this is, this is a pretty good summarization of what's happening. And may miss a lot of those key features in the core aspects of what you're trying to communicate. So these are just a couple of quick visual ideas. And this is more rudimentary that is used. You can see this is the order, we're going to do things. Just start here, you can move it over to finish. This is more for our folks who are on Zoom, we're going to get into this a little bit more in depth. One thing, though, that works, I don't care where you are on the spectrum is first we're going to do this and then this. So it's really trying to set that up. So those expectations. This was something that we use for Trevor, for a long time. You know, because he actually learned to read at a young age as well. Now he wasn't hyperlexic, we use a program, but it just makes sense to him. It was like a matrix. You know, that movie, and it was it matrix. You know which one I'm thinking of, with Keanu Reeves? Yes... In any ways, for him words and letters made sense to him. So he was able to pick this up very, very quickly. So this really works. And I'm going to tell you something right now, those of you who have friends or know somebody who's on the spectrum, you're never going to win an argument with somebody that has ASD, you're just not. So, but when you make something visual, you kind of take that argument out of the equation, because they'll be you know, really, you talk about stubborn, can really stick their feet in. But whenever you, you really work towards making things very visual, it kind of takes that out and it makes it much more clear. So that's an example of something I used. There's so many other things and other options available. And it's really just doing some research. The individual has to have buy-in those that that you may come in contact with that are adults or older, or high functioning, they've got to have buy-in and they may design some of their own communication tools. So that's very important. You don't want to dictate. Remember back who wants to be controlled and that we talked about? This is a perfect example. They don't have buy-in and they're not feeling like they're in control of that, it's not going to work. I wanted to put this slide in, because now in today's day and age, there's so much to do on apps and high tech stuff. And so this is one that my friend likes to use, and it's called Paperless. But there's so many other ones out there. But this is what he likes. And the reason why he likes this app, and because he can check off, it actually allows you to put a checkmark, so he likes to know that it's done. But there's so many options that are, that are out there that are available. So I did want to make sure that we talked about that as well, that doesn't have to be something that you're creating and making. There's great stuff you can get on iPads, and iPhones now. I bet we all have stuff too, right? Alarms that go off, our own lists, our own reminders. And so that's the other thing is individuals when they're, they're young, we will start off, we hear this a lot. So we'll put tools in place when they're young, like, oh, they're speaking now, they're talking, they don't need that anymore. This is a mistake that caregivers do, meaning us as parents as well. Oh, Trevor doesn't need that anymore. Now he's talking, he's able, you know, to do this on his own. And then you realize, oh gosh, we're getting ready to go in middle school and high school. And for some of you that wasn't that long ago, and you know, oh my gosh, you've got to be organized, you need to know when to turn your stuff in, all these things. That executive functioning that we all take for granted. Where that's when a lot of individuals, and it doesn't, it's not even just for ASD, I mean, it's the same thing for attention deficit and some, you know, other things that we all, anxiety that, you know, some of us deal with, what have you. This stuff helps us put order to those things. And what happens though, is they'll think that's from when I was a baby, I'm not a baby anymore, I don't need that. So they

don't have the buy-in anymore. So that's just one of my minor little soapboxes, is we've got to carry these things throughout because we all use it. So... And remember, just different is not less. Any questions? From you all, or from the peanut gallery?

>> I have a quick question. not related to library per say. But I know that there's some sort of correlation with genetics and autism. But while we do, I do have an aunt that is on the spectrum. My brother is completely against me testing for my nephews, even though they do display some traits, because he's terrified that they'll be put into like a system or pigeonholed into things. What are your thoughts on that? And are there any ways to do sort of confidential testing? That doesn't necessarily...?

>> Absolutely, this is it mentioned Dr. Piven earlier, and he's got some great research studies that he's doing on all that. So we can talk more about that. But just on how to talk to you know, your siblings, and what have you... No, they're not pigeonholed. You know, it's not like any of us, if we've got, you know, an anxiety disorder or attention deficit or anything else. That's not going to pigeonhole you. And if they were to need services, they're going to need that diagnosis. One. Two, if you know that, that's what you're, and you probably, I know, I'm speaking to the choir. If you know that, oh, gosh, okay, this is why they're having such a difficult time just processing, they're straight A students, everything's going great. But this is why they're having a hard time socially or processing this information, the way that you will help somebody who's on the spectrum is very different. Just the tools, all the things that we're going to be even talking about, like even making things more visual, using apps and reminder, there's some great things that if you know that that's what it is. It's like that light bulb that goes off, like, oh, okay, this is cool, we can figure this out, because they take in use visual structure and strategies are very meaningful for individuals who are on the spectrum. I keep bringing up Bill Gates, but even his wife has post-it notes, and even made him a special book so that he could do a better job socially. He was going around and he would just ask, where's that report I need, but not remembering that you just had a baby, or your parents just passed away or whatever it was. So his wife that made him visuals so that he would remember before he was even talking to people that he could say oh, yes, I'll need to make sure that I, I do that. It's just trying to help, help that aspect of things. So, but we can talk more. There are some great studies being done through the Spark... There's one called Spark and then you know, Dr. Piven's other one that is right here. I don't know if your brother was local. No. But there really isn't, it's it does not pigeonhole. That's, it doesn't that's not like it goes on a permanent record, it's not like a felony. Which, make sure you all make good decisions because they carry with you for the rest of your life. But anyway, is there any other questions from here or...? Any comments?

>> OK thank you!

>> You're welcome. You guys are great. You can get up and move around, walk around for a minute.

>> Thank you -- for those of you who joined us online, we're going to close out now.