REALTIME FILE

Association of University Centers on Disabilities
SENSORY MODULATION: AN UNDERUTILIZED TOOL FOR REDUCING ANXIETY IN PEOPLE WITH AUTISM SPECTRUM DISORDERS (ASD) AND OTHER INTELLECTUAL AND DEVELOPMENTAL DISABILITIES (IDD)
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>> The broadcast is now starting. All attendees are in listen only mode
>> Hello and welcome to Sensory Modulation: An Underutilized Tool for Reducing Anxiety in People with Autism Spectrum Disorders (ASD) and other Intellectual and Developmental Disabilities (IDD). I am a program specialist here at AUCD. We would like to thank you all for joining us today.

Before we begin, I would like to address a few logistical details. First, we will provide a brief introduction of our speaker, following the speaker's presentation there will be a time for questions. Because of the number of participants, your telephone lines will be muted throughout the call. However, you can also submit questions at any point during the presentations via chat box on your webinar console.

You may send a chat to the whole audience or to the presenters only. We will compile your questions throughout the webinar and address them at the end. Please note we may not be able to address every question and may combine some questions.

This entire webinar will be recorded and will be available on AUCD's website following this webinar. There will also be a short five-question evaluation survey at the close of

the webinar. We invite you provide feedback on the webinar and loss provide suggestions for future topics.

Today our presenter will be Dr. Lauren Charlot. Dr. Charlot is a developmental psychologist who has been working with individuals with intellectual and developmental disabilities and severe co-occurring psychiatric disorders and challenging behaviors for over 30 years. Dr. Charlot is Co-Chair of the National Center for START Services Research Committee, an Assistant Professor of psychiatry at the UMASS Medical School and an adjunct professor at the Eastern Carolina University. She has published original research, and has lectured widely on a variety of topics related to the care of individuals with IDD (Intellectual & Developmental Disabilities) and ASDs (Autism Spectrum Disorders) across the United States, Canada and in Europe. Dr. Charlot was a Co-PI with Dr. McIlvane, Dir. Of the E.K. Shriver Center on an NIH funded grant studying depression in children with ID and was the PI for a UMass Medical School Internal Initiatives Grant. She was the lead author on the NADD sponsored DM-ID 2 chapter on Depressive Disorders. Dr. Charlot and Shriver colleagues published research regarding medical comorbidities among psychiatric inpatients with ID. Dr. Charlot has designed and directed multiple acute inpatient and outpatient psychiatric services for individuals with ID and ASD, providing oversight in program development, operations and providing extensive training to personnel within these varied programs.

Please join me in welcoming today's speaker, Dr. Lauren Charlot.

>> Lauren Charlot: Hi, everybody. I'm really happy to be here today to address this topic. Just a quick correction. I don't know if it was clear but the grant on depression and kids is something I did a number of years ago at UMASS. I no longer work at UMASS but I still have an appointment there. But I was there for 15 years and one of the big things that I did there was run a locked in-patient psychiatric unit for adolescents and adults with intellectual and developmental disabilities.

And I draw a lot of my case examples and experiences from working on this unit, especially about learning how to use sensory modulation techniques for people with anxiety who had Autism Spectrum Disorder and other forms of IDD. And I learned a great deal from my colleagues who were occupational therapists. I had a couple who worked with me over time on this in-patient unit and I've applied a lot of these strategies through the years in different forums. I hope that some of what I share today will be helpful to you folks. Thank you for listening in today.

So I'm going to try to talk a little broadly about Autism Spectrum Disorder and the topic of anxiety and then sort of tie it all together with sensory issues and wrap up with a few of my kinds of very simple, not super sophisticated, strategies and tactics that I use in many different settings but especially on the in-patient unit when people were very, very anxious and that anxiety was linked to extreme aggressive behavior, what sometimes people call meltdowns, self-injurious behavior, and challenging behaviors that use those sensory modulation techniques that I learned from my colleagues, occupational therapy colleagues, have been just in valuable in helping folks be less stressed and calm.

As we know, there's a new, fairly new, classification system for autism. We used to have different sub types now in the DSM-5 we talk about autism says -- as a spectrum. So ASD includes core features that are frequently present and then the idea now is to sort of talk about people's individual and unique profile within the spectrum. And one of the things that is very, very common is to have an a typical sensory profile along with the other things that we're familiar with as part of the autism spectrum. In particular, there's a criteria that describes

sensory, atypical sensory challenges that folks with ASD have including being both hyper, over, and hypo, under, reactive to sensory input.

Those of you who are listening who are experienced in working with children and adults with Autism Spectrum Disorder have seen examples of these types of sensory input concerns. And, you know, studies that have drilled down and looked at sensory modulation symptoms find people with Autism Spectrum Disorder, children, adults, different ages, different severity of their symptoms profile in terms of their core features of Autism Spectrum Disorder regardless of any of those factor that there's something going on in terms of sensory modulation challenges.

Other core features of Autism Spectrum Disorder as well tie into this theme I'm talking about today which is, you know, what brought me to learn about the topic or wanting to learn as much as I could about the topic; that there seems to be a relationship between core features of an Autism Spectrum Disorder, anxiety, and then in turn that the anxiety drives these severe challenging behaviors that are the main reason that people with Autism Spectrum Disorder and other IDD will come to clinical attention for psychiatric or mental healthcare, which is most of what I've done for my career.

So there are kind of two sub types of restrictive and repetitive behaviors that are labeled this way in research particularly, including things that we're familiar with like stereotypic behaviors, repetitive motor and sensory behaviors, but also sameness is part of the RRBs, we say. So evidence supports the claim that these restrictive and repetitive behaviors are associated with anxiety in individuals with Autism Spectrum Disorder and possibly the different subclasses function in different ways to either increase or reduce sensory stimulation and that is in turn linked to anxiety.

One of the areas that fascinated me is this issue of insistence on sameness and its relationship to anxiety in particular for people with Autism Spectrum Disorder. So these behaviors that are associated with wanting everything to stay the same and feeling really anxious when things don't stay the same, when things are not predictable, and as expected, seems to be a link to arousal by sensory sensitivity. And also, avoiding sensory input that maybe overwhelming.

The other area that I'm very interested in as a developmental psychologist is some things that we've learned from neuropsychology about executive function challenges in people with various types of inflection developmental disabilities. And it's true, actually with more recent research, that we're finding that you can have areas of executive functioning, your frontal lobe functioning, that are challenged and it's disconnected from your overall IQ. I think people get confused about that and they think of executive function challenges as equated with one's overall IQ. And they're not necessarily at all.

In fact, this particular area that I'm interested in is mental flexibility because mental flexibility, which is kind of like when you get new information your brain lets you take that new information in, make a new plan about how you're going to respond to things, the executive function challenge that is most linked to the kinds of things that I'm talking about here. Especially about anxiety.

So when a person can't adjust their plans on new input, they get stuck and they perseverate. So the risk for these behavioral challenges is greatest when a person has most difficulty with change and problems shifting their response when that change happens and subversive or makes them anxious or uncomfortable. And layered on top of that are issues where many of the same folks have challenges to communication and they're in situations

where they don't control their own environment. Other people are telling them, you know, what they need to do and where they need to be. And sometimes that's putting people situation that are highly anxiety provoking. And then having a tough time telling someone that this situation is making me really anxious, these can be factors that contribute to a bad outcome.

So, just quickly, I won't spend a lot of time on this but neuropsychology taught me a little bit about the background of these executive functions challenges. In particular, if you look at the deck of cards with the different shapes and colors, those cards, it's a test of set shifting that gets used a lot in research. What you'll see that's fascinating is that there's a developmental trajectory for being able to set shift.

And set shifting basically means I've got one set of rules -- for example with these cards -- and I'm going to sort them into shapes. I'll make piles of all the triangles, stars, diamonds, circles. And then after doing that for a period of time, someone will say you have a new rule that you're not going sort by shape anymore, you're going to sort by color. And anybody is going to need a minute to sort of readjust and say, hey, I've got new information, a new rule, I have to have a new plan about what I'm doing here. So hopefully you see where I'm going. How rapidly you can be mentally flexible and adjust to the new rule is somewhat of a test of set shifting.

If you look at small children around the age of 3 to 4, that sort of age transition in that era there, it's really fascinating because before that time, really little kids don't know how to sort and then change with the rule. But at that point a 3-year-old might be able to tell you that I know there's a new rule. But then fascinating, they go on not to follow the rule even after they tell you the rule that changed. The rule changed, I know. Now we're going to do it by color now. We were doing it by shape. And they perceive to not -- they perseverate on the first rule. So it's definitely something that we know has an underlining, underpinning in sort of how our brain's hardware is developing.

On the other side of the screen, we see the Stroop test which is a test of interference control. So what our brains want to do when we see this card -- I don't know if you can notice it but you've got colors and words. And in the beginning they're congruent. But when you get down the list, they're incongruent. So what our brain wants to do if I say read everything out loud is you want to read the words and you've got to stop for a second to get your brain to shift and to name the color though the word and the color don't go together.

So again, part of what happens in when we see perseveration responses, difficulty switching, and then difficulty ignoring input, actually, that interferes with adjusting to a new rule, all of these executive functions are pretty subtle and evident in people who have various types of neurodevelopmental disorders in specific ways.

Another challenge is that research has demonstrated that individuals with Autism Spectrum Disorder in particular have difficulty with following and interpreting facial expressions, looking at faces and being more interested in them than other objects. There's been research about this over the years. But I was fascinated by the fact that people with Autism Spectrum Disorder, in this case there was a study of adults, were more likely than typical volunteers to attribute negative [Indiscernible] to a non-emotional face. So a completely neutral look on your face, some people with Autism Spectrum Disorder will see you as being kind of scary and they'll put something negative on to your flat facial expression.

I remember before I ever saw this research, recognizing that there was a subset of people that we treated on the unit for whom we needed to show in our facial expressions and gestures and not just words that the situation was ok and that you would be safe and that we're

here to help and that we had a calming appearance, perhaps smiling, being welcoming, all of these different things; that demonstrating it not just with words but with our facial expressions.

It's very important to some people who would look to us to decide if the situation should make them anxious or if it's going to be ok. Interesting things, tidbit to keep on tab for giving direct caregivers and others help in how to interact with somebody with ASD who might escalate and become very, very anxious.

It's a worry because people with Autism Spectrum Disorder are more anxious than even other people with causes of intellectual and developmental disability. Sources of anxiety are just so many. Those of you who are experienced in the field know that. But we're going to focus a little bit today on some of the sensory over reactivity that occurs with certain types of sensory input. Sound and light sensitivity and crowds are very common triggers for anxiety and then in turn for other types of challenging behaviors.

In this particular study they labeled people, I think, who were with average or above IQ.s as "high functioning" and those with intellectual and developmental disabilities as lower functioning. But in any case, the fact is that there's a lot of anxiety going on even though I'm worried a lot of times there's non-specific treatment of aggression that isn't really understanding the response of the -- importance of the role of anxiety. In fact, I think we miss it.

My photography here -- I'm interested in taking photos. And this was a beautiful peacock at a resort in Mexico that I went to where they adopted birds who had, you know, difficulties, rescue birds, and other creatures that they had a lot of birds. In fact, this guy every day would go over and the peacock would sit on the sign for where flamingos can be found, which I thought was interesting and an illustration of the fact that things aren't always what they seem to be at first glance.

I really think that anxiety gets missed in people with Autism Spectrum Disorder and intellectual disabilities over and over again as a source of aggressive behaviors and other challenging behaviors. I think people miss that it's fight or flight and not only somebody's angry because they, quote, didn't get their way or these other kinds of things that we hear at times.

It's important to imagine, you know, how we might feel or anyone could feel in these situations where you're both excited by overexcite order easily excited by stimuli and at the same time that you have difficulty identifying your feelings. Particularly when you're put in a situation that is anxiety provoking, not able to say, hey, I can't be here, this is just really difficult for me. And these things together add extreme risk for anxiety.

Another risk factor for anxiety is trauma. And I'll tell you most of the people that I've worked with intellectual and developmental disabilities of all types and Autism Spectrum Disorder, too, have some history of being bullied or more extreme trauma experiences but very few of them that I know have had none, sadly, or especially if you're a person who developed significant anxiety and you have trauma in your history, you are also going to, even if you have a neuro typical history, develop difficulties and challenges in regulating arousal states, negative arousal states in particular. You're going to see things as threatening that other people might not understand that you perceive as threatening.

And another sort of important area to keep in mind is that some people with Autism Spectrum Disorder will overreact to a sensory input because they're more likely to attend to them and have difficulty set shifting. So it's hard to disengage even if it's scary. So they get fixated. But it's a problem.

And I learned one time in a particular respite situation where there was an individual,

a lovely young woman with Autism Spectrum Disorder, Angela, we'll give her that name, would always assault Maribel, was always hitting her. It seemed terrible for Maribel because she wanted to be kind to Angela. And it was very frustrating. And Angela had many more assaultive episodes when Maribel was on duty and I was surprised to find that out. I was looking for all sorts of other contextual influences on increasing the probability that she was going to have a period of time where she became assaultive. And lo and behold, it turned out that Maribel never smiled.

I truly believe that Angela was looking for comfort for something to reassure her. She had a history of trauma, also had ASD, again, a transition-aged youth, very lovely person but she would have these big, violent outbursts I think one the factors was this difficulty for her to get reassured that everything was going to be safe and ok.

So trauma is an important thing to tune into as well. And trauma is something that we can apply sensory modulation strategies with as well because they work for folks who have this issue of sensory sensitivity, sensation avoidance, and even people with a, quote, low registration; meaning it seems like it takes a lot to engage them. This can be something, perhaps, that develops because we're avoiding feeling over stimulated or a person is avoiding feeling overstimulated.

So anyhow, sensory modulation, I'm not an OT, just to make you clear on that point, or an expert on sensory integration, per se, but I have a lot of fortunate experience of working with occupational therapy folks in helping people with mental health challenges who also had IDD. And these interventions in our case, were very specifically ended up using calming sensory input to manage hypersensitivity and physiological arousal associated with anxiety. In the folks that we served, these were all people with IDD and Autism Spectrum Disorder and most of whom the anxiety translated into some sort of an externalizing challenging behavior.

The term in research that's often used is sensory over responsivity or SOR for short, referencing, here, of course, extreme or unusual negative reactions to sensory stimulation. We all have some sort of reaction to these things. But, again, it's an exaggerated reaction. It's very intense. And for the person it's very painful and anxiety-provoking, as we've discussed. And these examples, many of you are going to be familiar with them. If it's too noisy, if it's visually overstimulating, seams in clothing, being touched unexpectedly, light touch versus deep pressure. And what I've learned over time, people and objects, being too close. It can be experienced as really stressful.

It brings me to my major significant case example here about Mathias where his issues were really significant when he was in the 6th grade and in grade school. And at that point, 6th grade, he was very tall, a large guy for his young age. He had a lot of, in quotes I say, behavior, according to his teacher, a term that I don't like because we have both positive eighth negative behavior but they would talk about him having behaviors. Mathias would push other kids. Sometimes he had explosive outbursts, sometimes would end up yelling and really upset and agitated. And he was also viewed -- I think I said hyperactive but I think a little more inattentive and non-compliance. His mother nearly lost her job because she had to pick him up from school so many times. And he was diagnosed with ADHD, attention deficit hyperactivity disorder, and oppositional defiant disorder. And they wanted him to have medication trials. There was a lot of serious stuff going on at this point in his life.

And I'm now going to show you [audio dropped] a number of years ago, a number of years ago still when he was in the 6th grade, and these things that he's going to talk about are very interesting from that perspective. Let me try to bring you to where he starts to talk a little

bit about himself. Of course, he sees himself -- and this is some years ago -- as having Asperger's Syndrome. So he wanted to talk to me about it as a young adult. I think he was like 20 years old.
>> The diagnosis of Asperger's Syndrome.
>> Mathias: Some of those are mistakes.
>> Yes.
>> Mathias: It's hard to tell whether they've got Asperger's Syndrome or something else.
>> Lauren Charlot: Absolutely. Do you have any friends who have gone through that situation?
>> Mathias: Not sure.
>> Lauren Charlot: But you yourself when you were younger?
>> Mathias: Yeah. I was misdiagnosed with that kind of stuff through 6th grade.
>> Lauren Charlot: I remember that. I think that was --
>> Mathias: Yeah, there was actually a bit of a misunderstanding there. I got arrested.
>> Lauren Charlot: You did? That's tough.
>> Mathias: Yeah. It was a tough moment but, hey, I got through it.
>> Lauren Charlot: [Inaudible] you're such a sweet person. It's hard to believe you got arrested.
>> Mathias: I got arrested because I wasn't listening to the principal there at the time. I was in his office. I wasn't listening, wouldn't stay seated and wouldn't stop making noise. I was kicking a cabinet at the desk I stood, was too close.
>> Lauren Charlot: I remember it was amazing to me that once you moved into a new school --
>> Mathias: Yeah, a different school. Everything changed. I was put in the right room.
>> Lauren Charlot: You were. So your teacher kind of understood Asperger's Syndrome or autism-type syndromes, and she really understood you better.
>> Mathias: Yeah.
>> Lauren Charlot: She really got you. And then all of a sudden you started getting fabulous grades.
>> Mathias: Yeah, especially in high school.
>> Lauren Charlot: You got high honors in high school. Great.
>> Mathias: That's a tough one to do. You need at least a B full-on average for the entire quarter.
>> Lauren Charlot: That was really, really awesome.
>> Mathias: I did not even expect that. But as soon as I got that, then my grades started to [Inaudible] a little.
>> Lauren Charlot: Do you remember back before people really understood you in school?
>> Mathias: Actually, high honors is marked B, B-plus.
>> Lauren Charlot: And A's, yeah.
>> Mathias: Yeah. It's mostly Bs and As while the best one is all As [Inaudible]
>> Lauren Charlot: You did very, very --
>> Mathias: That's the best one.
>> Lauren Charlot: Did very well.
>> Mathias: I did not even expect high honors.
>> Lauren Charlot: Going back a quick sec. When you were in grade school, and people really didn't understand you, there were things that just bothered you, like being too close, the desk being too close to you, and the lines, the crowds.
>> Mathias: That didn't bother me as much.

>> Lauren Charlot: What were the things that bugged you?
>> Mathias: Namely people getting too close to my personal space.
>> Lauren Charlot: Ok. That was tough.
>> Mathias: Without my knowing who they were at the start. Trying to get along with them.
>> Lauren Charlot: Right.
>> Mathias: I try to get along with anyone, even a teacher, to be quite honest. I actually want to get to know the teacher a little bit more so I know what I'm to do correctly.
>> Lauren Charlot: Yes. Because I don't think I've ever met anyone who cared as much about doing the right thing. You're a really good person.
>> Mathias: Yeah.
>> Lauren Charlot: You are. It's really true. You really always want to go the right thing as long as you understand.
>> Mathias: Yeah. I got to understand that sometimes I still do the wrong thing not knowing it.
>> Lauren Charlot: Well, guess what. I still do the wrong thing not knowing it, too.
>> Mathias: Oh, boy. I don't know why I'm doing something wrong --
>> Lauren Charlot: I'm going to stop right there. It's a long interview. But I think you get probably the flavor of the type of guy that Mathias is, just kind of a sweetheart who got dragged off and handcuffed. He was scary and still can be if he loses his temper and he gets upset. But clearly he had some super sensory issues early on. And he also didn't get his diagnosis in the autism spectrum because he was a really bright kid but clearly in the spectrum and suffered a lot with the sensory over responsivity issue and not being understood. It wasn't well understood that he had the Autism Spectrum Disorder in the first environment he was in.

I learned a big lesson because his psychiatric symptoms disappeared when he got into the right environment, where people understood his Autism Spectrum Disorder, taught me a big lesson understanding individual humans and how they're hardwired and what makes them function and what are their strengths and challenges are very important things if you try to help somebody who may have distressed, induced, challenging behaviors of various kinds, anxiety, etc.

So there's various hypotheses about the sensory over responsivity. Does anxiety cause it or does it cause anxiety or is there some third factor that's involved? It is sort of one of those chicken and the egg things. I was interested in this longitudinal study of toddlers with Autism Spectrum Disorder and it showed that the sensory over responsivity was evident very young. And what developed over time was more and more anxiety. And not only did more and more anxiety develop over time for these kids, it was also that the things that would trigger anxiety would grow outward from the original stimuli that caused it.

So, for example, a kid who they speak here about got really overloaded at a birthday party that may not even go into the room where the party was held after a while because they anticipate there's going to be something really -- aversive sounds at these locations and I think that's what we're working with at times with people like me who get called in to consult and folks say it just comes out of the blue; we have no idea what's going on. And sometimes what's going on is like people with trauma and like people with these sensory issues, you know, there's been an expansion of the things that are viewed with a sense of anxiety and distress and will provoke one of these kind of -- what my niece would call Mathias meltdowns.

Anyhow, we all have sensory profiles. It's a matter of, you know, again, whether you have extreme reactions to certain types of sensory input. But I think we all have a profile of one kind or another. And there are some things that just universally people respond to in one way

or another. I worry particularly about people with ASD and IDD about internal sensory states that uncomfortable and not being able to describe them to others. It's part of my work to research when we miss medical problems, pain, fatigue, and medication side-effects as causes of distress in people with IDD.

I'm going to show you quickly this checklist. I gave you the website. Please check it out for yourself. Sensory processing disorder checklist. It just has a good, long list of items that you might want to ask about if you're trying to develop an individualized profile to use to inform some interventions to help somebody who has these difficulties. In the interest of time, I'm just going to mention a few. And they have multiple subgroupings, visual sensitivity. We touched on a little bit. I've seen classrooms for kids in a special school that I went to for kids with ASD and it was just so overstimulating and it had to sort of tone it down. Sound sensitivity is the most common one that we find in particular. And it's not always just loud sounds. It can be very specific sounds that get people stressed. Interesting.

And back to my bird experience, the many flamingos that I alluded to, there was a whole bunch of them in a little area of water and a bridge, a walking bridge that went over their area. And fights would break out each time a tourist took a really loud roller board over the bridge in the flamingo area. There would be what my daughter and I call kurfluffles. It was clear it caused them upset and anxiety. And then they would end up fighting with each other. The attack would go on whoever happened to be next you at the time. And there was a lot of marching around, a lot of distress in response to this sound sensitivity that these guy has as well.

There are tactile sensitivities. Mathias would not like light touch but, boy, he could give you a bear hug or you could give one to him and he liked that very much.

So thinking about pathways, again. For me it's really important that we do comprehensive assessment that includes looking at sensory areas and atypical sensory profiles. I think we can see a pathway between this over responsivity leading to anxiety and then you're in these situations or a person with ASD who has this is in a situation that provokes anxiety and over time learning to react to associated stimuli. And then you get, in the end, this fight or flight response. And caregivers will see this sometimes as, again, like he didn't get his way or it came out of the blue, other kinds of reactions when I really think if you track back and look carefully and examine contextual influences is what I would call them, you can find that the sensory challenges are so critical so often.

And then aggression really is not really specific to any particular factor that might influence it. So we really have to treat it almost like a fever. When you go to the doctor, the doctor has to find out if your fever is due to, you know, a bacterial infection or something viral or something entirely different. And each time it could be something different.

Many of the people that we served on my in-patient unit, particularly a lot of people with ASD, with the sensory modulation challenges, were at the root of the anxiety-related depression and other externalizing behaviors. And not just people with ASD, many people with IDD as well. And what we would see is this fight or flight reaction that's really -- at the time earlier in my career I thought most of these folks looked like people in a panic and that it was self-protective. And then you would see people, you know, avoid certain experiences and then overreact if they're stuck in a situation that they felt the need that they had to escape that situation.

So goals of using sensory modulation, kind of in general for me, it was about trying to get people's autonomic nervous system arousal down because they were -- when they

overreact, you see people, they're sweating, people could tell you their pulse is racing when you have a panic. If you've ever experienced panic, you would know it's a pretty scary thing. And you'll do almost anything to get rid of that feeling.

Now, many of us use lots of these kinds of techniques I've listed here to help people with anxiety to help ourselves deal with stress. We might use physical exercise or yoga, lots of different strategies that can also be used with people with intellectual and developmental disabilities of various types to help them relax.

One thing I learned is that you can't just use these things like deep breathing in a reactive situation when somebody's already escalated and very, very anxious because then deep breathing turns into, I learned early on, hyperventilation. And I learned that, you know, as a young clinician that it was really important for people with ASD and IDD that we had a daily diet of these things. And I learned again from my colleagues with occupational therapy colleagues, actually very early in the career, about using diets.

Really a goal was to get that autonomic nervous system set point higher. Because people had this really low threshold for being overwhelmed. And you want to actually go into training. So runners aren't able to do a marathon day one and people with ASD and IDD who tend to get overly anxious rapidly in response to sensory input, that's distressing to them. It takes a long time and regularly to build up your system such that you have a better setpoint. So you want to sort of reinforce or strengthen what that individual person benefits from in terms of relaxation strategy using a lot of sensory modulation kinds of techniques which I think are just the best.

And often, you know, it's simple things. And the strategies involved using less versus more in many situations, even though I have a long list of things here, quiet spaces used to call it minimalist decor, soft, low lighting. Bean bags, thick, soft rugs, soft blankets. We used to have really cool lighting in our sensory room on our unit. We had weighted stuffed animals which, I don't know if all of you are familiar with it but you can go buy a stuffed animal, take the stuffing out, and if you're able to sew, unlike me, you can fill it with I think beans and sew it back up and Velcro so you can take it out and wash it. But these were heavy. So we had a big stuffed dog and you could sit the stuffed dog on your lap and sit in the rocking chair.

There was one gentleman in our unit who used to love, according to his family, a tight tuck-in. So at night he loved you to tuck him in really, really tight and feel that deep pressure. Rock chair, soft music, noise-canceling headphones, lots of sensory toys or items like Koosh Koosh, etc. A lot of these very simple strategies can be helpful to have around in spaces where people can be off and on during the day.

Avoiding activities in loud crowded areas sounds like duh but I can't tell you how many times I consulted to people who had sound sensitivities who went to the mall with their groups of kids or adults on outings. Avoiding activities that there's too many people. Allowing lots of time when meeting new people because anything knew, as we talked about, can be stressful pairing what we call preferred people, which is an interesting term, but I knew that on my unit I had a staff person in one particular who was just this fabulous fellow who just seemed -- a big, tall, gentle giant kind of guy who really connected with folks quickly. He had I think facial expressions that were calming and welcoming and always found ways to develop rapport quickly with people and help them feel safe and comfortable.

So these are very basic kinds of things that will help people who get sensory overstimulated and become anxious, very simple kinds of things. And we don't want to wait until somebody's already feeling awful to try to be helpful. You want to do things every day or

multiple times daily.

We use kind of the principles for desensitization. So, you know, being calm, I find is what helps people being calm. The more you're calm, the more you're calm. I used to work with people called adaptive physical educators. They would develop routine, an exercise routine. Sometimes it was just walking. If we have to adapt our breathing exercises when we use them preventively, it might be a little time where we're blowing on windmills and having fun, blowing bubbles, other kinds of things where you take a deep breath naturally, and using tons of visual supports for learning are exercises we might use or sensory modulation routines.

So in my early life I used to write positive behavior support plans. I wrote them for people on the unit. But we use like a broad model where a lot of our focus was on understanding antecedents, including remote antecedent conditions. You know where we're really looking at what are the potential contextual influences. And also the contribution of the individuals what some people call vulnerability but sort of what they bring to the situation. So somebody has Autism Spectrum Disorder and the sensory sensitives.

And then what situations are they in that are difficult for them? You hear about escape maintained aggression. Many situations are worth escaping, I would say. And you worry about people not using operant can being situations, understanding that because you can't say you're not going to get your reward unless you tolerate this terrible situation. That makes you terribly anxious. It just builds anxiety and it doesn't work.

Also, that attention seeking is normal human behavior. We like to promote it. And some people with Autism Spectrum Disorder it's a big thing. Mathias, you know, when he would isolate himself when he was younger, it was to get away from the crowd at my house. Because he always came when there was a party. So it was tough on him. But he loved his people. He loved me. Used to give me big hugs. I used to say don't break. Because he hugged really tight.

Anyhow, the issue is not that somebody wants attention but we really want to know why they want attention, what kind of attention they're seeking. Do they need comforting. Is the person lonely? Do they need help? Do they really want something that they need help they can't get on their own? All of those things are normal human things. And what we want to do is help people if they need skills to ask for help. We work on that. And we work on helping them, you know in a more positive way meet their needs instead of denying their needs.

So, the other important thing is to build success in whenever you're developing interventions for people. On our in-patient unit in particular we would have low demands until we established way that people could experience their routines and still be calm. We used a lot of transition tools. There are many. Using a visual schedule, place the completed item, picture, on the schedule, take off the next one. Many of you will be familiar with these strategies. Bring one item over to the person running the next activity to keep you busy and keep your hands busy. Having something nice that helps you jump-start the less preferred activity that you might have to engage in.

We have to choose our battles. There's some things we can't avoid in that part of life and we need to learn to do but we can always try to make the things less aversive for people. And be creative as possible in doing so. In terms of when people are escalating, potentially getting really anxious and that they might engage in some sort of a challenging behavior, I found distraction to be awesome.

Those of you who are familiar with the START model, I work with START often. They have a cross systems crisis plan with different stages in it. So in the early stage, like a

stage one situation, somebody might need help to find something that distracts them from being about more anxious. For example, I worked with this fellow and his staff discovered that if they had his puzzle out on the table, because they were hoping to distract him when he was getting anxious to do his puzzle, he'd want it put back. "Put it back." "Put it back." He just wanted the table cleaned up. And they would ask him to do it himself. And when he got finished, it took him a while to pick up all the pieces, he was calm. Because it distracted him. He wouldn't do the puzzle but he would pick it up. So I thought they were very creative because he could get very violent when he escalated.

Lots of different things that you can do will distract somebody. Hopefully you can find distractions that are fun or whatever. But when people are really past the point of having a chat, and many people with autism spectrum is disorder, talking at them when they're more anxious is not helpful, you want to go be in a calming place and use some of these sensory strategies. I love sensory kits. They're portable, individualized. They could be used, you know, in a more preventive manner. And just identifying individually the things that help people feel soothed and calm. Really relied on the sensory interventions in many, many cases over the years.

This is a video. I don't want to run out of time for questions very quick let's see. This is Temple Grandin.

>> Temple Grandin: Sorry if I'm sneezing.

>> There's a lot of that going around. I want to know if Temple's redesign on the machine you made in college, do you still have that squeeze machine today?

>> Temple Grandin: I do. It broke around five years ago. I didn't get around to fixing it. There's a lot of simple way that you can do pressure. Pressure is calming to the nervous system. You may have heard of things like the anxiety wrap or the thunder shirt for dogs, that deep pressure helps calm them down.

A lady named Camille, I helped her with study on the thunder shirt. It does have a calming effect. If you do pressure, only leave it on maybe 30 minutes, 20 minutes, then take it off for a while. Don't leave it on all the time. Do simple things, weighted vests. There's a future -- they sell these cute lizard toys that are about this long, stuffed with rice that are heavy. Like weighted blankets. There's a lot of simple ways to do pressure.

Again, autism is extremely variable. It doesn't work for everybody. See, this is the problem with this diagnosis. You got so many subgroups in there. It's simple to try a weighted vest. In some cases it can help with fidgeting some it doesn't. Sitting on a ball, makes them bounce. Sometimes doing things like weighted vests, swinging, or sitting on a ball can help get speech started.

>> Lauren Charlot: So anyhow, just -- I threw in a little bit of Temple talk about deep pressure because that was something we made a great deal of use of. And you do need a plan to help you so that you don't, like Temple said, overuse it. But these are strategies that can be very helpful.

So quickly, in summary, it's now recognized as sensory challenges, a very usual part of Autism Spectrum Disorder. We all have variable profile. The focus here is on sensory, over responsivity and how it's linked to anxiety and how that, in turn, drives challenging behaviors. That's been my work. Kind of help folks who are distressed and engage in any challenging behavers and making sure that we get to the root causes and don't just suppress the challenging behaviors but understand somebody's suffering from situation like this.

Also, recognizing that often what we're seeing is fight or flight, that somebody's

becoming anxious and that's what's driving the challenging behaviors. And if the source of that is the sensory over responsivity, the sensory modulation interventions can be extraordinarily helpful. We want to use them as a prevention as much as possible and early intervention, strategies, you know, of course work best.

So ready for some questions.

>> So we now have time for questions and answers. You can type the questions in the chat box and I will read the questions allowed for our presenter.

We have one question here. Do you have any applications or apps that you recommend for breathing/calming?

>> Lauren Charlot: That's an excellent question. I don't. It's probably because I'm old. [Laughter] Not as up on the apps. And I actually -- one of the people that was working with me in the clinic who is not there any longer used to find me all the apps for these things.

So I apologize I don't. But I'm sure somebody would be able to find you an app. There's got to be an app for that. We just did the old-fashioned thing. We used to do a thing called square breathing. A lot of using things, like I said, with folks, that were fun like blowing bubbles and other things. Because you know when you blow a bubble, you have to make that big, blowy thing happen to get a good-sized bubble.

>> Yeah. We had someone else say that they use Stop Breathe Think for kids. And it has visuals and fun ways to focus on breathing.

>> Lauren Charlot: Yes, I had forgotten about that. That's definitely one we used to use.

>> Ok. We have another question here. Do you have any studies that demonstrate the effectiveness of weighted vests or pressure vests?

>> Lauren Charlot: It's interesting. I didn't get into it because I realized this was a short amount of time to talk about the topic. I am not an expert in sensory integration. There's kind of a debate like is there really good research evidence for some of these strategies. But most of the time they study them, they're not studying what I'm really interested in. Like do these specific techniques work to reduce anxiety?

I think, you know, they use the kind of outcome measures they use aren't specific to reducing anxiety all the time. Sometimes. But there isn't a lot of great research. It doesn't get as much funding or attention as it should. But there's some research throughout that suggests it can be helpful. It's just not studied enough is my belief. And especially this aspect of using, specifically using, sensory modulation for anxiety reduction. I think it's just study design is challenging. How do you design the study where you can prove this is what's helping somebody become anxious is a little bit --

>> Ok. We have another question here. One second. Do you have any sensory questionnaires or observation checklist that you like to use for helping identify these types of anxiety?

>> Lauren Charlot: Generally I would engage in OT to do the initial assessment. I use different ones. I showed you one. There's actually the website right there, in the handout that you can get hold of, I understand. I sent them a pdf. It has that link. That's I thought a pretty good one.

This was very thorough. It had a lot of different items. I would use something like that. And we had a slightly shorter one that we used to use, I'm sorry I don't know the name, but, again, I had an OT on my team. They would do the screening and then I would develop a plan with them on what we were going to do to reduce anxiety.

>> Yeah. Ok. Another question. Do you have any experience working with persons who experienced Pierre Robin Syndrom?

>> Lauren Charlot: I have. And interestingly, recent research shows that this set shifting

challenge that I was describing to you is greater actually both in people with [Indiscernible] syndrome and person with [Indiscernible] syndrome than people with other syndromes like Down Syndrome, Williams Syndrome, or other syndromes that are sometimes associated with Autism Spectrum Disorders and are often associated with intellectual disabilities.

But that's -- that specific problem is more common for the folks. Interesting that people with Fragile X who have that problem are more prone to anxiety than people Prader-Willi Syndrome. In either case, it's associated with people having challenging behaviors. Certainly people with Prader-Willi Syndrome have this excessive food drive but they have a lot of these sensory challenges as well.

>> Ok. Are there any ideas on how to engage in meditation?

>> Lauren Charlot: I think sort of guided meditation strategies -- the population that I worked with, very few people that we would be able to do that with. But what you could do and what I've done with some people is develop things like a PowerPoint or other more visual guided relaxation kinds of things.

We used -- actually, some people would really respond to a particular therapist. I had an outpatient clinic and they would respond to the therapist voice. So we would tape record -- you talk about how long this was. We had tape recorders. You didn't do it on your iPhone. We had tape recorders and we would record soothing, you know, verbiage of various types walking people through relaxations. I think sometimes it was just the sound of a voice that was familiar, someone that when I'm with them, I feel calm. It was so helpful that kind of thing.

>> And we have another question. My 12-year-old son with Down Syndrome has always gotten upset when he hears babies crying or dogs barking. But it seems to have gotten worse. His reactions are escalating to aggressive yelling, hitting, or throwing. Distracting sometimes works but his reactions are consistent and stronger. What tips might you have for redirecting or desensitizing around these two specific sensory inputs?

>> Lauren Charlot: Well, I think -- I hope my message was that we can have all the tips in the world about what to do after somebody's getting upset but I think it's like sort of what -- I hope you saw in the presentation. It does grow and get worse if you can't get ahead of it. So my suggestion would be to be working with perhaps if you can engage would be best but working with someone who can help you have a preventive routine. It's not going happen overnight. But working on this over time over the long haul means having a daily diet of sensory modulation interventions that help him be more tolerant in a very slow, progressive way.

Because you can't do it all at once. That's my experience. In our out-patient clinic we would be working with somebody for a year or more trying to get them to be able to tolerate various sounds. And, again, using principles of desensitzation and relaxation.

>> Have you found that people who have ASD and are non-verbal have more subtle ways of expressing anxiety in addition to pacing? Could declining activities or choices be a sign of anxiety?

>> Lauren Charlot: I think that's an excellent point and I so think that's true. I've seen it many times. I think -- I don't know if you've experienced, any of out there have experienced this, but people get labeled as non-compliant and then sort of get forced into routines, they're really trying to tell you that I'm worried, I'm anxious, I'm really unhappy in this situation.

I always try to first presume that I need to understand why somebody's refusing an activity or why are they pacing or why is this happening and why is it happening now. And then, you know, really try to drill down and find out is this a sensory issue and is this anxiety.

Because I believe that anxiety is under recognized in people who are non-verbal, especially. So it's a very excellent question.
>> Ok. And how do you encourage a non-preferred classroom activity without causing anxiety and avoid reinforcing that aggressive behavior that will result in avoiding the task?
>> Lauren Charlot: That's an excellent question. In the two minutes left -- again, I would be working on -- I talked about building success and raise the bar slowly. So you try to get people in a -- you get kids in a situation where they can be as supported as possible in all of those way that's talked about to get through something and be successful, then relax a little, then do a little bit more, then relax a little, then do a little bit more. But you slowly raise the bar. It's a long haul to conquer these things.

So amazing that being successful happens more when you're successful. So I think that's really the key. Taking baby steps and not expecting someone to sit through an entire lesson getting aggressive from the get-go. It's have a little bit of success, highly supported in whatever ways that you need to, depending on what's influencing that aggression. Is it that I can't communicate when I need help? Is it the environment is not great? I just don't like this stuff? I understand that happens, too. Working on all of those. Just understanding. Knowing it's going to take a little while.
>> Thank you so much for that, Dr. Charlot. And thank you all for attending the webinar. This webinar has been recorded and will be archived in the webinar library at aucd.org. If you would like any more information about the Mental Health Aspects of IDD Special Interest Group, please feel free to contact us.

Please take a few moments to complete our survey.

Thank you.