TSBVI Coffee Hour:

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David Brown

Part 1 - Availability for learning for children with multisensory impairment

>> Kate: Good morning, everyone. We've got quite a few people joining us this morning, so we'll get started in a couple of minutes, get everyone in the room., but welcome. While we're waiting, if everybody would go to the chatbox, there's a little dropdown menu. Please make sure that where it says "To," it says "All panelists and attendees." So that way when you put something in the chat everyone can see it, otherwise it will just come to the panelists. Nathan just put that in the chatbox as well. Good morning, Gianna from El Paso. Welcome, Holly. We've got Tony as well. I did hear it was snowing in Arizona! You guys are lucky. I'm a Utah girl, Utah mountain girl so I always miss the snow. We have Denver, Albuquerque, Washington. Oooh, there's a lot of you from a lot of places. This is great.

>> Brown: Alamogorda. I've been there.

>> Kate: Nice. Also snowing in Michigan. That feels typical. I love Michigan. My God-sister is in Pentwater. We'll get started in a minute. We still have a few folks coming in. Good morning! Hi Debbie.

>> Brown: Someone in Germany.

>> Kate: Yeah. Minus 35 in North Dakota!!?? I'm so sorry. I'm so sorry. Good morning, Alderbrook. Great. We'll go ahead and get started. I have some announcements for you all and then we have lots of time with Mr. David Brown today and we're so excited about this. Okay. So just by way of announcements, again, welcome. Welcome, welcome. We are so excited about this session that we are doing in conjunction with the western regional early intervention conference. And since the conference is virtual this year and kind of this different format, you can consider this the opening keynote address. So welcome. Welcome to REC and welcome to coffee hour. If you have a question or comment during the time that David is talking, please post that in the chatbox. Be sure again that it says "All panelists and attendees" in the chatbox. We'll try to keep up with questions and whatnot, but that's where they will go. Your microphones and cameras are automatically muted so you don't need to worry about them. There is a handout for today. We'll share the link in the chat so that you can access that. Later you will be able to access this handout and other resources of past coffee hour sessions through a link on our coffee hour stage at TSBVI.edu/coffee hour. You will see the coffee archives and that's a link that takes you there. Please note that we are not recording the session today but there is a handout for you to have for information. To obtain your CEOs, including ACVBR credit, you will respond to the evaluation emailed to you from our email mailbox TSBVI works. You will enter the code that I will give you at the end of today, all right, so there's just one code, there's not an opening code. You will enter that into the evaluation and then your certificate will generate when you've completed that eval. All right. We will stop the presentation at 2:55 central time to give you the code and some closing announcements. Please know as well that we will have a short break, 10 to 15 minutes, in between Part 1 and Part 2. So David Brown will announce as we get there. So without further adieu, I'm so excited to turn the time over to David Brown. I'm going to ask him to introduce himself more. David, again, thank you so much for spending the time with us. We are so excited to have you.

>> Brown: Thank you, Kate. Let me get my slide show up there. I hope you can see it. All right. And now I can't find the chatbox.

>> We're not seeing your slide show either, David.

>> Brown: You're not? So what's happened. Oh, I have to do share screen. Sorry. And I'm going to use presenter view, which means the big slide on the left of the screen is the one I'm talking to and the smaller slide over on the right in theory is the next one coming up, but sometimes I skip them. But this facility allows me to see all my slide show down at the bottom of my screen and I can Zoom forward and back and skip things. So I hope you're not too distracted by having the other slide there. And sometimes you might see an upcoming slide which I then won't deal with, and let me know if you're really disappointed if it's something you were hoping I was going to talk about. Good morning. It's 9:00 in the morning here. It's a beautiful day in San Francisco, but we're having rain later. We're very excited. We're in deep drought, and we're expecting rain this afternoon and all day tomorrow and all day Thursday. Unfortunately they've now told us it will be torrential rain, and they've issued all sorts of warnings. And some people have already been evacuated from areas where they're expecting landslides and mudslides. So at the moment it's like the peace before the storm. It's about 68 degrees and beautiful. The sun is shining right on my window next to me, which is why it looks a little dark because I have to pull the blind. Well, a little bit about me. I'm from Wales in the UK. So I'm not English, I'm Welsh. And I began life, my professional life as a high school history teacher. I was a complete failure at it. I did it just for one year. And I was lucky enough to meet some children with disabilities at an autumn fair, children with down's syndrome and a couple of people with orthopedic disabilities. And I enjoyed my time with them so much that I started volunteering at a residential home for children with disabilities. And after I gave up history teaching I went into residential care and I worked at that for four years. And I don't have children of my own, but I worked with a huge range of children, some of them permanent residents and some of them there temporarily. And I learned a lot about being up all night and cleaning poop off the ceiling and all those kinds of things. And then after four years I was asked to join a non-profit who wanted to set up a home visiting program for families with young children with all kinds of developmental difficulties in north London. And that got me to be itinerant. It got me into homes and eventually into schools and sometimes into hospitals, which is what I've done ever since. Even when jobs have changed I've always been itinerant. And initially in the UK early intervention, but subsequently working with the whole age range through the educational system. I joined the DeafBlind association in England in 1983 so I've specialized in DeafBlindness for 20 -- 38 years now. And the first child I met in that job was a 10-old-month baby boy with CHARGE Syndrome, which was brand new and nobody had heard of it or knew anything about it. And of course, I've worked with a lot of children with CHARGE Syndrome over those 38 years, and those children, I will mention them quite a lot today, even though I'm talking about the whole population of children with multi-sensory impairment,s, because they are the most multi-sensory impaired as a group and they teach us all kinds of things. I've learned so much from them. I notice quite a lot of people on here who know me and have heard me present, and a lot of my slides will look familiar and a lot my anecdotes will be familiar, and I just commend you for coming back and volunteering to sit through this once again. I'm obviously talking about generalities, so if you do have questions, they're very welcome, but I think it's important that you don't get too specific in your questions. I can't really deal with a question like "We have a boy who keeps banging his head. Why does he bang his head" that's one I get asked quite often when I'm presenting like this. But I'm hoping that those kinds of questions, if you have those questions in your mind, some of the things I'm talking about will perhaps put a little spotlight on those issues and perhaps give you an idea of why things might be happening. And I've made a note here that says attitude. Today I'm talking more than anything about our attitude to the children. Ostensibly I'm talking about the children, but really it's about our attitude. If our attitude isn't right, nothing is going to work and our educational approaches won't be relevant and won't achieve things. So if you feel challenged by the things I'm saying, that's good, that's excellent actually. I'm not having a go at anyone, but if you sit there writhing because I seem to be criticizing all the things you've done, just be aware that I've been doing this for 38 years and I used to be dreadful at it. My approach to assessing children was to strap them in a chair and make them do things and it took a long time for me to realize that there were other ways that were much more effective. Now, I've never done like a four-hour webinar before and it feels a bit daunting to me at the moment, and it probably feels a bit daunting to you. I've created two slide shows, but the first slide show is much longer than the second, so if we have a break halfway through the break won't come between the two slide shows, but don't get too concerned about that. But the two slide shows are linked and do follow one from the other. I have to thank Nathan Widener in Texas because he's been helping me with the tech support. He looked through my slides yesterday and he found some of the links in some of the slides were out of date and I'm very grateful to him. Late last night I saw his email and I was able to correct and update the links. And right at the beginning I will give you my email address and I know that's a bit risky given that we have so many people tuned in today, but it takes me awhile to get back to people, but I do try and respond to emails. If I get a lot sometimes I miss them. They get pushed down in the inbox and sometimes I find them months later. But if there's anything that you feel I could be helpful with like resources or ideas, then I'm up for that. I've been retired for six years so in theory I've got time to do that kind of thing. Okay. So one last bit of explanation. I'm by nature a synthesizer, I am a synthesizer. I see connections all the time. And the connections lead me -- I can be focused on one thing, see a connection and go off to the connection. And my presentations are a bit like that. I look through the slide show and I can see all kinds of jumps I've done in my thinking as I'm putting the slide show together. But everything at the end I hope will add up and make sense. So I want to start with four basic propositions. First of all, DeafBlindness includes the most complex conditions that we know, and the unique combination of true multi-sensory impairment with multiple other anomalies can lead to extreme variability in functioning and periods when the child may be unavailable for attending and learning. And that's built in to the situation. Proposition 2, the right educational program for each individual child with DeafBlindness never already exists, but must be created. The program must be fitted to the child, not the child to the program. I realize some of these propositions are very hard to impose on reality, but I think it's important to lay them out as non-negotiable ideas right from the beginning. Proposition 3, that a successful and appropriate educational program begins and depends upon skilled assessment which is flexible, ongoing and sensitive. Every child with DeafBlindness can be assessed successfully provided the people doing the assessment know what they're doing. And I'm sure a lot of you have a wry smile on your face because we've all worked with children who can't be tested, they're untestable. You can't assess them. They don't cooperate or they're too disabled or some other kind of nonsense. And I will address that later on in this session. And then proposition 4, that anyone responsible for designing and delivering a child's educational program needs some familiarity with DeafBlindness which is kept up to date. With the increasing amount of information about DeafBlindness now available, this is perfectly feasible. Because of the Internet we're in a very different world to the way things were back in 1983 when I started. And when I had to go to various libraries at the royal national Institute for the Blind or the Royal National institute for the deaf or the British medical association and I had to paw through volumes in order to find articles and things like that. So those propositions kind of set the scene for the whole day. And at the beginning the longest session I'm going to be talking primarily about the senses and sensory systems because that's the start of everything. And then I'll talk in a little more detail about assessments. And if the time allows I'll say quite a bit about assessment. And I'm hoping by the end of this four hours that you will have perhaps a better understanding why a child might be doing this. You see a boy aged about six standing on his head with his feet back against the wall. He's standing on his head and his two hands. His feet are bare and pressed against the wall. In fact, he's pushing with his toes quite hard on the wall. This is him taking a break from a lesson that he's doing sitting at the desk. Here's a boy with a high chair with a tray, but he's not sitting in the chair, he's got his -- he's kind of up, facing down, his calves are on the back of the chair, his body is stiff like a planning. He's resting on fully extended arms on the tray and he's looking very intently at a tablet. And I don't know if it's a video or a game. And the point of these pictures is they're the kinds of things people say oh, that's bizarre or that's crazy or he does weird things. And I'm hoping by the end of this session none of this stuff will look crazy or weird or bizarre. It will look functional and adapted behavior. Functional adaptive behavior. Here's a baby doing something babies never do if they don't have specific orthopedic disabilities. He's crossing his fingers. You see his hand and his two middle fingers are crossed. This is voluntary. He does it with both hands and he does it for purpose. And I found this meme recently. It's that keep calm series. And it says "Keep calm and fingers crossed." And if you think about that and look at this baby's hands again, it might help give you an idea of what's going on. Is this baby calming himself? What he's actually doing, I think, is giving his brain a better understand of where his arms and his hands are. And once the brain is feeling the body better effectively, anything that helps the brain get in better contact with the body will be innately calming. So you know, think about teaspooning calm. Think about waking yourself or calming yourself down. Here's a boy at the pool. You just see his legs on the sun lounger. And he's got wonderful trunks on covered in skulls and cross bones. And he's realized the rubber slats on the lounger are quite loose and he can weave his legs in and out and get his legs kind of bound so that he's more effectively fixed. Two more pictures to begin with. This is a boy in a classroom wedging himself into a narrow shelf. It's the bottom shelf and he's pushed himself side ways into the shelf. His head is compressed. He's pushing with one hand to the top of his forehead and he's pulling his feet back to extend his knees up so that they press on the bottom of the shelf above. And the text is from my colleague Tim Hartsong, who said many people seeing this would say that's weird, it must be autism. And I left that there just as a reminder, when we see the crazy, weird, illogical stuff, I think it's important to look for an explanation rather than a label. And it's too easy to say that's autism, that's OCD, that's ADHD or whatever label you're into. I think it's much better to think what's this boy getting from what he's doing. And last picture, here's a young lady asleep in her cot. She's flat on her back, but her legs are extended up the side of the cot. One leg is pressed with the knee bent against the wall and the other leg the ankle has been brought right up and it's pressing on top of the other knee. So there's an awful lot of twisting and deep pressure going on in the lower half of her body quite deliberately, but she's fast asleep. And when you look at these pictures, when I look at these pictures, I'm thinking about sensory diet. And their sensory diet it is a concept that comes from the occupational therapy field. Specifically from the sensory integration therapy area of occupation A therapy. And what sensory diet is very simply, very crudely, is the kind of sensory input that a person looks for or wants or gives themselves. So just as you have a nutritional diet of the food you want, and I give these examples, there are times that you need to drink and times when you actually need food. Times when you want a cold drink or a hot drink. Times when you want savory food and times when you want sweet food, it has to be chocolate, and your body tells you that very clearly. And I always -- full confession, my body sometimes tells me that it wants a single malt whiskey and I don't overindulge, but there are times. And when I heard there are over 400 people signed up for this today, my body suddenly decided it would love a shot of whiskey. I didn't succumb. But that's the nutritional diet. Sensory diet is the kind of sensory inputs you want and you're looking for. And when we look at these children, I'll go back. Is the boy standing on his head, here's the boy resting on his arms on the tray of the table. Here's the baby with his fingers crossed. The boy with his legs wrapped in the rubber straps of the sun lounger. The boy squeezed on the shelf. And the little girl asleep. They are all in different ways giving themselves sensory inputs. And in most cases it's the proprioreceptive sense that they are trying to stimulate and I will talk a lot about that in a moment. I just looked at the chat. People are -- someone's thrilled I mentioned single malt whiskey. I just have to get it out of the way right at the beginning. So let's think about me a little more. Where do I come from? Failed high school teacher, residential worker. I came into the -- the disability field with no training or prior experience. I was a high school teach: I had no clue what to do when given a group of five to seven-year-old children with down syndrome, seizure disorder, spasticity and orthopedists and so on. And I feel back on what seemed to be common sense but also on the parenting I got from my own child as a family, and fortunately I was well parented as a child. Acknowledged it was very helpful for me because I came in without any prejudices. I hadn't been set up with a certain way of looking at children and evaluating children. And people told me quite early on in residential work they really liked the way I respected the children. While I couldn't really scrap them because I didn't really know what to do. And for somebody who has spent most of his career training teachers, it's rather odd to admit that one of my successes at the beginning was coming in with no prior experience. But it meant that I focused much more I think on what was happening there and then right right in front of me rather than coming in with preconceived ideas about what you were supposed to do with a five-year-old with Down Syndrome or whatever. When I came into the blind field I had a lot of experience by then from my itinerant teaching and I very quickly came across three gurus and the first was Lilli Nielsen who many of you will be familiar with. She was a Danish teacher of the blind and she created an approach that she called active learning. And I know that people at the Texas consecutive for the blind and visually impaired are particularly strongly committed to the Active Learning approach. And meeting Lilli and spending time with her and watching her work was a revelation for me. And my take on Lilli, she was always promoting hands off. She said we're touching and holding and directing the children far too much. We should step back and actually observe them. And that was very much already my way of working, not at least because I didn't know what quite not to do, so it seemed sensible to wait and see who the child was before I decided to dive in. She promoted hands off very assiduously. She had a big focus on children's self image and self-esteem. She always stressed time, allowing the child their time, not our time to work. Meticulous observation of the child. And the most valuable thing she gave me, the idea that if you change the environment around the child, you could change the child without doing anything with them directly. And as part of that she devised a whole range of equipment. And the two pieces of equipment I love are the Little Room and especially the resonance board. And I don't have time to go into them today. But in England where we had a center and a classroom, we had both pieces of equipment and I used the resonance board with -- I was there 18 years so I worked with a whole generation of children. I used the resonance board with babies six months old and teenagers who were 14 years old. I had children lying on their backs, their fronts, their sides, sitting on their butts, standing on their head, standing up bare foot. I used it for a huge range of skill assessment and skill teaching, and I think that idea that maybe if you change the environment you will be more successful in your teaching, without worrying too much at first what you're actually doing with the child can be very helpful. And of course, both are important, but Lilli really revolutionized that idea that we need to think about the environment around the child. My next guru was Jan van Dijk, who is even more well-known, who sadly died several years ago. In fact, yesterday was the -- I think the fourth anniversary of his death. He was a Dutch psychologist and teacher of the deaf, and he moved into DeafBlindness very early in his career in the 1960s. This was taken from his website. He says, no intervention without assessment. I always liked that. That's very him. He traveled the world, so many of you listening today will have seen him I'm quite sure and may even have met him. And he was an extraordinary guru. Where Lilli Nielsen became a little bit stiff and insistent as she got older, Jan van Dijk always was open to admitting mistakes and learning from mistakes. And from Jan I got more than I've got from anyone else, but this is my take on him. Follow the child. In other words, observe the child, sigh who they are, see what they're into, identify and use motivators. Look at their timing and pacing. And get all that absorbed by you before you start trying to intervene and teach. Then credit everything the child does with meaning. And that was a revolution for me. You know, if it looks crazy or weird, it's because you don't know why they're doing it. It's not because they don't know why they're doing it because they probably are fulfilling a need. Think of them as adaptive functional behaviors. Respect and seek the opinions of others. He was very hot on team working and the team approach. Because of his deaf background he very much worked with the conversational approach. His teacher in the Netherlands was a priest actually who developed a system called the maternal reflective method. And the idea is that everything that do you with a child you structure like a conversation. Even if it doesn't involve language. If it's just about using objects or gesturing or manipulating the environment, if you do something you should pause to give the child an opportunity to respond to what you just did. And if you ever saw him work you can see that in operation. I talked about this to students at San Francisco State when we were training students there, student teachers. And then one of them came with me on a school visit where a child I had known for quite some time, I had an hour of me playing with the child, working with the child of course through play, she said to me I see exactly what you mean about I the conversational approach, the way everything is turn taking. And you keep giving the child the option to respond because you're also responding to their response like a dialogue or a conversation. He talked about using the can child's preferred modes of communication and how their preferred mode can change for all sorts of reasons from moment to moment. And he also talked about relationships having to be built rather than just happening. And the importance of relationships. And then my third guru is Jean Ayres. She was an occupational therapist here in California. She died a long time ago, but she's the person who came up with sensory integration theory and then developed sensory integration therapy. And I'm not a therapist. I don't do sensory integration therapy, but I've been very influenced by what she developed and the way other therapists have developed it subsequently, particularly since her death. And my take on Jean Ayres, the theory of sensory integration, the idea of sensory modulation enhancing and inhibiting. In other words, the idea that at the beginning our sensory systems are being bombarded by stimulation from all around us, sounds, smells, touch inputs, movement inputs, visual inputs, temperature changes, air movements, you name it. And the baby very quickly has to learn how to modulate their senses. In other words, how can they put a lot of that input at the back of their mind, inhibit it so that they can then enhance certain things and just focus on certain things. And we all need to learn how to do that fairly quickly in infancy and early childhood. And of course many children don't, and they don't have to be children with a diagnosis of some kind of disability. And I have a brother -- I have three brothers and one of them has never really developed sensory modulation ever so well in my opinion, though now he has three adult children and he's an archeologist and he's written books. So it's not like it's a big problem. But he has great difficulty with the modulation and enhancing and inhibiting. She also promoted the idea of observing children closely to see which sensory inputs they seek and which they avoid. It was one of her designs he wills, if you like -- disciples, if you like pat Wilbarger, who came up with the sensory diet. And she stressed the connection between sensory inputs and levels of arousal and I will talk about arousal at the very end of this talk today. Which reminds me to say sensory inputs are very powerful medicine. And you can do a lot of damage to a child if you're administering sensory inputs that are too intense or go on for too long. And obvious examples would be too much movement, rhythmic movement on a child. You could stimulate seizures, you could stimulate nausea and vomiting and worse. So we need to remember that all sensory inputs can be very, very powerful. Jean has wrote an article about -- she was asked to define the key principles of sensory integration therapy. And I loved it because what she did to me was outline the key principles of effective teaching. First of all you have to create the just right challenge for the child because it's the -- the challenge is where they have to come up with the next key principle and adaptive response. Something isn't would be working, they have to think about it, they have to do something differently or something extra, and that's the adaptive response and that's where they grow, that's where you get the growth in the child in every sense of the word. How do you know the just right challenge? Because you've got to know the child. The chances of getting the just right challenge called as it were the moment you meet the child is pretty low. It's much better to get some familiarity with them first through your own observations and through talking to people who know the child better than you, like family members or the classroom staff. Or the child's local therapist. Then she says the child has to be actively engaged in the activity. You don't do the therapy to the child or on the child just as you don't educate on the child. The child must be an active participant, not least because you need dialogue or conversation. And most revolutionary, the approach should be child directed. And of course, all three of my gurus are big believers in child direction as the guiding principle. And if you put all three of the gurus together they're all individual child focused to a huge extent. They are all child led in the way they work. They're all inclined to be hands off much of the time. They were all brilliant observers, but then they were very skilled at interpreting. And you put those two together, observation and interpretation, and that's where you become the perceptive, receptive detective that I use as the title for my second slide show today. Observation by itself is no good unless you then interpret and your interpretation will take time, and it may involve consultation with others, which can be really helpful. And at some point you're going to have to act on your interpretation and test to see whether it's right or not. And that goes on all the time. They all believe that we needed to work on guaranteeing success for the child, but with a built-in challenge because they all believe that the child's positive self-image and self-confidence was the key to effective education. They all recognized that sensory functioning depends upon many issues and they were all very opposed to the perceived opinions of the time. Remember, these threw gurus came of age in the '60s and were very much revolutionaries and got quite a lot of criticism for it. [phone ringing]. Now my cell phone which rarely rings is ringing in the background. So I jump on to -- I was asked once to define the classic DeafBlind strategies and I remember coming up with this list and people looked -- I think they were a bit disappointed. But I've written the missing imperatives because they are really important. It's not try to follow the child, it's follow the child. And that will be apparent in everything that I say. Know the child. And if you don't know them, get to know the child as a priority. Individual eyes. These are not children who can be -- individualize. These are not children who can be grouped in most cases, certainly not at an early age. Do with not for. So active engagement of the child. And create conversations in everything you do. And the big message from me today is use a multi-sensory perspective for assessment and teaching. So I'm still on my general introduction and I've had 40 minutes. There you go. So I'm talking about availability for learning. It's a big, big topic and I want to share with you this article by Chris Russell. I only discovered the article and I only discovered Chris Russell a couple of months ago, and I saw his article in a slide show based on it and I contacted him and I said I thought it was fantastic. And the article was in a journal. I asked if he had it separately so that I could send it to people. And we had a little correspondence. It's very, very interesting, and he talks very much about bio behavioral assessment, in other words, looking at the child's almost vital responses to things. And I don't know if -- I don't know who is online, but if Chris is online, I just want to thank him again because I really, really like the article. And I was today going to put some of his slides in with -- fully referenced, but I couldn't get them out of the slide show. It was beyond my rather primitive technical skills. But anyway, I would recommend that. And if you can find stuff from Chris Russell, he's going to be people's guru if he's not already, he's well on the road for that. So some general points about availability for learning. If you're interested in that topic, you could go to any of these areas to consider. Arousal level and bio-behavioral state and I will talk about that towards the end of this talk when I talk about self-regulation and self-stimulation. Assessment. Self-regulation and self-stimulation. Both internal and external factors. Medical issues like health, energy, pain, nutrition level, medications, which can have an enormous impact on whether the child is available for learning or not. Motivation and meaning. And that's the meaning to the child rather than to us. Previous experience. Good memories and bad memories. Socialability. Communication level. Current range of expressive behaviors. Being understood by others. And time, the time necessary and the child's time and pacing. So I'm not going to talk a lot about much of that list, but I've already mentioned almost everything in the list. I am going to look very much at sensory issues and I should put a plug in here for the NCDB, the National Center On DeafBlindness, which has an enormous website which you probably know about. And I will put a link up to the section of the website that deals with assessment later in this talk. And also a training program for intervenor. Interveners being the one on one staff who are allowed to welcomer with a specific child with DeafBlindness. There's a multi-modal training course now which is called open hands, open access, or OHOA. And if you go there, one of the modules is all about availability for learning. And it has some very nice stuff in it, including some very nice information about the fourth thing on this list, the internal and external factors that can affect a child's availability or not. So over my 38 years I've seen the population we work with become increasingly complex and change in nature. And the changes I've seen, first of all it's become a much bigger population because we have allowed all kinds of children in under the umbrella of DeafBlindness, who were being excluded 38 years ago. Multiple etiologies, when I came into the field, my agency was called the national reRubella association. Because the rubella virus, when people were pregnant and caught the virus it could do quite a lot of damage to their fee suss that they were carrying. And most of the children we worked with in the early days with congenital rubella syndrome, but that started to change very quickly because we were aware of other children who didn't have rubella syndrome. But back then if you knew a lot about DeafBlindness it meant you knew a lot about rubella syndrome. If you knew a lot about rubella syndrome, you knew a lot about DeafBlindness. Those days are long gone now and there are so many etiologies and I've acquired through decades of experience, I've acquired the reputation of being a specialist in CHARGE Syndrome, but there are so many other etiologies either that I've never heard of or I've never worked with or I'm not very familiar with, so that's become much more complicated, and new etiologies pop up all the time. There's a new range of vision and hearing loss and ability in the population. There are all sorts of neurological issues. When I came into the field, many deaf agencies in the UK would not work with children with auditory neuropathy, for example. The child had to have sensorineural deafness with an audiogram that showed the severity of the hearing loss. And equally many vision services and low vision services would not work with children with cortical visual impairment because they were not considered to be appropriate. Well, those days are long gone now, but as we let those children in, we faced a lot bigger population with a lot more complexity in the challenges. The population now have multiple additional anomalies, all kinds of medical issues and medical priorities, many, many specialists need it and are involved. An increasing scarcity of professionals who are skilled in assessment and teaching as the population gets more complicated. And a growth of technology, medical technology, sensory technology and educational technology so that teachers have had to become much more tech savvy in what they do. And this photo shows a baby in the hospital linked up to all kinds of monitors and tubes and pipes and blindfolded. And I show this picture only to remind you that many of the children in this population now, the younger population, have experienced the world at the beginning like this. This has been their first experience of the world. And in many cases not just for the first couple of days or the first couple of weeks, but maybe for the first many months and even for the first couple of years and that has big implications both for them and their families. The National Center On DeafBlindness has a child count that's updated every year. This is the latest count 2019. There were 11,335 children. Many, many different etiologies, CHARGE Syndrome was the biggest with 1,033, but there were cytomegalovirus, hydrocephaly, microcephaly, meningitis, head injury and a large group of complications of prematurity, which isn't a very precise etiology. It's the biggest numerically, but that could include all kinds of things. And in fact, quite a lot of children with these other etiologies that I'm showing were born prematurely so it's a kind of movable beast. And interestingly, of all those children, 87% had at least one additional disability and 42% had four or more additional disabilities. So we're talking about a very complex group. I always get a little worried when people describe a child with DeafBlindness as lazy and of course if you're DeafBlind you can be lazy. I'm not DeafBlind and I can be very lazy. But I think it's a dangerous label to put on a child if you don't really understand who they are and what they're doing. And I found it was having used a lot with children with CHARGE Syndrome so I made this list. 21 issues commonly found in CHARGE Syndrome which can contribute to fatigue. And remember, the point I'm making if a child has any one of these they will get tired more easily than a child who doesn't have any of these anomalies. So visual impairment, it's hard to function in our world if you have significant visual impairment. You need breaks, you need all sorts of modifications and accommodations: You need things slower and you need to rest more. Hearing impairment just the same. Significant vestibular problems. Breathing issues. Poor nutritional absorption, anemia, a all kinds of medication. Seizure disorder, repeating migraines. Severe constipation. All these things you take any one of them and it's going to wear you out much more often than your peers. I don't think I've ever met anyone with CHARGE Syndrome who has all of these thank goodness, but I know children who have at least half of them, sometimes more than half. Are we surprised that people who don't understand call them lazy? I can understand why people do it. And another complication, this is a quote from Natalie Barraga, who was one of the great pioneers in the visual impairment field in the United States. I've picked out some of the words in this quote. Visual functioning is related in part to the condition of the eye. More explicitly, visual functioning is determined by the experiences, motivations, needs and expectations of each individual in relation to whatever visual capacity is available to satisfy curiosity and accomplish activities for personal satisfaction. In other words,, clinical evaluation from the medical profession is important and very helpful. We need ophthalmology reports, we need audiology reports, we need physical therapy reports and so on. But that medical information doesn't necessarily tell you how the child will function because their functional abilities are influenced by all these things, experiences, motivations, needs and expectations. So if you're trying to evaluate a child's vision it's good to think about the whole child, not just their eyes because we don't see with our eyes, we see with our brains. And that is wonderful. And it opens up all kinds of possibilities. But it also makes things much more complicated because brains are heavily influenced by emotions. Eyes are not, but brains are. And brains are influenced by all those things, motivations, interests, previous experience, aversions and all the rest of it. So brains can actually see things that the eyes can't and I'll show you a couple of pictures. Here's a van with with the sliding door open on the slide and it has the crest of Starbucks, but the word next to it says sucks. And we know that it's because the door is open and part of the word Starbucks is missing and it just happens to spell sucks. And we laugh because, well, if you're like me you don't think their coffee is very good so it makes sense. Because our brain is seeing what's happened, even though our eyes can only see the side of a van with the word sucks on it. Here's a lady holding a dog, but the dog has raised his face in front of the body of the woman's face so it looks like the woman is human at the top of her face and canine at the bottom. She has a dog's nose and a dog's mouth and she's covered in fur. Here's a cat sitting on the lawn. There are two tall dandelions behind the cat and they look like they're growing out of the cat's head like antenna. We know because of visual experience but also we know that a cat can't have dandelions growing out of the top of its head. On our brain is compensating for the misleading information. Here's a cat sitting again on an armchair against a cushion. The cushion has a picture of a deer with antlers, but the cat's head is in the position of the deer's head so it looks as if the cat has the antlers. And here is somebody sitting on the bus and the yellow -- we can't see their head, only their trunk and their arms. And part of the handrail much closer to the camera is covering their head and it makes them look like an alien. There are two screws in it that look like eyes. There are examples of our brains seeing things that our eyes can't. So when people come in to work with a child or to evaluate them they're very inclined to focus on the disabilities. And I'm always seeing if you focus more on their abilities, this might be reveal more about the difficulties they face and the disabilities they have, but it will also help you pull your attention to the strategies they use to function effectively. Those adaptive functional behaviors that I've already shown you in some of the photographs. All of the children in those photographs could have the label disabled applied to them, but I chose photographs that shows them doing weird things which actually give us an idea of what strategies they've learned all by themselves in order to function more effectively for their own purposes. Important point. Everything that children with DeafBlindness do has meaning and the first obligation on the teacher is to ascertain that meaning or at least come up with a really good guess. So I'm almost getting to the senses one hour in. Here's a quote from Thomas Edison. The only function of the body is to carry the brain around. Lovely quote. And two quotes from me. The brain is connected to the body through the senses. Without the senses, the brain knows nothing. It doesn't know where it is, it doesn't know what the body is doing, it can't direct the body to do anything, and if the body does something, the brain doesn't know whether it did anything or not, and what happened as a result. The senses have to be there to provide that information. And I believe that most children with DeafBlindness are not in touch with their bodies or don't feel their bodies very well because of their multiple sensory disabilities. And I've got five lessons in life from Dr. Seuss. And I'm only interested in number three because I want to in a way disagree with him. It says "You have brains in your head, you have feet in your shoes. You can steer yourself any direction you choose." But you can't if the feet in your shoes are not connected to the brains in your head very effectively. It's a big problem and it's very evident in the children, but it hasn't been really recognized, I think very effectively. DeafBlindness involves many more senses than just vision and hearing and it's not enough only to consider the tactile sense as a compensatory channel. And in fact, in the UK, we replace the word DeafBlindness a long time ago with the words multi-sensory impairment. When I got my-- the first year we had the university level credential in DeafBlind education I went on the course, it was a one-year degree level course in Birmingham in England. And the course title was education of children with multi-sensory impairment. And my degree certificate says that I am a qualified teacher of children with MSI or multi-sensory impairment. And MSI is a very, very common phrase in the UK. We still say DeafBlind, but we like multi-sensory impairment because it reminds people that there are a lot more things involved than just vision and hearing. Here's a list of senses and I say congenital DeafBlindness increasingly involves problems with the perception of. And this isn't all the senses, but I've expanded the traditional five senses and I've listed vision, hearing, touch, proprioception, temperature, pain, vestibular, smell and taste. So in addition to the five traditional senses, I've added pain and temperature perception because they are sensory systems, but I've also added the proprioceptive and vestibular senses because they're very important and people often don't know much about them. And I'll talk about them a lot for the next hour or so. Here's a diagram called the pyramid of learning. And it's a pyramid, like a large triangle. And at the bottom the base of that pyramid is the central nervous system or the brain if you like. And then as you go up the pyramid you notice the foundation of the pyramid is the sensory systems. Everything starts there and they need to be there and working on some level, otherwise everything is higher as you go up and won't develop properly or effectively. But if you look at the sensory systems on the bottom you'll notice they're on two levels. On the very bottom you've got tactile, vestibular and proceedioception. And then on the next level you have smell, vision, hearing and at the same time. And it's all organized like that deliberately because touch, vestibular and propioreception are the important senses that provide a foundation for the development of smell, vision, hearing and taste. And vision and hearing will be compromised even if there are not visual impairments and hearing impairments in a child functionally they will be impacted negatively if there are significant problems with the vestibular and propriorepresentation senses. And then if you move up from the senses you go to sensori-motor development, developing postural security, motor planning, awareness of two sides of the body, bilateralty, maturing reflexes, ability to screen input, in other words, sensory modulation. Then you go up to another level of perceptual motor development, hand-eye coordination, posture Al adjustment, attention functions, visual spatial perception. And at the very top you have cognition and intellect. Daily living activities, control of behavior and at the top you've got El Dorado, academic learning. And one of the problems if you're a teacher in the education world is our bosses, the politicians and the bureaucrats, are in Commission for the Blind to think that education is all about the top of the pyramid, academic learning. And they have no idea that all these other things have to be developing in there if academic learning is ever going to take place. Which is why I love this diagram and I think it -- we need to be providing this for those bosses sometimes. So the senses play this incredible part in it. And I've got a quote from Krishmurdi, which was a yoga specialist, who says if no one observes one will see that the body has its own intelligence. It requires a great deal of intelligence to observe the intelligence of the body. And since I've been observing the intelligence of the body ever since I came into the special education field, I felt great about myself which I don't often do because I'm self critical, but I thought yes, observing. So let me talk about those two senses. First the proprioceptive sense. This is a sense that helps us to plan our movements, position our approvals and grade our movements using just the right amount of energy, without looking to see what we are doing. This is how we walk once we've learned to walk. We don't have to look down at the floor, we don't have to look at our legs and our feet. We do it automatically because our tactile, but especially our proprioceptive sense is sending constant information to our brains about what the legs and the feet are doing. So we know. The word, it's a strange word and it comes in two Latin words joined together meaning an awareness of your own self or a feeling of your own self. It's part of a very broad sense of touch. I call it internal touch. It's how I can feel my knee without putting my hand on it. I can -- I think knee -- if I say to you, your right knee, all of a sudden you're all hyper aware of your right knee and you can feel it and you know where it is. And if you just bounced your leg or waved it side to side, you've increased the proprioceptive stimulation coming into your brain so you know where that knee is. The receptors are located in the must sells and the joints all through the body. They are stimulated by three things. Anything which compresses that part of body. Anything that stretches it and anything which twists it or turns it. And anything that puts pressure or stretching or twisting on the muscle or a joint is going to fire proprioceptive information to your brain to tell you what's happening. And because of this if it's working well, we always know where all of our body parts are and what they're doing. Why does it go wrong? Well, significant injury, especially kind of orthopedic injury. A broken bone, a torn muscle, a ripped tendon, those kind of -- a sprain even, can affect the proceedio accept active functioning of that part of the body, that limb or that joint. Orthopedic surgery where they're cutting through muscle or cutting through bone, the proprioceptive perception will certainly be dampened for some time until the nerve pathways can heal and reconnect. Arthritis can be a problem. My mother had bad arthritis. She always used to complain that she couldn't feel her legs properly. My father used to make crude jokes in response. But that was a very typical of the impact of arthritis on functioning. If there's cerebral palsy or other types of brain damage, anything that stops the body from having a normal range of muscle tone, if the muscle tone tends to be much too stiff and tight with spasticity or if the muscles are much too loose and floppy, then the proprioacceptors won't be working well and in fact the child won't be moving very effectively anyway. And I think for the majority of the DeafBlind population of young children, the muscle tone tends to be low for a variety of reasons and that's one of the reasons why therapists like to get the muscle tone up in them. Poor circulation. We've all experienced this. You sit on your leg, you cut off the circulation. And we use the phrase that your leg goes to sleep. Of course, a leg can't go to sleep, but you can't feel it anymore. And if you try and get up and walk on it you can't. You have to get the sensation back in order to walk safely because that ankle and knee, and to some extent even the hip, you can't flex and extend them just enough to stay up right and use the leg function. You often find poor propioreception with touch and Vess tablet fibula and vision problems and lack of use creates problems. Vestibule bar. Children don't like to be facedown. Gravity swishes squishes them into the floor and they would rather be flat on their back. When they are facedown it's very hard for them to bring their hands up and push, extend their arms and push their arms up. And if they can do it it often goes wrong and they drop like a dead weight and they smash their face in if the floor. Equally if you lift them and try to stand them to bear weight they often get terribly upset. They often bring their knees up and scream and turn blue or they become more droppy and go back down to the floor. And they can't feel the joints in the toes, ankles, hips, but also can't feel it in a vertical, stable position. They often prop a lot. And this lets them labeled lazy, of course. Lots of leaning and propping. When they are weight bearing, even if they're just cruising before they manage walking, they even bend the knees and stamp the feet repeatedly and they often like their feet bare in order to maximize tactile information. And I call that feeling the feet. But when the children are walking independent, sometimes you see tiptoe walking. What they're trying to do is maximize the measure input through the bottom of the feet, but also if you go -- if you stand and go to to tiptoe it's really interesting. The muscles in your toes, your feet, your ankles, your calves, your knees, your thighs and even your butt tighten up. They seem to just wrap and tighten and you get much more proprioceptive information about what your legs are doing. And of course, tippy toe walking isn't a good idea. You don't want children doing it a lot, so that's where a therapist would come in with ideas like maybe heavier shoes, maybe walking up an incline. You can't go up a slope on tiptoe. It just doesn't work. It forces the heels down. Maybe they would recommend a weighted vest for the child to increase their body weight which again brings the heels down on the floor. The children tend to be very clumsy. Their motor coordination isn't good, particularly when you add visual impairment, of course. They don't grade their movements well so they may not use enough force or they might use too much force. So they might be called aggressive when they're touching, patting, grasping, pushing and pulling, lifting. I always say a child with significant proprioceptive issues you probably wouldn't give them a raw egg in a shell and ask them to carry it across the room. And they would squish it because they would either hold it too tight to feel it or they would drop it because they're not just holding it tight enough. And then the one I'm going to focus on, the child's own behaviors. Looking for strong pressure or stretching or swifting inputs. Self stimulating through the proprioceptive sense. Squeezing into tight spaces. Crossing or twisting limbs. Twisting a foot or leg around the leg of a chair. Binding body parts with cloth or string or rubber bands. Pulling the teeth in the lower jaw down. Grinding the teeth. Tapping on the teeth with hard opens, hand clapping, hand flapping, which is my favorite self-stimulation behavior. And our wonderful ASL interpreter did it beautifully through excitement before we started. I was thrilled to see a fully responsible adult self-stim by hand flapping because we all do. Leg swinging, hanging from a bar and so on. So let's think about the self-stimming postural behaviors. We often see postural behaviors which really are self-stimulation behaviors involving all these things, the head, the legs, bending, stretching, hanging, the hands planking, propping, squeezing, climbing. I'm going to show you a series of pictures like you've already seen to some extent of children doing these things and I will talk to the pictures. These postural behaviors have always been present, but largely unseen. And that's what struck me many, many years ago that I was noticing these things that other people didn't seem to be noticing. And I think the problem was that people didn't feel these things were valuable or important. They also doesn't believe that they were functional adaptations. They either saw them as just something a kid does or they saw them as the child being weird or trying to avoid working and that kind of thing. Well, children can be weird, children can be lazy, children can do things to avoid working, but there may be other explanations of these things. And sometimes people might be amused by them and if the postures seem very weird the child may be corrected with no attempt to understand or recognize or honor what the posture means or what function it serves. So let's have a look. This is a boy who came to one of our picnics a long time ago, 15 years ago. Very low functioning, completely blind, profoundly devil, low muscle tone. Hadn't been in a great educational program. He's about 12, I think. His mom led him with great difficulty to the swing. He's pulled his arm down, put it on the swing. He's cried out and dropped to the floor and his mom's walked away. The boy has instantly reached up to find the swing again with his arm, then brought the other arm up, pulled himself with great difficulty to kneeling and then got himself up on his feet and leaned forward like you see in the picture so he's hanging over the swing on his belly. And once he's hanging over the swing he's pushed with his toes to make the swing move and he's moved his belly forwards and back a little bit to get it in just the right position where he's balanced. And then once he's in the right position he pulls one arm out of his sleeve and jams it into the other sleeve very, very tight. And he can only get the second arm a certain distance in because it's so tight. And what that boy is demonstrating, percent first of all, is a very precise idea of what he wants to achieve based on previous experience. So we've got memory, we've got spatial awareness, we've got body awareness. We've got a an awareness of what a swing is and what you can do with it in terms of hanging over it on your belly because then you can push back and forward with your toes and get wonderful swinging or vestibular stimulation in a very, very safe position. He's media sure that there's no way he's going to -- immediate made sure there's no way he's going to fall off by experimenting that he gets everything in the right place. This is smart. This is not crazy, this is not weird, it's not lazy, it's not autism, it's not OCD. It's smart. And he's telling us things. And amongst other things he's telling me that he needs a lot of proprioceptive input because he has very low tone and no useful vision and no useful hearing. One of my colleagues became his DeafBlind specialist and a lot of changes occurred over the next 12 months and here is the same boy exactly 12 months later. He's in a different program. He's wearing pressure clothing from the occupational therapist. He's getting deep pressure massage at the beginning of the school morning and the beginning of the school afternoon. He's going in a hydrotherapy pool several times a week. The family have just started therapeutic horse riding on weekends. So a whole range of approaches are being used. That boy's brain is now in much better contact with his body and what you see is that he's actually socially engaged now with his around family around him. Here's a teenager who was born prematurely with the orientation and mobility instructor. They reached a familiar spot with a bark on the floor. When her feet reach the bark she knows she can take a break and reorganize her system on the swing. And she gets into a position on the swing that she's lying on her side, her head is dangling down in space. Her legs are crossed, the knees are bent and the left leg is crossed over the right leg very dramatically so the left foot is actually standing on the swing on which she is lying. And then her right hand, the two -- first thing is pressing just under the eye socket and she's swinging her body just enough to get swinging movement. The left hand is extended up around the chain of the swing, but she's not actually holding o the hand is there ready to catch if she starts to lose balance. Before she got on the swing she was sliding her feet along the floor. Her knees were bent. Her whole upper body was flexed towards and her chin was down on her chest. After a few minutes in this position on the swing, they tell her it's time to get going again. She's now lifting her feet instead of sliding them on the floor. Her upper body is erect and her head is erect with much better posture. She's reorganized all of her body through this break on the swing. Here's a boy in his stroller, he's having a tube feed. You can see the tube pump feeding him. And he's brought one ankle up on the other knee in order to fix his body. Here's a boy fast asleep. He's on his back. He's put his sweat top over his head, presumably to block the light out. He's put his hands under his butt to there's deep pressure on his hands. And again, he's bent both knees and brought one ankle up on the other knee in order to know that his body is stable and fixed and it's okay to go to sleep. Here's a young child who can't stand and bear weight yet, but she's on the floor. She's doing a dramatic head stand. She's got two feet. Her legs extended. The top of her head down on the floor and she's released her arms and put them up in the air actually kind of behind her head. And when you think this is a girl who can't stand unsupported, think about what's happening. She's of an age where children who are developing regularly give themselves a massive range of propio receptive and vestibular inputs. They jump and roll and spin. And they climb on the couch and they jump off and they land with their ankles and their knees locked to maximize the impact of landing on the floor' their feet. And then they climb on the couch and do it again. And there is research that shows that in those early years the brain stem, the growth and development of the brain stem is encouraged by a rich diet of proprioceptive and vestibular input. And the children give themselves that because their brain actually needs it. Now, they don't know they've got a brain stem, they don't know about the brain stem, but they sure as hell know that's what they need. And of course if you lived with them, it's pretty exhausting, I don't need to tell the parents who are here. Anyone who has lived with a toddler knows that they go through this phase of incredible movement. This girl is not getting that kind of input through standing and cruising and walking and jumping, but she's found another way. Think of the proprioceptive input coming through her skull all the way through her spine, all those vertebrae, and then down through her legs and those joints. The hips, the knees, the ankles. And one leg is even up on tiptoe, which is increasing even more the pressure coming through the foot. Wonderful, wonderful behavior. Here's a much younger child doing exactly the same thing. This is a little boy who you saw his fingers crossed. He's on the bed because his mom had heard me present, she emailed me this picture and said guess what? I wrote back and said, do you need me to explain? And she said no, because I heard you talking about it in Arizona I think we were. He's standing on his head on the bed. Legs are straight. The body is up ready for a bear crawl. He can't actually crawl in this position, but there's deep pressure going from the top of the head down the spine and all the way through the legs to the feet. And his arms are supporting him. And he can't yet sit unsupported. Just bear that in mind. So if you've got an idea of a hierarchy of motor ability, you might need to reevaluate it because it is possible to not even be able to sit safely, but do what this baby is doing in the picture. I'm going to cut out a lot of these pictures. Here's a young boy squeezed on a shelf under his TV. And here's a girl who has come home from school and got into the toy box and jammed herself in and she's looking at a tablet. She's on her back with her knees bent and she's pretty contained and squeezed there. And I think it's a way of chilling out, calming down and getting over school. I was just looking at the comments. There aren't any specific questions for me. Now I'm going to talk about vestibular sense, which is much more complicated. This is the sense that tells us about our head position, head movement and the pull of gravity. It tells us all the time which way is up. It detects any kind of head motion and it links closely with the vision sense and the proprioceptive sense. And there's a picture of two older ladies sitting on a piece of playground equipment which is obviously going up and down and spinning. And they very bravely let go with one hand so they can wave at the camera. Not something I would do at my age. Here's a diagram that represents what you should find in the inner ear on both sides of the head. At the top you have a thing like a snail shell, which is the cochlea or the organ of hearing. And everything below that is the vestibular. Everything here is very small because nits the inner ear on each side of the head so it's duplicated on the left and right, very small, very frank I'll and easily damaged. -- fridge I will and very easily damaged. Everything there is very hollow and full of fluid and lined on the inside with nerve hairs. And we know how the cochlea works in response to sound waves. The vestibular apparatus works in response to head movement. As the head moves the fluid inside this apparatus moves and it swishes over those nerve hairs which then sends messages to the brain about where the head is and what the head is doing. And if you look, you will see two bulbs, two circular objects, the utrical and the Sack trical. One responds to moving forward like in a car and the other to vertical movement like in an elevator, linear movement. And there's a question. For a 13-year-old with multiple disabilities, is there a benefit to provide this form of movement now if it was missed during infancy and toddlerhood? And I would say yes, it's never too late. By 13 you certainly have missed the optimal period, but you can -- you never know what kind of outcomes you will get if you allow the person to access these kinds of movements and these kinds of pressure and twisting inputs. You might find that they're already giving themselves some of these things when I talk about self-stim in a little while. And just to finish the diagram, beyond the two bulbs, you will see three curved -- you can see two and one is coming towards us. They are the semi-circular canals. And they give more specific information to the brain about the head moving. Is the head nodding up and down, forwards? Is it turning in a no pattern?, left to right, horizontally? Or is it moving in a diagonal kind of position? And if all of this is working we know all the time where our head is and what our head is doing with no great difficulty. Sorry, I've gone too far ahead in my slides. I'm also keeping an eye on the clock. Here is a quote from Jean Ayres, the occupational therapy I talked b she said the vestibular system is the unifying system. All other types of sensation are processed in reference to this basic vestibular information. The activity in the vestibular system provides a framework for the other aspects of our experiences. What she's saying is this is by a long way the most important of all the senses. And if this sense is missing or not working properly, all the other senses will be compromised even if they're perfectly intact and okay. But if they also have problems, then you're dealing with a very complex situation and you do need to address the vestibular issues. Now, I've learned a lot about the vestibular system through working with children with CHARGE Syndrome because almost everyone with CHARGE has vestibular problems, but vestibular disorder in children has multiple causes, and this is a list. I started to dop this list with Kate and Jim Dirkle at the Texas School for the Blind and Visually Impaired a long time ago and then I added one or two things. So head and neck trauma, chronic ear infections, maternal drug or alcohol abuse. Cytomegalovirus infection during the pregnancy. Meningitis infection, assuming the child survives. Migraine. And I don't have migraines, but during a migraine, vestibular functioning can be very compromised. People can severe migraine often tend to like to lie flat on their backs. They often like to be in the dark and they describe all kinds of vestibular and visual disturbance. Certain metabolic disorders like diabetes if they're not treated over an extended period of time. The use of ototoxic drugs, a brain tumor, certain neurological disorders like cerebral palsy and hydrocephalus. And then some of the genetic syndromes. CHARGE is the big one, but also wall enberg syndrome and usher syndrome type 1. We identify three types of Usher Syndrome. Type 1, the vestibular dysfunction is part of the diagnostic actually. If there's a family history of vestibular issues then there's a possibility. If the child has a cochlear implant fitted, there's very -- statistically very minor, but there is some evidence of the -- of when the implant is switched on the child shows some evidence of vestibular dysfunction. And I learned that from Jim Dirkle at the Texas school. And like all our senses, lack of use can be a problem. If there are movement issues, fear of movement and difficulties negotiating gravity and ill health and hospitalization. They can all be very problematic. And significant vestibular problems may adversely affect the organization of all sensory information. Obviously postural security and muscle tone will be affected. Use of vision. And I will comment on that in a bit more detail in a moment. The reception and processing of sound will be impacted. Remembering auditory and visual sequences and short-term memory. And if you put those together, reception and processing of sound, remembering auditory and visual sequencing, use of vision and memory development obviously there will be speech and language implications. A bilateral coordination will be impacted. This is a sense that plays the biggest part in developing good bilateral coordination. Behavior will be impacted. Breathing, feeding, digestion and nutrition by extension will likely be impacted. Socialability. Babies with vestibular problems don't like to be picked up and moved. In fact, they're own terrified of it. And if it's not handled carefully, if they're not lifted carefully with warnings and then with a strong feeling of pressure and being contained, they may well not like being with people. And then this is the sense that plays the biggest role in developing effective self-regulation, and I always say in my caseload which is the group of children with the worst self-regulation? Children with CHARGE Syndrome. Which is the subgroup with the highest level of significant vestibular difficulty? Children with CHARGE Syndrome. I'm sure there's an absolute connection. Someone is asking me what about children who have issues with riding in a car seat, especially backward? I think that very likely might have multiple causes, but vestibular dysfunction is likely to be a big part of it, especially if it's allied with vision problems. And I think some work on vestibular functioning could be very helpful. And then there's a question where can I find more information about feeding, digestion, nutrition issues related to vestibular problems? You probably can't because I wrote this myself and as I said, by extension. So these children like to be flat on their backs. That can often -- if they have difficulties with fluid, they can get more congested because they're on their backs rather than up right, which is just going to make the breathing problems even more significant. Also gravity plays a part in our digestion and nutritional absorption. And many of the children who like to be on their backs much of the time are prone to chronic constipation. And again, there are other reasons as well as the loss of gravity pulling the bolus through the digress Siff system but they work together. So if the kids like tore horizontal as much as possible, you are going to have problems with feeding and with movement of stuff through the digestive system, but also with dealing with secretions. Yeah, and someone says I have a child on my case book with CHARGE. She only eats a blended diet from a bottle lying on her back. All sorts of negative implications, quite apart from choking. Things to do with breathing, draining secretions and feeding and getting food through the system. And I'm not here to talk about what you do about that, but I'm here to point out it's a big problem. And how do we achieve balance? The vestibular sense is often called the balance sense, but actually it's one of the three balance senses. We use vision, proprioception and vestibular input in order to acquire good balance or equilibrium and it's important to remember the role of vision in keeping us up right. Again, I'm not here to go into a lot of detail on this, but a lot of children with knees problems develop a 5-point crawl. Many of them never go into the crawl position. They back scoot or they set up and butt scoot. We call it bottom shuffling in the UK. But traditional crawl on two arms, two legs with the head up is very threatening because they tend to pitch forward and smash their face. So you get the five-point crawl where they bring the head in as the fifth point of support. And just as by the by, in the charge field, one of the big break throughs over the last few years has been the discovery that hiking poles can be very helpful to the children. I talked to this girl's mom at a conference a couple of years ago and she sent me this picture about three weeks later and said, you know, she's now -- she doesn't need somebody to hold off to and she's coming off of flat firm ground into these very unpredictable surfaces with the poles. And somebody is mentioning back scooting. Yes. Vision and the vestibular sense. It's good to remember that vision is a directional sense. You can't see all around you unless your posture allows to you do that and it means moving the eyes by moving the head, by moving the body. And I know you know that, but it's good to remember. So vision drives posture and we know if there are visual field losses, for example, the child's viewing posture can often indicate what's missing and what we might need to do about it. But also postural difficulties can confound functional vision. You can't use your vision if you can't point your eyes in the correct direction or keep it there. And one of the issues is actually to do with a missing reflex. The vestibular ocular reflex is largely a vestibular reflex, which enables us to do something quite sophisticated. The definition says in normal head movement the eyes move in the opposite direction to the head and at the same speed to stabilize the retinal image. What that means is if you look at my little picture if you can see me, I can look at the picture -- I can look at the picture and I am blind in one eye and have acuity in the other. Now I can move that eye around to my right, to my left, all the way down, all the way up, and I continue to look at the slide because my vestibular system is keeping the eye in the right place. As I stand up, I want to remain looking at the slide so my vestibular sense through a cranial nerve is telling my brain oh, the head is moving up so the eye needs to move down otherwise you won't be looking at the slide anymore. Now, you stop standing up so you need to stop moving the eye down. Now he's sitting down so you need to bring the eye up. Now he's got his butt on the seat so the eye can just stay where it is. And the same if I move side ways or diagonally. If my vestibular system is not there and not functioning, when I stand up, my eyes go up with my head and I'm no longer looking at the slide, I'm looking at the wall in front of me and I then have to look to find where the slide is. Equally if I turn my head to the right and my vestibular sense isn't working, my eye has to go with the head and then I have to search like this to find it again. And the children learn this and find strategies. Here's a child flat on her back, she's brought one ankle up on the other knee and she's lifting the book above her head. It's going to be a difficult position to support for very long, but can you see how firmly she's fixed her eyes by fixing her head, by fixing her body. And the legs, ankle up on the other knee gives confirmation that the body is well fixed. You ain't going to fall, everything is okay. All your attention can go into vision and looking at the book. Availability for looking. Here's a boy I know. This is taken from above this photograph. He's sat on the back of the couch and then dropped back so his head is laying on a cushion on the seat of the couch but his butt is up on the back of the couch and then his legs -- his knees are bent, his legs are wrapped around each other and he's holding a little tablet or something very close to his eyes and with his thumbs he's typing a message to one of his friends and he uses these complex positions a lot. Here's a much younger boy. He's kneeling side ways on on the couch, he's leaning forwards resting his forehead on the arm of the couch and then the tablet that he's watching the video on is down on the seat. And you can see Hess positioned himself to that his head is fixed, his eyes are free to look at the tablet. And if he needs to we can bring that left arm up and use it to operate the touch screen. Who teaches the children these things? Nobody. They learn all by themselves. They experiment to find adaptive functional postural behaviors which will facilitate whatever it is they want to do. Here is somebody who because his lower body is much stronger than his upper body, he is much better muscle tone and better postural control. He's laying flat on his back, extending his legs up straight, he's barefoot and he's holding the tablet in each foot between his big toe and the next toe. So he's using his feet -- what's the word? I can't remember the word. Monkeys do it with their tail. I want to say comprehensive. Pre-hen sale. Pre-hen sale feet. And again his fixed raise body. And what the children are doing is fixing the body to fix the head, to fix the eyes so you can use your vision in the best, most reliable and best way possible. These are adaptive functional behaviors. And if the child does this laying on their back, if you keep lifting her up and making her sit on a chair, you might well be stopping her using her functional vision. And somebody's made a quote, I wonder how often visual inspection like this is mistaken for ASD red flag? Absolutely? People want to label rather than an explanation because labels are quick and easy and you're trained in labels so you can find it all over the place. Think about what the child's getting from what they're doing. Think about multi-sensory and think about compensatory functional adaptive behaviors. Remember that the vestibular sense doesn't just give her an effective vestibular ocular reflex, but it also answers the question where is my head? And yeah. Somebody is saying as -- also teachers probably tell children to sit up straight in their chairs. You get that all the time. Sit up straight. Lift your head up. Lift your arms off the table, take your elbows off the table. Don't cross your legs. All these kinds of things which we all heard. I heard that all my childhood starting with my mother, but of course I didn't have all these sensory issues. I had sensory issues like everyone does, but not like this. Leslie is saying I wonder the same thing. I often have children on my caseload who are pre-language or limited language and may be DeafBlind or CHARGE and get flagged for autism spectrum and that happens a lot. And I always say there's no reason why you can't be DeafBlind or have CHARGE Syndrome and also be autistic, but that's a bit of a long shot. And actually, when I see children with autism, to me they look like children with CHARGE system because they have CHARGE system type behaviors. And these are always called autism type behaviors, but actually they're DeafBlind type behaviors, you know? That's the problem with labels. They're quick and easy and dirty and they avoid explanation. People think they explain things, but actually they don't. What I'm trying to do in this talk is explain things in a bit of depth and in a bit of detail. So if there's that question where is my head and your vestibular system isn't answering the question, you might do things like head weaving and the children often do a figure eight like I'm demonstrating. They might bind the head with a tight hat or a sweat band, swarve, string, a plastic bucket, a sandwich box. They might hold the head or tap the head. They might press the head or stand on the head or push it against the wall. And think about the oral behaviors. The jaw muscles can give intensely strong proprioceptive information to the brain. Think about jaw clenching, teeth grinding and biting or chewing on something. Have you ever seen a child who can't walk effectively unless they're biting on something in their mouth? It makes perfect sense. Have you seen children who walk with terrible posture, their gait Saul over the place, but if you give them a chewy thing to bite on they're more erect, there's less side to side swaying, their head is more erect, their arms are more down and less out to the sides. And as I should have added biting chewing and sucking because sucking is a major source of proprioceptive information. And -- oh, it's Megan. Teeth grinding. I was so happy to see you present this -- many years ago. Is he asking where is my head? Yeah, I think it happens a lot. We need to acknowledge it. Here's a kid with a bucket on her head. It's not just on her head, but she's pulled it right down, tight. Somebody says my -- my son likes crunchy food. I figured it was textual preference, but it could be proprioceptive rich. It could be both because it is clenching. Where are my arms? Where are my hands? And here's a boy -- this is taken from an advertisement. This is a commercially produced necker chef, how often have you receive children in a shirt or blouse and the bottom is soaking wet with saliva and it might be ripped and torn because they've bitten through it? And they need that kind of input. And that behavior, what this boy is doing, it's often called oral stimulation. And yes, he's using his mouth, but I like to think of it as proprioceptive stimulation rather than just oral stimulation. You know, is it just in his mouth or is he biting on it? Because if he's biting on it it goes beyond just the tactile impression of having something in your mouth. Children -- I know children who they've been encouraged, shall we say, not to use a pacifier, but when they're walking they like to have it. It makes sense. It makes perfect sense. And of course there's a range now of these wonderful chewy jewelry things that we didn't used to have. And Deana says yes, I rather dislike the word stimming, it always seems to perceive the perception that we need to stop the behavior. I'll come to that in the second half I'm going to talk about self-stimulation a lot. I find in America people tend to say stimming. -- stemming. They mean stimming, but they say stemming. To me stemming means like breaking the stems off strawberries or something. Stimming. When I go to schools and I meet the staff and they say something like we'd like you to help us -- he self stimulates a lot. We would like you to give us some strategies to help to stop it. And I always say what kind of things does he do? And then I say, well, I notice you're stimming. You're swaying from foot to foot. Or I notice you're wrapping your hair around your finger as we talk. And anyway, I'm doing stimming after the break. But I always dislike the word because it's a very dirty word in education. One of the most horrific things a child can do is stimming, and I think no, no, they have to and we have to. Back to pasture. Jean Ayres again, after air to breathe, postural security is our next most urgent priority. So the kinds of behaviors you've seen in some of these pictures where the children are confirming that their body is fixed and safe. Sorry, I'm reading the chatbox. I'm learning from the chatbox, you see. I'd much rather be reading the chatbox than talking to you. Isn't that terrible. But I know I have to talk to you. What this quote is telling us is for a child to be available for learning, for a child to be available to take in information from the environment around them, for a child to be available to your teaching, their brain has to know that their body is safe. Because if they're going to fall and lose postural control that's a big, big primal concern and it's a primal need to ensure the body is safe. And maybe in all sorts of situations the child doesn't feel that their body is safe, you need to learn that and be aware of that and maybe before an activity, before a lesson you can evolve individualized to the child something very simple like doing a jumping game or giving them some deep, deep pressure on the shoulders and the neck or doing a patting game, clapping game with them. There are all sorts of things that you can do that might get them in a better place or make them more available. Somebody, Paula is saying, what can we do to help children with CHARGE achieve that postural security early in their lives? Is the best thing to do is just to allow them to explore on their own? Can we help? I won't have time now, unfortunately, but after the break I will talk about what helps. So I will get there. And you will have the slide show at some point. So let me see. There's self-stimulation. So I will jump on to what helps. Oh, I'm sorry. No I won't jump on to what helps. I'm trying to cram too much in. So let me -- I'll coming back to what helps. Incidentally, while we're talking about CHARGE, the Cincinnati Children's Hospital has a CHARGE Syndrome clinic. I've been twice and sat in. And they only have medical professionals who are very familiar with CHARGE Syndrome. And they did a conference, they did their third conference back in September or October. And it had to be virtual because of the Coronavirus pandemic. And they've now set up a vestibular clinic and the very first presentation was about the vestibular clinic and it describes some of the physical therapy and occupational therapy type approaches that they're using to improve their vestibular functioning or to help the children compensate for their vestibular anomalies more effectively. And I can't give you the link, but if you search the Cincinnati Children's Hospital CHARGE clinic, it's all available and available free of charge. Also the New York state's Deaf-Blind Project did a virtual CHARGE conference also in September, October. And that is also available if you go to the New York state Deaf-Blind Project. It was all filmed and it's all available. And I believe Chris Russell does -- I think, I can't remember now. I think Chris Russell does. Kay see Stratton does a fantastic keynote, so recommend it. And we're going to take a break now. We're going to do a 15-minute break while I try and organize myself because I've got all in a mess with my slides. And when you come back I will talk about strategies to help with proprioceptive issues and vestibular issues and he we'll go on to self-stimulation and maybe I'll talk more about assessment, but there might not be time. So if you come back at quarter past.

>> Kate: That would be good. Thank you so much, David. We will see you all in 15 minutes. That's 1:15 central time, so quarter past. One thing that I failed to mention in the opening announcements and I apologize, I wanted to give special thanks to the New Mexico Deaf-Blind Project for supporting today's session. Our accessibility for today's session. Big thanks to them for that today. Okay. See you in 15 minutes. The room will stay open so you do not need to log out. You can and come back in if you would like, but you do not need to. We'll see you in 15 minutes. [15-minute break].

TSBVI Coffee Hour:

01/26/2021

David Brown

Part 2 Ð Being a perceptive reflective detective: a multisensory approach to assessment and learning

>> Kate: Welcome back, everyone. We may still be waiting for some people, but let's get started because David has a lot of information to give us.

>> Brown: Can you hear me okay?

>> Kate: Yep.

>> Brown: I just went through my slides and this is typical of me. Because I'm a synthesizer, I put more and more stuff -- I was asked to talk about the sensory stuff and I wanted to put in self-stimulation and assessment and self-regulation because it all joins together. And it's far too much. I thought with four hours I could do it, but obviously I can't. So I'm going to say a little bit about self-stimulation, then I'll come to very briefly what kind of thing helps when they are vestibular proprioceptive issues and then go on into my assessment talk in the next slide show and see where we get to. But I have to thank you for your questions and comments because I was worried with so many people that the chatbox would just be whizzing away. But so far things have been coming in at a reasonable rate so I've been able to -- I think I've been able to see questions and respond, I hope. And I know that Kate is going to give me a shout-out if I really miss things. So when people talk about stimming they rarely say self-stimulation and I don't know if they know that the word comes from self-stimulation, which is why they say stemming because they think stimming is a word all by itself, but it's just an abbreviation. And the correct term is self-stimulation, doing something to stem late yourself. And I've got a couple of slides like my take on self-stimulation. So what is self-stimulation? We have to remember the constancy of sensory feedback, that our bodies are being bombarded all the time with sensory information. And all of our senses are picking it up and passing it to our brain endlessly simultaneously. And insofar as we've acquired the ability to modulate our senses, we're able to survive, but we all have to go at times, we all have to go somewhere brighter to read or somewhere quieter to concentrate or sit down because we're tired of standing or stand up because our back is hurting from sitting. We're constantly adapting what we do and the environment because of the sensory information coming into our brains. And I think self-stimulation is any sensory input we seek that is not directly the result of a specific activity. So if you're making coffee, drinking from a glass, getting dressed or walking, there are certain sensory inputs that you need to be focused on, but you might do other things as well. So if I'm making coffee, I'm waiting for the coffee machine to do its job and I will probably pick at my fingernails and go back and forth across the Kitchen. Now, picking my nails and walking back and forth does not help the coffee get made at all, but it does pass the time while I'm waiting. And self-stimulation I think is any sensory input through any sensory channel that we seek which facilitates our functioning. It might be helping time pass, it might be helping us stay awake or calm down or think even. And I know that a lot of people say I go for a walk because it helps me think. And it makes sense. So I've got three slides with some thoughts about sensory inputs. First of all, as I said the constancy and the interrelatedness of all our sensory inputs. Secondly, the senses connect the brain to the body. Thirdly, sensory inputs have a significant and direct input on arousal levels. And that's what I meant when I said earlier that sensory inputs are powerful medicine. They can knock us out or get us to screaming pitch if they're not right, if they're too intense, if they're too continuous. So they can be very dangerously powerful. Some senses may be more important to us than others at certain times and it's pretty obvious that when we're going to sleep, postural security is more important than using our vision unless you're somebody who has to use television to fall asleep. But there is also a sensory hierarchy and we know that the proprioceptive and vestibular senses provide that fundamentally important information that once we have it our brains are free to concentrate on other things and postural security is the main thing. Most children with DeafBlindness are not in touch with their bodies very well or they don't feel their bodies very well, I believe. And I think simply by observing them we can see that. Why did we self-stimulate? Well, you tell me. It could be a huge list. We all self-stimulate to maintain alertness, to wake up, to calm down, to maintain postural control, to get comfortable or to keep comfortable, to occupy our minds, to self-regulate, to fight boredom, to maintain attention, to keep sane, and generally to improve our functioning to achieve our goals. And self-stimulation is crucially important. Far from stimming being a bad thing, it's essential, but I'll come back to that in a moment. Sensory deficits and poor sensory perception make children with DeafBlindness self-stimulate in mostly normal ways, but often with more intensity, more persistence and for longer periods of their lives than what we consider normal. The big exception tends to be the visual stimulation activities, especially those that involve things like eye poking, when children eye poke, that is normal. You rarely see that in children or young kids who are developing in a regular way. But most of the other things they do, the rocking, the hand flapping, the jaw clenching, the teeth grinding, the picking at the fingernails, they're all part of a normal spectrum of stimulation. Follow various reasons children with DeafBlindness might have poor social awareness so their self-stimulation behaviors may be more obvious. It's difficult for them to understand that there are certain things you shouldn't be doing in public or shouldn't be doing in a very obvious way or shouldn't be doing in such an extreme, intense way. Attempts to stifle and stop self-stimulation behaviors may result in worse self regulation and generally less good functioning. And finally, observing how and when a child self-stimulates will offer invaluable insights into who they are and how they work. For our assessment, our teaching, our behavior management and our relationship building. Now, I'm sure a lot of you are sitting there thinking now what if the behavior is -- what if the self-stimulation is quite dangerous? What if they're harming themselves or putting other people at risk? And I'm well aware that can happen. And I think if the self-stimulation behavior isn't dangerous or illegal, in which case you need to intervene immediately, but if it's not dangerous or illegal, you need to ask yourself and other people what does this behavior mean? What's it coming from? Why is it happening? Why is it this self-stimulation behavior rather than something else? And then to to intervene to try to answer that question, not to the stop the behavior as the primary aim. You should all the time be working for understanding. Understanding is the key to everything. And just stopping behaviors because they're stigmatizing isn't a good idea. Yes, you're asking what it means in order to reduce the behavior, but you're not going straight into reduce the behavior unless it's dangerous. And then Lisa says in the chat, my daughter loves to spin and does it very fast, but it's one of herself-stimulations that gets more attention in public, more so from other children. And yes, I can imagine that's quite stigmatizing in the sense of drawing children and looking very unusual, and we're into that bizarre, quote, bizarre, weird, crazy kind of list of labels. So if she likes to spin, think about -- take a sensory diet view of it, take a multi-sensory view of it. It's probably primarily vestibular input she's looking for, but there's quite a lot of tactile and proprioceptive in the feet going and she spins and there's quite a lot of pressure on her muscles as she twists around. And then think about how does it tie in with her emotional state, with her state of arousal. And often you find like the person I mentioned earlier who did hand flapping it came at the moment of excitement and great relief and that made perfect sense. You think about hand flapping, which is one of the most despised stimming behaviors in my experience, though I love hand flapping. When do children hand flap? And it tends to be at times of heightened emotion or even stress. It's when they're very excited, when they're very frightened, when they're very hurt. When they're very bored. And if you look at them before and after the hand flapping, you often see some visual evidence of what's improved, what's being achieved by the hand flapping behavior or that [Panting] that type of loud hyperventilation behavior. And often they look less stressed after the hand flapping. Their shoulders come down, their breathing is more -- less shallow and rapid and more regular and slower. Don't just glance at them every couple of minutes and see how they're doing, but look at them, and look at all of them. I remember when I first started in the DeafBlind field, if I was trying to evaluate a child's vision, I'd only look at their eyes and their face, and I felt that's what it was all about, and the same with hearing. I assume you evaluated the hearing by seeing if they could turn around to a sound, because that's what I'd seen other people doing, and specialists doing. And it took me a while to learn that we should be looking at the entire body of the child. And I will talk about assessment in ten minutes, 15 minutes or so, and go into that. And there's a quote, many behaviorists attempt to eliminate the behaviors you were describing. What you were stating makes a lot of sense. And I would agree. I've worked with behavior specialists and I've done this kind of, you know, talk with them, and tried to get them to see that they haven't evaluated the meaning or the value of the self-stimulatory behavior, but they are trying to reduce it. And they're trying to reduce it maybe for all the right reasons because it's a bit dangerous or because it's very stigmatizing, like your daughter who spins and you don't want the child to stick out so much, or because they're doing it in inappropriate situations where it's disruptive, or because it's actually blocking the child from learning. But, if they're the reasons you want to stop it, you've got to then say, why is it happening in the first place? And I think -- let me see. I've got in such a knot today with my slide shows. Yes, this is where I was going to go. We all self-stimulate for very good reasons, and I'm saying this about all of us. The multisensory perspective is crucially important. Sensory issues inspire and initiate these behaviors. Social meaning is acquired later. So when you see a child who knows if he pokes his eyes somebody will come over, or who knows when he pokes his eyes, people will go -- or when he starts spitting, people will move away. That's social meaning that's been acquired through experience. But the spitting and the eye poking almost certainly initiated from a sensory need or a sensory motivation in the child themselves. I do believe these behaviors are inspired and initiated by their sensory issues and their sensory motivators, and their sensory deprivation. And even if the child now has really self-abusive behaviors and is damaging themselves, so where would that kind of thing come from in sensory terms, because that might well lead you to a strategy that could help them. The concept of the sensory diet can provide us with insightful and powerful strategies. Sensory needs and sensory inputs control attentional priorities. Notice the child's posture and movement requirements and remember these things apply to all of us. So, you know, a lot of you will listen to me today and you'll go home -- well, you're probably all at home now, because we're all at home. But you may be thinking of your partner, or your own parents, or your siblings or your best friend, because this is a spectrum of human behavior and human need and human adaptations to those needs. But they stand out much more clearly in the children we're thinking about today for the reasons I've said. The whole point of looking at sensory diet, going back to Gina's and the OT perspective is if the child is actively looking for vestibular input or deep pressure input, maybe we can come up with a program to give them that kind of sensory input. Maybe we can give it to them in a much more organized or much more intense way, so that they won't need to be looking for it so much themselves. Because their brains will be satisfied with what they're getting from our program, which is what I meant when I said maybe before a desk sitting lesson, if that child does some jumping or some rhythmic clapping and hand clapping with you, or get some deep pressure massage on their shoulders, or their neck, or even the top of the head, or even you on the top of the head giving them rhythmic compression down through the spine, whatever seems to work for the child. Maybe those inputs will last long enough in their nervous system to have them more available for what they're doing. And you may know that sometimes therapists, especially occupational therapists, may well recommend a brushing program with a specific brush, along with rhythmic joint compression. Because those inputs last for a certain amount of time in the child's nervous system. And I was about to give a big callout to the OTs. If you want more on this topic, join Lisa, an OT, on February 18th at noon central time. She will review the terms Sensory Processing, sensory Efficiency Skills, and sensory integration. She will discuss the what and wheres of the vision system, sense of smell, limbic system, touch sensation, vestibular function, and proprioception. There you go. So you're getting my amateur teacher version, and then you will get from the horse's mouth -- not that I'm saying Lisa's a horse, but from Lisa's mouth you will get the OT trained version. I've given this talk to large groups of therapist, and they've said to me, boy, I didn't realize that my input had such a huge impact on the child's education. I didn't realize I was such an important part of the team. That's what I bring as a teacher, is that they are valuable, important members of the team and need to be looked at like that. I was going to talk a bit about external factors in the environment, but there isn't time. As I say, I was being over-enthusiastic. And I was going to talk about the three key elements in the environment. My old professor in England, Tony Best, wrote this in an article, structuring the environment. Think about people, think about time, and think about space. They are the three main external features that we can manipulate and play with. So now I come to the end of my first session, and these are just a few general points. But if you've got Lisa coming, she'll really be able to talk about these in much more detail. So what helps? Well, any activities which improve muscle tone and controlled movement and reinforce the connection of the brain with the body. Examples might be Tai Chi, yoga, climbing on a climbing roll, dancing, those kinds of activities. Deep pressure inputs. Things like jumping, deep pressure massage, swimming. Why do so many of the children on my case loads love swimming? Think about it. If you have low tone, if you don't feel your body very effectively, if gravity is a big challenge, first of all, you're buoyed up, so you're not going to fall. Secondly, the moment you go under water, you've got water pressure on your body. And I've seen children with DeafBlindness not just get in the water, but actually try and go down to the bottom because they want the maximum of pressure on their body, because it's so liberating. Because suddenly their brain is getting a really good idea. Plus, there's water resistance, of course. When you try and move your limbs through water, you have to push really hard, and the water pushes back. Binding. Things like Spandex pressure vests and pressure cuffs. Good physical support and appropriate postures. Sometimes children do better, they're more available for learning if they're standing. It's kind of -- we see that as counterindicated. If they've got all these issues, surely they should be sitting. Well, sometimes they're more attentive when they're standing or might need an adaptive seat and that's where the therapists come in. Variety in postures and movement, and horse riding is the greatest one of all. Because the child's body is going to be -- they're going to have to be reacting to all those movements all over the place. They need regular rest periods to reorganize their systems. And some children might literally need what we think of as rest, maybe flat on their back. Other children might need to spin on the spot or do jumping and clapping, or stare at the ceiling fan and turn around with it. The environments need to be controlled, and in the DeafBlind field, that's fundamental to the way we work, controlling the tactile and visual and auditory environments very much so. We need to find strategies that are motivational, and if we've really observed the child's sensory diet in their self-stim behaviors, then the kind of sensory inputs we provide will be inherently motivational because they're kinds of things the child is already seeking for themselves anyway. And when you do early language work, it's good to include the appropriate vocabulary for things like body parts and movements, physical feelings, emotional states for the desired activities, you know, to make this a more comprehensive part of what they're doing. There's a question from Samantha. Please explain time, if you can. I didn't understand that in the discussion about the gurus' contributions. Okay. Let's go back to that slide. People, time, and space. What it means is that a child with multisensory impairments is going to need to do things on a different timeline and a different pacing to their peers who don't have multisensory impairment. And generally speaking, they will need more time because things will happen more slowly. Of course, there are children -- I know quite a number of children with Charge Syndrome who go the other way. They have problems with -- what's it called? Controlling -- they do things too quickly. They just fling themselves into it rather than pausing and monitoring what they're doing, because they have executive function problems, they don't monitor their activities well, and they also don't have good proprioception and vestibular sense and vision and hearing, so they rush things. With those children, one of your educational goals might be to slow everything down a little bit. But the other type of child, one of your educational goals might be to try to speed things up a little bit, to make them more efficient in the way they use their vision, or their hand-eye coordination or whatever. But the time they need and the pacing can vary a lot compared to ours, but it can vary a lot depending on how tired they are or how much nutrition they've had. Some children are much better straight after lunch, much more attentive and available. Other people like me are much less available after lunch because it's not a good time for me to be focused and thinking. So I hope that helps. Impulsivity. Thank you, Samantha. Why couldn't I remember that? Because I'm getting old. They don't have good impulse control, so they tend to fling themselves into everything. And they're not even worried whether they do it well or badly or whether they finished it or not finished it. They just kind of do it. And that's part -- yeah, impulsivity, pacing, and time. And that's something that Gina talks about, is pacing and time. So, where was I? The last two slides, and then I'll change slide shows. Why is all this so important and why should we be observing for it? Why am I talking about it at such length? Well, it's important to understand the child's challenges. It's important to gain a more accurate idea of the child's needs. It's important to appreciate the child's adaptive behaviors and that's the big one. But, you know, I'm so used to being in situations, and the child is on the floor, and I say, what kinds of things does she like? And people might, you know, roll their eyes or sigh or laugh, and they'll say, oh, she doesn't like anything really. And I'm looking at the child rocking side by side and sucking her fingers, and banging her left foot on the floor. So I'll say very quietly, do you think she likes rocking side to side? Oh, she loves that. This is the person who just told me the child doesn't like anything. Do you think she likes sucking her finger. Oh, she does that way too much. And when they say she doesn't like anything, what they mean is she doesn't like anything that I want her to like, or I want to do with her, which is not answering my question. I didn't say what does she like of the things you want her to do. I said, what does she like, because it's about her, not about us. It's about her. And we need to get into that mindset that almost every child you meet has achieved things all by themselves. They've taught themselves things all by themselves. They're not dumb. They're not stupid necessarily. I mean, they might have cognitive issues, but even with cognitive issues, their brains drive them to find stuff that they like, to find stuff that's interesting, to find stuff that helps them deal with the tedium and boredom of the world that we provide for them. You know, children achieve things, and those things are not honored. They're not even noticed. And if they are noticed, the answer is, how can we stop him doing that? Well, you know, that's not a good approach to assessment or education, I'm afraid. Even if what they're doing is a pain in the ass, basically. And my last bullet point, we need to be able to introduce the essential child to other people. How can I introduce this girl to you if I don't even know who she is or what she likes or how she does things. And, you know, this should be so fundamental. And I go on. My last slide here, why is this so important? To be aware of the fundamentally important things which often get overlooked or forgotten. How does that child get up from a chair? How does he sit down in a chair? How does he walk? How does he walk on firm ground compared to grass? What kind of way does this child look at things? How does she hold her head? Where does she need the object that she's looking at? At what kind of times does she flap her hands? What kind of emotional state does she seem to be in when she starts to rock? All those kinds of things are really important. And we've been too inclined in education. First of all, in the DeafBlind field, to jump in looking at vision and hearing and not bother with all this stuff, which is why I've been pushing it for almost 40 years. But also, we're very inclined to not see it as terribly important, but actually we could get the child far more available and far more operating in a team with us if we would be aware of these things and actually work on them to get the situation in a better place. This knowledge also helps us remember that everything the child does probably takes more time, more planning, more energy, more concentration, and more attention than it does for their peers. Think of that slide I showed of the 21 CHARGE Syndrome issues, every one of which can cause fatigue, and think that nobody with CHARGE only has 21 of those issues. They all have at least three or four and some of them have 11 or 12 of them. And that should make you think about things like time, planning, energy, concentration. And finally, to realize that things that look crazy might be functional, and clever, adaptations. Perfectly individualized to the child. So, that's the end of that slide show. And somebody is saying team approach to sensory issues. And, of course, the child should be a member of the team. That's really important as well. And I hope it's okay if I move on and talk about assessment. Actually, everything I've said today is about assessment. I should explain my title. There's a wonderful teacher in Scotland called Paul Hart, and he's been to Texas. I think he's been to at least two DeafBlind symposium. He's a bit younger than me, but he's one of the old guard. Very skilled teacher of people with DeafBlindness. He's more experienced I think in the adult field than my early intervention field. He gave a talk once about the need to be a perceptive detective, and we all wrote it down, and I talked to him afterwards, and I said, I think it should be perceptive reflective detective, because it's no good being perceptive, which is noticing if you don't then think about think, reflective. And I see Paul Hart is going to be part of the Texas symposium in March, and I haven't registered yet, but I have to, because I'm going to be one of the -- I'm not presenting, but I'm something. Oh, that's great. So, Paul Hart. He's amazing. People always say to me, I remind them of Paul Hart. We couldn't be more different. He is so organized. And I'm so all over the place. Oh, I'm registered. Oh, great. Excellent. So, being a perceptive reflective detective means both noticing and thinking about it. And he is -- the ability to observe without evaluating is the highest form of intelligence. You know, people are -- oh, Suzanne did it for me. Oh, wonderful. Thank you. I forgot all about it. What was I going to say? Yes. You probably know Oliver Sachs. He wrote a book about music and the way music affects our brains, and he was a wonderful case study person, which is very me as well. I've often been told my approach is very anecdotal, and it's said with a kind of sneer, because I don't do -- I don't deal a lot in numbers and tables and numbers and things, because I don't understand them. And I think anecdotal evidence is some of the best stuff we have in the DeafBlind field. It's got us a long way. He talks about the technological developments and scanning, for example, and how we can now look at a brain, and we can actually see which parts of the brain are being activated by external stimuli, and he says how wonderful it is. But then he goes back to clinical observation, which is what I've been pushing, you know, all morning. And there's a quote, and I took it out of the book. The book is Musical Philia. And he says these new insights, in other words, the technological equipment, these new insights of neuroscience are exciting beyond measure, but there's always a certain danger that the simple art of observation may be lost. That clinical description may become perfunctory. And the richness of the human context ignored. And I immediately wrote that down, because I thought, yes, this is what I keep saying, but he says it, you know, in a much more succinct, organized kind of way. And, of course, he was from a very different discipline, much more organized discipline. And I think, you know, if I've brought anything to my professional life, it's a skill in observing. It came to me naturally. I fell back on it because I didn't know what else to do, because I hadn't been trained. And I think it's easily missed. You know, in education, we're all in a world now where we're being pushed to record and to justify and to come up with numbers for all sorts of things for all sorts of reasons. And when I talk, sometimes people say, yeah, we wouldn't be able to do that. Or, we wouldn't have time to do that. And I think, well, but that's the education of the child. How can you educate them if you can't even observe and learn who they are in a controlled, targeted kind of way? So, on the basis of what I've said so far, you remember those photos I began with. Here are a few more. And now you know why the children are doing this. Here's a boy wearing a backpack -- he's standing up wearing a backpack, but it's on the top of his head. And of course, we don't wear them on the top of our heads because it doesn't work, because the straps are pulling up hard on his armpits, and the backpack itself is pressing down on the top of his head. What he's doing -- oh, not seeing current slides.

>> Kaycee: We're still seeing your previous slides, so you may need to stop sharing and reshare.

>> David: Oh. You're seeing my previous slides?

>> Kaycee: Yeah, we're seeing the slide show from the first step.

>> David: Oh. Let me close it then.

>> Kaycee: Now we see you. We may need to share screen again. Presenter view. How's that?

>> Kaycee: We still just see you.

>> Kate: Hit share screen again. On Zoom controls.

>> David: Yes. I'm sorry. I forgot to share screen. Now you can see what I'm doing, I hope.

>> Kaycee: Yes, perfect.

>> David: And you can see him with his backpack? Great. Thank you. Now I've lost the chat box. Let me just get the chat. Okay. So, yes. So now you know what he's doing. He's answering that question, where is my head. He's also probably standing and walking with better gait and much more postural security in his own mind because of what he's doing. Here's a young man wearing his T-shirt up over the top of his head. And in just the same way, you can see that it's pulling under his armpits, but it's also pulling down on the top of his head. Where is my head? And the point of these pictures is, first of all, to say aren't these kids smart to come up with these ideas? Because nobody's teaching them this. But also, what they're showing us is that they're not feeling their heads very effectively and they're looking for more deep pressure inputs, and we need to address that and we need to get therapists involved, I think, to help us with it. Here's somebody with a stack of plastic buckets on top of his head. And he's actually looking under the buckets in order to give visual regard to whatever he's doing with his fingers. Here's somebody on his back, in the most extraordinary position, fixing his body to fix his head to fix his eyes by lying on his back, bringing his legs way up, and then weaving both arms through behind his legs and holding the toy that he's looking at. And then finally, a girl who's inside her toy box. It's a tall, narrow toy box. And you can see she's put all the toy boxes -- all the toys out on the floor, and she's sitting in the box, jammed in, presumably getting deep pressure and chilling out, I would guess. And, you know, calming herself down possibly after school. I don't know her, but I would guess it's a chilling out, reorganizing kind of behavior. A lot of people are asking about getting the slides. I can't give the photos out. I don't have permission to actually give the photos, but you do have the slides with the text on and the quotes, I believe. And you also have my email address, which I gave at the beginning. But I can give it again at the end. So, let's think about assessment. To me, assessment means asking questions. You know, there's something you don't know and you're trying to find out. That's assessment. Which to me is like asking questions. Maybe in your own -- just in your own mind. And I think there are three main types of assessment questions. One that you get from parents very often, and they might have a newborn baby that they're talking about. Will she be able to get a job? Will she be able to drive a car? Will she be able to live independently? Those are very legitimate questions. And of course, for a baby or a toddler, it's impossible, usually impossible to answer those questions with any degree of certainty. But they're perfectly legitimate questions. And if you're like me, if you work in early intervention, you'll be very familiar with these concerns, and you'll have strategies to help respond to the questions. And bring the parents, like, looking ahead to something much closer to here and now. Then the most popular type of assessment question is the second one, can he stack three one-inch blocks, can he sort shapes and colors? How many manual signs does he understand? You know, how many manual signs can he use expressively with meaning. And those kinds of things. And they're the kinds of things you often see in checklists, developmental checklists. They often involve numbers, and progress is usually measured by, you know, you can stack two one-inch blocks. Next can you stack three. And then can you stack four. And I had a checklist -- I remember my colleagues and I in London, we joked that you could make an entire ten-page checklist, can the child stack two one-inch blocks, three, four, five, six, seven -- all the way up to 100. And every day in school, you could just work on stacking one-inch blocks. And we were being kind of sarcastic. But then there's another type of assessment question that I've been talking about today, which is, what do you do? In other words, you know, who are you? What do you do? Not what can you do. What do you do. Let's think about why people assess the children. There are many reasons why. I've come up with a list. Not a comprehensive list, but it's a list. To determine need or eligibility for services. And of course, eligibility is a big issue. And the child -- for that, the child basically fails or passes. They either get the service or they don't on the basis of the assessment. We assess to provide a baseline of current skills, current knowledge, and perhaps current experiences, and we as teachers, we need that baseline to give us a teaching point so we know what to build on and where to start. To identify the supports and the services needed by the child. To provide a guide for intervention and instructional techniques to help the child develop more skills and knowledge. Very important to measure the child's growth and skills based upon normative standardized groups or results. To evaluate the effectiveness of our educational program. Have we got this right or do we need to tweak it? Does the child need something very different, maybe to what we've been providing? And finally, to present the child to other people. You know, they're all fairly standard. And this is where I come to my links, which you will have in the slide show. And I have to thank Nathan Widener in Texas for spotting the dead links and helping me get them correct, so I now hope all these links are working. If they're not, just look up the name of the author and the title, and do a search on that and it should get you. First of all, on our California DeafBlind services website, two articles, one by me and one by my colleague Julie Maier about assessment. I wrote one called what does follow the child mean? And Julie wrote one about capacity assessment. Capacity or deficit. The lens we use to view students does make a difference. And if you put them together -- Julie and I have often co-presented on assessment at a couple of conferences, and we combine both those articles together. And then, another very useful tool is this one. It's called assessing communication and learning in young children who are DeafBlind or who have multiple disabilities. It was created by Charity Rowland, who you probably know. She created the communication matrix, a very popular approach to assessment and recording progress. What charity did, she did a grant, I think a federal grant -- gosh, in 2008, I think. She got a group of experts together and they began by contacting lots of DeafBlind specialists in the United States, and saying which assessment tools do you use and do you like best for your population of children with DeafBlindness, and on the basis of our responses to them, they picked the 12 most popular, and then they critiqued them. So if you download this booklet from the Internet, you will see the 12 assessment tools. It tells you who they were devised for, because most of them are not devised for DeafBlind children. They're devised for children who were visually impaired or hearing-impaired or had cognitive disabilities. And then they critique them. In other words, what's good about these assessment tools and what's not so good. What's clumsy about them. And it's very useful to see. It's not very long, so it's an easy read. But in the beginning, they have an introduction for parents to assessment, an introduction for teachers, an introduction for school psychologists, and an introduction for social workers. They're all very brief, but it's very, very down to Earth, very real, and very practical. So I would recommend you look for that, and maybe I would download it, because you'll probably go become to it quite often. So, why is assessment so difficult? I wrote an article. I think it's what does follow the child mean, and I say at the beginning why does it seem to be so difficult to assess children with DeafBlindness. It presents a very diverse and complex population. So we say DeafBlind as if that means, like, one type of child. But, of course, it doesn't at all. And there couldn't be more diversity and more complexity than there is in our population. And it's one of the reasons people look down on DeafBlind educational approaches, because we don't have such a clearly defined group. It presents a wide variety of very idiosyncratic behaviors, but I've talked about them all day so far. People doing assessments usually only know one type of assessment process and it might not be appropriate for this particular child. There are very limited resources and assessment tools available. And people doing the assessment often forget the reason why. They get too hooked on the child passing or failing the assessment. And I always say no child has ever failed one of my assessments. I can proudly boast that failure is not an option. Not because I'm a superb teacher, and I can carry them through, but because I'm measuring them against themselves basically. I can see that for a 2-year-old, they're not at the kind of skill level one would normally expect a regularly developing 2-year-old to be at. I can see they don't seem to have any language, certainly expressively, maybe receptively. I can see they can't sit unsupported. But I'm measuring them against themselves, because I have very specific reasons for doing the assessment, and I'll come back to that. I won't go into -- well, maybe I will. What goes wrong. Deficit assessment. And you've all experienced that. Some of you as parents, I expect. Many of you as professionals. You do an assessment, and at the end of it, you've got a lot of information about what the child can't do. Skills the child doesn't have. But almost no information about things the child can do. And that means your approach is wrong, and you're using the wrong kind of assessment materials, really. And as I always say, you know, my mother had no knowledge of special education, but you can put these children in front of my mother, and with no training, she could tell you the things the child can't do. But identifying the things they can do is much more skillful and much more complicated and vitally important. So, let's get away from deficit assessment and the damage it does. They're often not interested in the child motivators. So they come in with a rather dry, clinical approach that doesn't allow for a child with a human being with emotions and a self-image. And, you know, the child's motivators are left out of the picture. As a teacher, it's the thing I most want to know. I don't want to start messing with this kid if I don't know what he likes and what he dislikes, because I'll probably do the wrong thing. And I might have to risk that, but I'd much rather get an idea of his motivators. You'll always hear me saying what kind of thing does he like? Or does he like that, what he's doing? Or what you were just doing with him? What does he like? The pacing. Time and pacing again. The pacing is inappropriate for the child, their health, their alertness level, the time of day, the place, the activity, the people present, and the materials used. You know, we need to be sensitive to that. The task is too complicated and too challenging. I went the a specialist center with a high reputation in London once, and I was allowed -- rather reluctantly, they allowed me to go the other way of the mirror next door and observe. And with no preamble, they read some medical reports of this little girl who was about 4. They sat her on a chair, there were two adults who she'd never met before, and they produced a whole set of miniature objects, and they had a miniature table, with a miniature teapot and lid. This was England, so there was a teapot. There were miniature cups. And they said to the girl, put the lid on the teapot. Well, the girl didn't know what a table was, let alone a teapot. I mean, it was pointless. The girl was here and they were like, you know, five years down the road, ten years down the road. And at the end of it, they produced a massive deficit assessment. And I had to say, well, let me intervene. And, yeah, bye-bye boxes, Heather says. Crazy. Maybe it's too serious. You know, assessment can be fun. As I always say to people. And I've -- you know, between observing and having fun, I've been into so many classrooms and I say -- sometimes they say, we've set a special room aside for you. I've never met the child and I say, no, no, no. I'm just going to observe. I'm going to be in the corner with my notebook. I'll be scribbling notes. You're welcome to see my notes. I'll be making notes about everything the child does or doesn't do and what you're doing and how the child relates to it. And then they'll carry on with the day and I'm in the corner. And I can write five pages, ten pages, 15 pages of notes. And some things will be underlined and there will be asterisks and I'll have arrows joining things together. And then after an hour or so, somebody will come over and say, what time are you starting your assessment. And there's an idea that an assessment has to be special. It has to be in a special place with a special person and special equipment. And we've got to get people away from that idea. It can be in a special place with a special person with special equipment. But assessment can be anything, anywhere. And we're all assessing things -- every time we walk out into the street, we're assessing the situation. You know, it's -- it's just a silly idea of assessment. We have a role to play in educating people, including assessment can be fun. Think about observation. Think about motivators and make it fun. And then there's that expectation that the child will pass or fail. And obviously, if your role is to determine eligibility, there's going to be pass or fail. And Debbie says, assessment happens every day while working with the child. Yeah. You should be assessing every moment that you're with the child. But not in a sitting down in a special room staring at them over a table with special equipment. That doesn't really make sense. What also goes wrong. Well, inappropriate assessment. If the only thing you've got is this particular checklist, that's what you're going to learn, and it might not -- it might not be relevant for the child. And Kathi says, I think the idea of assessing and reporting on what the child can do is so great because it allows you to focus on what the next steps are going to be for that child when you're talking to the teachers and family members. Exactly. Rather than what the child can't do or won't ever do. People often mimic standardized clinical assessment procedures. You know, everyone has to be quiet and there must be no distractions. Well, I've worked with so many children in homes where they turn the TV off and the child changes. And I've said, do you usually have the TV on? Here in America -- in England, people have smallish TVs. Here their whole walls -- at least in California. And I say, well, you know, if she's used to the TV on, why not put it on again and we'll turn it off later. But she was doing stuff, and as soon as you turned the TV off, she went still and she changed. So I can tell she can hear the TV. Let's think about that. This isn't a dry, clinical approach. Though it can be. Lack of a whole child perspective. Are you only looking at the eyes when you're assessing vision? Are you only looking at the ears? You need the whole child. It's all too fast. The assessor is saying, this is what I want to see now. The child is doing all kinds of other things, but they're not even noticing because they're only thinking about visually directed reach or hand-eye coordination or color matching. And then missing all these new wonderful gifts the child is giving them, because that's not what they're thinking about. The assessor is assessing the wrong things. And they don't understand response. You know, we learned a long time ago that the correct response to a sound behind you is not necessarily turning in the correct -- on the correct side to look. It could mean changing your breathing, it could mean blinking, it could mean, you know, stiffening your posture or relaxing your posture. It could mean twitching, it could mean wiggling your toes. It could mean all sorts of things, just about anything. And I'm going to skip that because -- and I've just done that. But I wanted to go back to this. Why is what I'm saying about assessment so important? To understand the child's challenges to gain a more accurate idea. Of their needs. To appreciate their adaptive behaviors and to be able to introduce them. I don't know if you're familiar with capacity building assessment. It still gives you a learning profile of the child, but it highlights current skills, interests, knowledge, and experiences. In other words, what the child can do, and where the child currently is. It focuses on the individual, not on any kind of norms. You're still looking at needs, but you're focusing on identifying the supports that are needed for the child. And you're expecting and looking for the child's intelligence and adaptive skills and developmental potential. And as Lori says, also a way to write a more positive tone. And Heather says, perhaps we should use the word study. Study of the child. The capacity building model allows you to look for and recognize the unique characteristics, skills, talents, and interests of a person. And it -- you know, sometimes it's relevant to say, oh, he can spit a long way, can't he? I'm just saying that because everything they do might give you information. And if he's spitting to see where it lands, that gives you the idea about visual acuity and distance vision. Boy, he's spitting that far and he can see -- you know, it's important not to dismiss all kinds of evidence, because it might be very, very helpful to you. It's a way of understanding the individual. It allows you to recognize potential, and it's completely individualized. I think I'm going to speed on. So if you want more on that, think about Julie Meier's article that I mentioned on the California DeafBlind services website. So my view of assessment, the view I'm promoting, unfortunately, it's still unusual. And I would hope it's not that unusual to all of you, but there's like over 300 of you, I think. So there might be some -- oh, we're down to 299. We've gone down through the 300 barrier. And Heather is suggesting a watermelon seed spitting contest. Why not? If that seems to be an effective way of carrying on. And if it's motivating to the child, why wouldn't it be. Except, of course, a lot of kids would eat the seeds. It's positive. My approach is positive. It looks at positive skills and achievements. It identifies learning styles. It looks at preferences and interests and motivators. It considers the whole child and it credits the child with intelligence. And my goal in assessment is to improve my understanding of the child, to help me to build a positive relationship with the child, if I'm going to interact with them. It seeks to help me to know what to teach and how best to teach it. And it seeks to give me a clear focus for measuring progress. In other words, in the context of this student, this is real. I'm only interested in the reality. I don't want to go outside the real. Because that's all that matters, actually. And Hattie says, yes, we never know what we're going to get. That's true. But assessing to build from abilities is much more accurate about who the child is. It's so obvious, and yet you see this not being done still all the time. So I'll come back to my approach, but let's go on to the gurus. Jan van Dijk. Follow the child. He said this the first time in print. His quote from 1966. In the educational atmosphere I describe, the child holds the central position, the featurer follows the child and, when the child responds, the teacher is present to answer the child's request. teacher follows the child and, when the child responds, the teacher is present to answer the child's request. In other words, it's child-led. And I think that speaks for itself. So when van Dijk would talk about assessing children, he often used to lose people partly because he was Dutch, so he was always working in a foreign language. But also his style was pretty unique. And you had to get to know him and you also had to pick up on his accent and his pronunciation. But he produced a document with Kathy Nelson in Utah in 2001. He said, when you begin an assessment, you should first of all make the child at ease. In other words, try and get it as -- you know, the child as relaxed and receptive as possible. Determine the child's bio-behavioral state. Are they anxious? Are they relaxed? Is everything okay? Are they drowsy and falling asleep? Are they at screaming pitch? Because you want to get them a good biobehavioral state. Determine the child's interest. Follow the child's interest. In a nutshell, that's his approach. And he always got pressured to produce more and to write more. And finally, American Printing House For the Blind issued this book, child-guided strategies: The van Dijk approach to assessment. For understanding children and youth with sensory impairments and multiple disabilities. And he was the primary author, but Catherine Nelson, Teresa Oster, and Andrea McDonnell were involved also. I've picked out some slides for the key points. So what does he say about his approach to assessment? It's child-guided. It's fluid. You don't quite -- as somebody just said, you don't quite know what you're going to get. And you don't know where you're going, but you're going where the child is going, to a large extent. Looks at the processes children with multiple disabilities, including sensory impairments, use to learn and to develop. And at the end of the process, the assessment is summarized in terms of strengths and next steps for intervention. In other words, as we've already said, this is where the child is, so this is where we need to think about going next. Very practical, very real, very child-led. And then he looks at what are we assessing, basically. Are we seeing if the child can stack three one-inch blocks? Are we seeing how many manual signs the child understands visually? And he says no. Let's assess very different things to rigidly skill-based assessment, concrete, skill-based assessment. What's the child's ability to maintain and modulate state, biobehavioral state? And I will come back to biobehavioral state a little later in this session. We have about 45 minutes left, if you're still with me. What's the -- what are the child's preferred learning channels? Through which senses does the child learn best, or does that change depending on where they are or whether they're standing or sitting, and things like -- oh, good. Jennifer is still here. And Kaycee is. I can see. Thank you for letting me know, Jennifer. I'm glad you're loving it. What's the child's ability to learn, remember, and anticipate routines? Very, very big part of DeafBlind education. We tend to go for routine-based predictability and move on from there, for fairly obvious reasons. But, once the child has mastered the routine, I remember van Dijk saying the golden rule, is the routine mastered? Then you need to change it. But you need to change it in a way that the child is challenged but can cope with, and we're back to the just right challenge. What's the child's ability to accommodate new experiences with existing schemes? In other words, if you change something in the routine, can they deal with it? Do they have a meltdown? Do they give up? Do they persist and work through it? Do they turn to you and ask for help? Do they pull your hand over and ask you to solve the problem? How do they deal with that? What kind of problem solving approaches do they have? And problem solving is one of the keys to good DeafBlind assessment. Present the child with a problem and see how they get around the problem. Look at their functional adapted behaviors to deal with these issues. What's their ability to form social attachments and interact with others? And what kind of communication modes appear to be the most relevant? So that's a very condensed view of what he is assessing rather than the traditional vision skills, auditory skills, fine motor skills, gross motor skills, and self-help skills. I mean, there's a place for all that, but this is coming from a very different angle, looking at a very different aspect of the child, and actually, looking in a lot more depth and breadth at the child. Then he says, what are the challenges to evaluation of this approach, and they're big. And this is what puts a lot of people off this approach. There's no prescribed protocol. The moment people know that, they freak out, because it's like, good lord, how would you know what to do? How would you know where you were going? It takes quite a lot of confidence to dive into this, but it also takes a lot of skill to do it and make it work. But it's doable. It's very doable. I build a career out of it and so did van Dijk. I should say of my three gurus, he was the lifelong one. I learned thing that were invaluable, but Jan was the one who kept me going and kept me on my toes. There's also no specific implementation order. You don't go through a developmental hierarchy, because the child is leading and guiding you. There's no set of testing materials. There's no checklists. There's no briefcase with miniature objects. There's no flashlight and hand bell. I mean, you just use what's around and what the child is used to and what they're interested in. Each assessment is unique and there's no set interpretation scale because it's all individualized. And when you look down those five bullet points, you can see how challenging it is to get this across to people who is never been trained in this way of thinking and this way of looking. And then he comes up with quality indicators, so what should you make sure you're doing when you're assessing in this way to make sure you're getting it right. You should respect the caregiver, in this case, the parent or the class teacher or the intervener, they are part of the team with you. You are not the expert specialist who has come in to do it. You're doing it together with them. But also respecting the child. That's another message going through everything I'm saying today. Education is not about disrespecting kids and doing stuff to them. It's about exactly the opposite. Following the child's lead, communicating with the child. Remember, make every interaction a conversation with the child. Utilizing turn taking routines. Creating enjoyable routines, motivators. And if it's child led, they're probably not going to take you to something that they hate or they're frightened of. One day you want to get on to stuff they don't like, but at the moment, we're not there, and we need to sort out where we are to start moving towards stuff they're not motivated by. Samantha says, the child is the expert on the team. They certainly are. For decades, people have said to me, what sort of assessment materials do you use? And I used to be a bit embarrassed because I don't, and I used to think, maybe I should say something. Make something up. And then I realized the main assessment tool I use is the child. You know, that's what I use. Through observation. And yes, I've learned a lot and I know a lot about child development. I know about the hierarchy of skill development. I know about sensory issues and I know the role of the senses and I'm aware of how each sense interacts with all the other senses because they all work in combination or not. Depending on the child. So I've got all that knowledge at the back of my brain and I got a lot of that knowledge through carrying developmental checklists around with me 40 years ago everywhere I went. There's a checklist called the Callier, and I was given that early on. For about four years, that checklist went everywhere I went in England. It was like, you know, more important than my trousers. I mean, I wouldn't go out without the Callier and I would sit on a bus or train going on a visit, poring through it to make sure I knew about these sequences. And one day, I realized I never took it with me anymore because I'd absorbed enough and I'd got the confidence to know that I could observe the child and get an idea. I still have my old tattereded copy as well, Cyral. So the things I'm stressing today, I'm not dissing things like developmental checklists. They're very important. I'm not dissing clinical medical evaluation at all. And I'm not saying don't involve therapists because we can do this. But what I'm trying to say is what we as teachers can do and what we can focus on. Catherine says you also have to gain the child's trust and build a relationship so that they will be open to what we bring or add to the routine. Yeah, absolutely. And if you look through this list, it's all about creating an atmosphere in which the relationship can be developed positively. And then finally, he talks about fidelity. The importance of using the stop-start structure within routines. The conversational approach. Introducing a mismatch with the child's expectations. That's where the routine is disrupted in some way. And Hattie says, as we assess the child, they assess us. They certainly do. Returning to established routines in order to examine memory. Creating situations that allow for problem solving. And utilizing various sensory channels. This is quite a good overview of van Dijk, but it's still used -- it still leads you in this very exposed situation where there is no set protocol. It's all terribly fluid. It's all child-like. But you can go a long way. I've often observed a child for an hour and tell people things, and they're amazed, and I go, well, I've been watching the child for an hour, I should know those thing, or at least guess that they are the case for that child. Which eye does she see with? What kind of audiogram might she have? Those kinds of questions, just from your observation. -- van Dijk, I would go to the Perkins school for the blind website. I would go there anyway because there's lots of things there. There you will find two lovely webcasts on him. One is on child guided assessment, which is great. But the one I love is the second one, the role of the emotional brain. And he -- you know, towards the end of his life, looking back, I don't think any of us, including him, knew he was coming to the end of his life. But he got even more open when he was presenting about the emotional side of life and the emotional side of his work and the emotional side of himself. And he talked -- I heard him live twice. He does it in the webcast, I think. He says, what you're working towards with a child are what he calls moments of joy. That's when you're really teaching. That's when the child is really developing. And it's a very subtle point. And it's very easy to laugh at it, because it sounds like gobbeldy-gook. But he's right. The moments of joy. Because in a moment of joy, you've got a positive relationship, you've got a motivator, you've got something that got through to the child in a way that they could perceive and interpret and understand. You've got the child demonstrating their emotional state very clearly, so there's expressive communicative behavior. You know, those moments of joy are worth working for, and I -- you know, something else people have always said to me, and I'm very proud of it because I work at it, I've done home visits and at the end, parents have said to me, I was so anxious about you coming today, and you were coming all the way from San Francisco, and, you know, we're like 300 miles away. We were very worried you'd give us lots of bad news. But actually, I've never laughed so much. And I even laughed about her wetting the carpet. And I think, well, of course. It's not a real assessment if there's no laughter. That's really important. So anyway, now I'm getting emotional. And there's my cell phone again, which never rings. Now, I won't go into this in too much detail but another seminal article for me from another guru, Robbie Blaha of Texas. I don't know if she's listening today. Robbie is up there with my gurus. One of the reasons is this very article. Thoughts on the assessment of the student with the most profound disabilities. This is the group that I am most drawn to. It's the group who are the most challenging to everything and everybody. It's the group whose parents are the most likely, I think, to feel deskilled. And sometimes, they're deskilled by the professional agencies working with the child. These are the children who get written off most through deficit assessment, and that Robbie with with the much more able group of children with DeafBlindness was able to devote all this attention to this other group at the other end of the developmental spectrum, is an enormous tribute to her. I'm tempted to show all of it -- well, we've still got just over half an hour, so I think I will. Can the child reach the active alert state, rather than hyperoveranxiety or drowsy falling asleep. Is the child able to maintain the quiet alert or active alert state. Are there problem shifting states from one to another. And what variables affect the child's biobehavioral state. So this is very much after van Dijk. So Robbie's approach just like mine is very much modeled on Jan van Dijk, the grandfather -- I told him once he was the grandfather, and he said don't say that, it makes me sound so old. And I didn't say, but you are, Jan, you are. Robbie and I and many other people are very influenced by him. So, biobehavioral state. And Chris Russell in New York talks about this. Somebody is on the edge of her seat listening to me and wants me to keep going. I'll keep going. We have 15 more minutes. Then, which are the most effective sensory channels for gaining attention. Which are the best sensory channels for conveying reliable information? So you can see now that Robbie, again, is still following van Dijk. But she wrote this article a long time before he produced the book. You can see the parallels very clearly. So I'm speeding up a bit here. About memory and routines, what did the child used to notice but they don't notice anymore? So can they habituate to things? Does the child stop responding after two or three times? I'm sorry my slides do odd things here. These all went wrong once and I should make new slides that don't do this. Does the child know familiar from unfamiliar people? And so on. And then she goes into things like what voluntary movements does the child exhibit, in which positions. So she's now allowing for maybe movement difficulties or orthopedic difficulties. And so on. Well, I'd just recommend Robbie's article. And it's on the website of the Texas school for the blind and visually impaired, which just like Perkins School For the Blind is a website. If you don't know it, you really should know it and go there. There's lots of stuff there. If you go there to find rob by the way's article, you'll get absorbed. One of the things I love about the Internet, like YouTube or the national center on DeafBlindness, I go to those sites for one thing and I end up two hours later thinking, what was I looking for? So I wrote an article in in England in the '90s called Follow the Child and I reprinted it when I came to California in 2001, and I said, when I -- when I am assessing a child, when I begin, it's about asking questions, and I have four main questions in my mind. How do you feel, what do you like, what do you want, and what do you do? How do you feel tells me, is this a good day or a bad? Is the child ill, or are they in reasonably good health? Did they sleep okay last night or was it a disrupted night? Have they recently been hospitalized or not? If they have a seizure -- have they had a seizure recently or is everything calm? But just to set the scene for me. So I know whether I'm seeing the child functioning at their optimum level or am I seeing them fairly wiped out and distractable. What do you like? Motivators. Second question, because I'm a teacher and I want to know what turns the child on. What do you want? Means, what range of expressive behaviors does the child have that express what they want, how they're feeling? Do they have expressive behaviors? And parents are particularly good at saying, she's getting tired of that now. And I think, how do you know that? And the parent will say, well, you can just tell. And I say no, no, you can't just tell. I can't just tell. You can just tell because you really know her. And when they think about it, they say, when she does that with her eyes. Or when she starts breathing faster. Or when she wiggles her legs. They've picked up these expressive behaviors and what they mean from the child. And the last question, the most important of all, what do you do. When no one is involved with you, and you're just doing your thing. And then there's a fifth question, which is the traditional one, what can you do? And that's what people think assessment is all about. Assessing a child means getting to the limit, the threshold of their abilities to get a baseline so you know what to teach next. But before you get there, before you do that, I think you should be asking these questions. Probably in every interaction with the child. One of the most important questions of what can you do comes a bit later. I'm going to skip lots of slides because we're almost done. I've got to talk about arousal or biobehavioral state. And this is one example, this is the Carolina Record of Individual Behavior. I think of it as a ladder. At the top you've got uncontrollable agitation, and at the bottom, you've got deep sleep. At the top, you've got the highest level of arousal, and at the bottom, the lowest. And we're all on this ladder. And we all go up and down the ladder for all sorts of reasons. And the difference between us and the children we're thinking about is, if I ask you where are you on the ladder at the moment, you could tell me absolutely where you are, I'm sure. You'd need, like, 15 seconds to think about it, and then you could tell me. And you might be between two steps. And most of you by now -- I think when this started, you were at active awake, fussy awake. Now you're at quiet awake, drowsy. Some of you might be slipping past drowsy even, but we've almost finished. The other difference between us, the children don't know that. You know where you need to be on the ladder. So if we were all in the room together, and you've dropped to drowsy and you can tell you're going to go down to active sleep, you probably know through social training that that's not acceptable in a group of your colleagues with me presenting. You will have strategies to bring yourself up the ladder. If you're not sure whether you've turned the gas stove off or not before you left this morning, you're going to shoot up the ladder, and you're going to think, I'm an hour's drive from home and I've been gone for three hours already, and I probably did turn the gas stove off. But there was no pan on that anyway, so if it is off, it will just be burning. And you can talk yourself down the ladder again so that you can pay attention. Because if you go too high or too low, you're no longer available for learning, because you need to be really on active awake or quiet awake. And I do know people who do best on quiet awake drowsy, because that -- for some reason, that clears their mind of other things. And I do know people -- I had a colleague for years who worked best at active awake/fussy awake, and she was fairly trying, because everything was -- but that was where she functioned best, but not where I function best. So it's variable. But generally, we need to be in the middle and we need to know how to get ourselves up or how to get ourselves down. And if the children have difficulty with that, which they may well have, we need to work out where they are on the ladder, where we need to be, and how we can get them there. And then part of our educational program should be helping them work out where they are, where they need to be, and how they can get there. I showed you one form of the ladder. The ladder could have much fewer steps than nine. You could use a very individualized vocabulary rather than the one I used. You could use written words or picture Sim. Bolls or photographs. You could have smiley faces and screaming faces. And sleeping faces. You could use revisiting or social stories. Social stories are being used more and more now with this population of children, and they can be very powerful. Revisiting means if the child's had a meltdown, for example, is it possible when they're back to normal, is it possible to say, so why did you bite Mary? Or something like that. To try and examine why. If that's too risky or if the child won't have that ability, or that level of language, a social story might work. I'm impressed by how many children I've known with DeafBlindness who love a story where the child in the story gets in trouble, where they do something really terrible and everyone's upset and they have to go see their mother and all that. And of course, you're teaching because you're trying to make a point and you're trying to get the child involved in the story. There's role play as a possibility. And there's that simple question of like/dislike, want/not want, which is the starting place of the child's expressive behaviors. Self-regulation. So when we're thinking about this issue, can we help the child to recognize and deal with excessive levels of overarousal or underarousal in socially acceptable ways? If self-regulation is difficult, can the individual learn ways of asking for help? I talked about this to a family in California for a long time, and out of the blue one day, my phone rang and it was the girl's mother. And she was very excited and she started to cry, and she said, we're having a really difficult day. The girl had English. Really difficult day. And she came to me and she squeezed my arm. She'd been crying. She squeezed my arm. And she said, "need to calm down." And the mother started the cry because the whole point was, the girl realized herself without being told that she was too far up the ladder. And she needed to calm down. And then the mom said to me, so what do you need to do? I think she used a ball. And she twiddled a ball on the palm of her hand and on her face. I'm sorry, I'm racing through. But we have about five minutes, I think. The jobs for us. Reading the student more effectively. Observing and interpreting, to see where they are on the ladder, where they're going on the ladder, and maybe to work out why. Making connections to work out why are they getting so overaroused. Do we need to change something in the environment, or is it something internal in them? Helping them to feel their body more effectively. Especially through providing an increasingly precise vocabulary of emotions and states. This is something deaf programs are really good at, you know, vocabulary for emotions and feelings. When I'm not in a deaf program, and they've got an early -- you know, early vocabulary that they're teaching, and I say, it might be nice to introduce some emotional states, and people say, well, they're very abstract. And I understand -- I can see that dinner is more concrete than being tired, or being frightened. But they're not abstract to the child because they're fundamental to the center of the child. So I think making sure emotions and states are there and being talked about. Leave in three minutes. Okay. Directing the child's attention to what they're doing and the indicators of overarousal. Reminding them of strategies and talking about your issues as well as their issues. So, these are repeat slides. To understand the child's challenges, to gain a more accurate idea of their needs, to appreciate their adaptive behaviors, to introduce them to others, to be aware of the important things, which might be very small or trivial, to remember that everything they do is more challenging than for their peers, and to realize that things that look crazy might actually be good stuff. So, that's it. That was a lot of talking. And a lot of slides. I've skipped a lot of slides. I'll show you one that I do like. I talked about this in England, and a mom sent me this. It was originally a weather chart, and she's changed it. And at the top, you've got the sun out and it says happy. And then it says calm, quiet, something else -- I can't remember. And the bottom, you've got thunder clouds and lightning. And it says cross. Which is an English word for angry, of course. It's very British. And the idea is the child themselves can move that arrow up and down to let you know where they are and what they're feeling. But I've seen other brilliant visual systems. So, I'm sorry, it was pretty disorganized at times. But you've got the text of the slides. You should have my email address, if you need to contact me. And thank you for listening. And thank you, western region early intervention conference for asking me to do it.

>> Kaycee: Thanks so much, David. This was so wonderful. Lots of love coming your way in the chat right now. Also, we have on January 28th, we will have VoiceOver, the intermediate level. And on February 21st, we'll have driving with low vision. And on the 4th, we'll have Canvas accessibility with John Rose. So you can check out our website, TSBVI.edu/coffeehour for the registration information and more upcoming sessions. Also, the handout, transcript, and chat information for this and past sessions are available through a link on our Coffee Hour page. Once you're on the page, you'll scroll down to under the list of sessions, where it says visit the new TSBVI outreach Coffee Hour archives. That's a link and it will take you to all of that information. On the evaluation you received from ESC Works, there's two boxes for additional comments you'd like to share with the presenters and the event planning committee. Please let us know if the days and times that these are offered are working for you or if you have other suggestions, and we'd always love to hear your ideas for future coffee hour sessions. I want to give a special thank you to the New Mexico DeafBlind Project and the Colorado DeafBlind Project for supporting this session and helping us provide the wonderful accessibility team. I also want to remind you guys, we have the mental health symposium for deaf and DeafBlind youth coming up. That will be April 22nd and 23rd. And I'll drop that registration information right now into the chat for you. And another huge thank you to David Brown for talking for four hours today. You've earned a nap. That's a long time.

>> David: I'm probably going to take a nap. Well, thank you, everyone.

>> Kate: Thank you so much. Appreciate you.

>> David: Good luck.

>> Kate: Thanks, everybody.

>> Kaycee: You earned a malt whiskey, David.

>> David: I'm thinking more of a snooze at the moment.

>> Kate: That, too. David, we'll make sure to -- there's just a lot of great comments coming through, so we'll make sure to get you a copy of the chat transcript so you can see.

>> David: Great, thank you. Okay, I'm off. Bye.