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5/20/12 [Captioner present. Please standby for real time.]

I believe the caption pod is now active.

When the webinar begins, I'll issue a mute all command which mute everybody's phones. And star 6 mute and unmutes. Presenters will need to reenable their phones by pressing star 6 once we do that.

And I presume you will kill my web cam right after I introduce David brown; is that correct?

Yes, I can do that for you.

Mine says start sharing but last time I started sharing for whatever reason, it's killing it. Is everyone seeing me?

I can see you but your image is frozen. But that's okay. We can at least who you are.

My image is frozen? Oh, yeah. Probably cause my for whatever reason --

Hello?

Hello?

This is Olivia.

Randy, can you reenable my web cam? It booted me out. I don't think it has me enabled or doesn't appear to.

I'll move you up to presenter.

I don't know that's going to help. I think it's the same comcast issue we had before.

Okay. Let's see what that does for you.

It says I'm stopping my web cam. You don't see me now right?

Correct.

It's having an issue. We'll see if it comes back. If not, Lisa are you able to get on?

I can probably get on just voice. So I don't think I can do audio from up here. I don't have enough band width.

All right. I will go ahead and figure it out unless it changes dramatically.

Okay. So we're right at the top of the hour. When you are ready to begin, let me know. I will issue the mute command and start the recording. And then you can do the introductions.

I will do it by audio, I supposed.

That will be fine.

I'm going to start muting the phone. You'll hear that come across.

Might be a good to PUT everyone in mute now. I don't think people realize they are on.

I'm attempting to do that but it's not accepting the command. I need to check something else real quick here.

Good evening. This is David WOLF. And welcome to the forgotten senses. David brown is our second speaker in the webinar that we have planned. And I want to go through the ground rules of this webinar briefly. Everyone should be on mute. And you will see a chat box which is for questions and comments to David brown. Just so everyone knows, this webinar is recorded and so is the chat box. So if you click on a particular individual under the participants, you can send them a private message but even that is viewed by any of the hosts. So please use the chat box only for questions for David brown. It will make his job much easier and it will enable your question to be answered throughout the presentation. David brown has told us he is going to try to answer questions as question go through. So if you have questions for David Brown put them in the chat box. I'm sure when he comes to a convenient portion, he will be happy to answer those. I'm pretty sure that everyone on this call knows who David Brown is. Although, he's probably not going to be happy with me for reminding him he's been at this for over 35 years. It has indeed been that long. He first met an individual with charge syndrome when he joined in the UK way back in 1983. For over 15 years he's been an educational specialist with the deaf/blind project. David Brown has a strong and enduring commitment with working with children with charge and their families. He is a well-known presenter in the United States and internationally. His sessions at the charge syndrome foundation conferences continue to be among the best attended and best received. David brown has been doing this since I was involved. He was one of my favorite speakers when I first heard him and it gives me great pleasure to welcome David Brown and turn it over to David. Thank you so much David and enjoy.

Thank you, David. I hope I'm off mute. I saw a sign saying I was off mute. I'm assuming everyone can hear me.

Yes, David, we can.

Yes, good. Thank you.

Thank you for the introduction, David. Actually, I was going to confess that right from the beginning in August of this year, it will be 40 years SINGS I became -- since I became a teacher which occurred to me with a bit shock. I have to thank the foundation for inviting me to give this webinar. I'm aware it's a great honor. I'm even more aware and concerned it's a great responsibility. And I know that people listening in the audience come with almost like a commitment with their child. I'm very aware I carry a bit responsibility this evening. I'm also aware that it's a great honor to follow the first presenters of the first foundation webinar Casey and Tim. They are both close friends of mine. But they are also professional colleagues who I've seen very highly. I really feel that I'm following in their footsteps and feels very comfortable to be doing that.

Tonight I have a complicated topic. We don't have very much time and I'm going to do my best to cover as much as I can on the topic. It's likely to take -- lead you with more questions than answers. I'm hoping that I can provide you within sights into some of the with -- insights into some things. I hope you'll go away with different things than you started.

I don't know if you can all hear the voices coming on my line. Somebody thinks I'm trying to send them a message.

It appears somebody's phone has went to voicemail.

There, I think we're clear now.

This is such an adventure. Not quite in the way I was anticipating.

I'm hoping you'll go away from this session with a slightly different view of your child. A different way of looking at your child and thinking about what they are doing and not doing and different questions in your mind. And I think learning and progressing through life is all about asking questions. We tend to be as a society, committed to finding the right answers. But I think really finding the right questions is the challenge. And I'm hoping you'll go away in two hours time with different questions for the one you may have been having in your mind previously. I have no formal training for what I'm talking about tonight. I'm poaching on the territory of occupational therapists and a little bit of physical therapists. I'm a

teacher but I have been working for almost 40 years. I worked for 17 years with a wonderful teaching [Inaudible]. And I learned a lot from her. And although I'm not advocating integration therapy, I've learned a lot from the philosophy behind it that I'm delivering to you tonight in this session. As it's been adapted and morphed and filtered through my mind in many years working with many children trying to find answers to the puzzles the children were presenting. If you are really interested in this topic and I'm sure many of you know, there's a growing body of literature out there. If you go on Amazon and look at sensory therapy or sensory function, you'll find books. I particularly like the one out of SYNC child. And the second one is the one out of SYNC child has fun. The books I've discovered myself Sensational Kids by Lucy Jane Miller. And one I liked by Sharon Heller which is called too loud, too bright, too fast, too tight.

And if this goes too fast for you and you feel you are getting confused by everything I'm saying which I hope won't happen but it's likely, remember that everything is being recorded and it should all be posted on the Charge Foundation website so that you and other people can go back and tune into it any time you need to in the future.

Okay. So now I'm going to attempt to scroll through the slide show which is not responding.

Let me see if I can advance it.

I don't have any control over the slides, unfortunately.

David, can you see the navigation arrows?

I found them. Sorry, I scrolled too far. Thank you.

I'm better with children than I am with technology. Honestly.

I just want to begin about making a point. More and more in my job lately I've been getting annoyed with polling approaches of assessment questions. Children suffer from assessment procedures. I wrote a paper over 10 years ago here in California called follow the child. And I tried to make the point that when I meet a child, if I want to find out what's working and what's not working, I go in with a couple

basic questions. I want to know how the child feels, is this a good time or a bad time. Is the child having a good day or bad day? What kind of things do they like? That's always right at the top of the list of questions. What do they like? What turns them on and motivates them? What do they want? In other words, how do they demonstrate what they like and what they want? What kind of expressive communication do they already have? Even if it's not deliberate constant communication to other people on their part? And finally, what do you do? What do children do? What children do when they are all alone and left to their own devices gives you lots of ideas about what turns them on, what they need, what their comfortable and familiar with, what they are interested in. And my philosophy is if the child is doing it, it probably serves a function for them. It might be enjoyable or necessary or might be both. And that's where I want to come in and introduce myself. So that I'm likely to be accepted and acceptable to the child and I think if we approach children more in that kind of way, we'd get a lot more success in what we're trying to do. I'm talking about two senses this evening that are overlooked. I call them the forgotten senses. And I have a quote here from a British orthopedic specialist sir Charles bell. And this is the way the handworks. Published in 1833. The language is very archaic but he makes a good point. He says there is inconsistency and something of the child's propensities still in mankind. A piece of mechanism as a watch or dial will fix attention: Yet the organs through which he has a thousand sources of enjoyment, and which are in themselves more exKWIS it in design, and more curious both in conTRIFBance and mechanisms do not enter his thoughts. We use the limb without being conscious, or at least, without any conception of the thousand parts which must conform to a single act. By an effort of the cultivated mind we must ROUS ourselves to observe things and action of which the sense has been lost through long familiarity. Everyone loves an iPad I'm all for all kinds of technology but I do think that we often runaway with the technology and forget we haven't really got an understanding of the child on a level that we need.

And a reminder for you of the senses. People talk about the five senses but I'm going to focus on two that aren't included in the five. The distance senses of vision, hearing and smell. And we call them distance senses because the stimulus can be a long way from the receptor in the body and yet we can still proceed. We can see or hear or smell that there's something there.

And then we have the near senses where the stimulus has to be in direct contact with the receptor. And taste and touch are the ones we're all familiar with and then we have the vestibU lumbar -- VESTIBULAR and PROPRIOCEPTION. They are particularly important and in some ways if you look at that list on the slide, they are the two most important senses there because they provide the base along with touch on which the others develop and function. They need well functioning if they are to function normally. And if not, that person is going to have difficulty and going to have to adapt and find other ways of developing and functioning which is what children will do. Most multi sensory impaired of all the syndromes we know. So that everything on that list, vision, hearing smell, taste, touch is likely to be damaged or under functioning for a person with charge syndrome. And this has big implications to development and learning.

A few general points first about senses. It's our central nervous system or our brain which plays the main role in taking information from the senses and deciding what to do with it. Processing it. So it's the brain that takes that information and decides to attend to it or ignore it. Seeking it out or avoid it. Going for more or getting away from it. And this process of receiving sensory information begins before birth, it begins when a baby is a fetus in the womb. Vision doesn't get any stimulation in the womb until the baby is born. All those other sensory systems in a normal developing pregnancy, the baby is born at term with all those other senses already experienced. And smell and taste are stimulated because the fetus takes in amniotic fluid and that fluid contains chemicals from the mother's body and from her body from the diet she's eating, the air she's breathing and the environment around her. And those chemicals can trigger smell and taste receptors. So babies are not born as a blank page. They are born with quite a lot of sensory experience. And that means they are likely to have sensory preferences as well. For children with charge, that's not necessarily the case because they may well have all kinds of anomalies that prevent the systems working properly or prevents their brain from processing information. So it's a more complicated picture.

Natalie BARRAGA was a player in 70s and 80s in the world of visual impairment. She talks about visual functioning in an interesting way. It's related in part to the condition of the eye. We can all understand that. You need eyes. The eyes need to be intact and working. But she says this a lot more to it. More explicit, 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, what you've got is important, but what you do with it is as important if not more important. And we all know people have wonderful gifts for all sorts of reasons. We also know most children have things not working or missing or not working properly and yet because of an intense sense of curiosity and drive but also because of their families and the professional teams supporting them, they develop a real need to use what they've got in the best possible way. And it's good to think about encouraging children to be good listeners, good feelers because that kind of mind set is going to take them a long way. Whatever kind of anomalies they have that they were born with.

Although every sensory system in that list is unique, they have fundamental similarities. And basically each of those sensories is responsible for collecting information and conveying it to the brain for the brain to process it. And the obstacles to that happening come in three basic groups. First of all the sensory receptors themselves might be mall formed or damage. There's a whole range that mean the sensory receptors are not working properly or not at all. Secondly, there can be problems with the nerve pathways so that the receptors are collecting the information that they need to get to the brain but then

the nerve pathway along which that information needs to be conveyed isn't working properly or isn't working at all. So the information can't get through to the brain. So basically that person doesn't know that information exists. And then thirdly, there can be a problem in the brain itself. So the sensory receptor might be fine. But the information when it reaches the brain, the brain isn't able to do its job of processing -- working out what the information is, recognizing it and attaching meaning to it. And deciding, I like this, I want more of it. I don't like this I want less of it. Or I'm not too sure what that is. I need to have a closer look and investigate more fully.

And in charge, all three of these kinds of problems might well be present. Problems with the sensory receptors. Problems with the nerve pathways and problems with the brain itself. So it is a very very complicated picture.

Every sense is designed to work simultaneously with all the other senses for maximum efficiency. That's an important point. There are myths around. For example, the most common myth is that children who were born blind have super hearing. And in fact, their hearing is just like everybody else. There's nothing super about it. But overtime and with good development and good teaching, they can develop their hearing sense to a very very high level which means that then their hearing tends to be more acute than say someone like me because I've had vision all my life. But if a child is born blind with normal hearing, they have problems developing their hearing in the beginning. They don't understand about direction although of sound because they don't have vision to confirm where the sound is coming from. They also have problems attaching meaning to sound again because they don't have vision to give them instant confirmation. I hear that voice, I see who it is, it's my dad or my mom or my grandma. So in that way, all our senses need all the other senses working at the same time for them to work at their best and at their optimum. And if other senses are not working properly or missing, any sense which is intact, will become potentially more important. But will also be more challenged in the beginning. And this is all I'm trying to paint a picture of great complexity for you before I get going.

And then back to what the senses are for. Information comes in through all our sensory systems and processed in the brain for two reasons. First of all, to make us aware of stimuli in the environment. In other words, what's out there? What's there? Where is it? What's it doing? What does it mean? Do I know what it is? Do I like it? Do I dislike it? Do I need to go get it? Do I need to get away from it fast? Do I need to shut down and ignore it? Or do I need to investigate further?

And also the information comes in AZ -- DUNN talks about our systems helping about constructs environment for organization and planning. In other words, information coming in not just helps us what's around is but works out where we are in relation to all those other things.

This is a long quote from an article I wrote five, six years ago now. I said in the field of deaf blind education we have traditionally and for obvious reasons focused on the senses of vision and hearing on the strategies for improving the use of any residual function and that may be present in both of these distance senses. At the same time we have also paid some attention to the sense of touch as an important information channel that can help to compensate for loss of visual and auditory information. The other sensory systems the taste, smell, have received very little attention from us even though together they provide the essential foundation upon which all of our higher vision, hearing and touch skilled are based. These are sensory systems also offer valuable channels to the children for learning to us for teaching. They should have been a starting point for us.

Here's a diagram that looks at the way the sensory systems develop and help us to develop. And at the bottom you'll see the central nervous system. And the very first level, the foundation of the pyramid is sensory systems. And not by accident the three senses at the very bottom of the touch, VESTIBULAR and PROPRIOCEPTION. The next one, smell, vision, hearing and taste. And the pyramid things like understanding body, motor planning. And the next section is eye hand coordination, pose do you recall - - POSTURA L5 justments. And very top, cognition and intellect.

And also in education all the emphasis is on that very top item on the pyramid. Academic learning.

And big decisions are made about children's eligibility on the basis of whether academic learning seems to be accessible to them or not. And I'm always fighting that assumption because it seems to me academic learning is just one part of the whole business. And I'm not quite sure how much my academic skills affect me in my ordinary life. When I'm walking the dog, a lot of my sensory systems and perception AI mode for development come into play. And I need to fall back on my academic skills. But there's a lot of other things we need in order to function and we've often neglected these other things. We've ignored them particularly for children who are at the top level and doing academic learning and following an academic curriculum. All the sensory issues are dealt with and if there are behavioral issues, people tend to fall back that just pigeon hold the child or old assertives or those kinds of labels.

I'm going to skip some slides and get on to the pro PRIceptive senseproprioceptive sense

he says I can't feel my legs, doctor. And she knows him well and says well you can't feel mine, either. He's meaning he has a proprioceptive problem. She knows him well and thinks he's thinking of active explore Tori touch. -- EXPLORATORY touch.

This is the sense that helps us to plan and position and grade our movements without looking to see what we're doing. You see two photographs of me in the slide doing that game we've all played where you close your eyes and isolate the index finger of your right hand and bring it out and touch it on the tip of your nose. And you may want to try that as I'm speaking. And bare in mind, everything we do relies on sensory feedback. We only know what we're doing and what we've done because our senses feed us the information back. And if we do this exercise and close our eyes, we've taken away the one sense that can help direct this. Proprioceptive senses is what enables us to guide that finger up and touch our nose. And it's the proprioceptive receptors in the right shoulder and arm and hand and finger and the proprioceptives in our neck which help to tell us where our nose is. And together that enables us to touch our nose. And if we miss the first time, we can usually get it right on the nose the second or the third time. So we can train this sense. This is the sense that helps us to plan and information and grade our movements without looking to see what we're doing.

The word comes from two Latin words joined together meaning an awareness or a feeling of one's own self.

It's part of the complex sense of touch. I call this internal touch. The receptors of the sense are based through the joints and muscle of the body and stimulated by stretching or compression or twisting. So anything that stretches a joint or compresses it or twists it is going to find messages through the receptors to the brain saying this part of the body is now being compressed or stretching or twisting. And they tell us which way it's twisting.

So at the moment if I mention your left ankle, you could feel your left ankle before I said the words but you weren't consciously feeling it. Your proceptive receptors were firing away messages to your brain. You didn't need to concentrate on them but your brain did need to keep getting the information. Yes, there's a left ankle and it's where it's supposed to be and not doing anything unusual so you don't need to worry about it. Now I've mentioned it, you are all thinking about that ankle much more consciously and much more aware of it.

This sense keeps us constantly aware of the position of all our body parts and also tells us if they are moving or not all the time. Except when we're asleep.

I'm going to skip slides here. Why does this sense go wrong? Well, if there's an injury of some kind especially a significant orthopedic injury like a broken bone or torn ligaments or muscle, surgery, means the limb beyond the surgical site is likely to have poor proprioceptive condition. Arthritis causes very poor body awareness because if you talk to people with arthritis, it's hard to feel their hands or feet or legs. Cerebral palsy and other kinds of brain damage and anything that leads to abnormal muscle tone leads to poor proprioceptive Pro-ception. If the muscle tone tends to be too stiff or too high so the muscles are too tight or the opposite too low so the muscles are floppy which is the case most children with CP. If the person can't alternate the muscle tone very easily, then proprioceptive Pro-ception is going to be difficult for them. And in children with CP, I think most of the proprioceptive difficulties are because of very low muscle tone and the fact that the muscles are not -- muscles are not being used very well in a regular or normal ways of things like weightbearing.

Poor circulation is another issue that is likely to cause poor proprioceptive. All of us are aware of that. You sit on the leg watching television. Somebody rings your door bell and you find it difficult to walk because you can't feel your leg any longer. And you will give your leg a whole range of stimulation. You will stomp the foot and slap the leg and rub it hard. All kinds of proprioceptive inputs which will get the circulation running and wake up the nervous system there so the brain can start to feel where the leg is and I say there's a question. Does this also include a genesis of the corpus CALLOSUM MISHGS? That's an interesting condition. I've worked with many children where their only brain malformation. That's the bridging part of the brain that links together the left and right hemispheres. And most children often develop normally. I've never quite understood what the implications are likely to be. I think the issue of brain damage is more likely to be with level of arousal and with muscle tone, the way the muscle tone is reflected of arousal levels would be my guess. My rather uneducated guess.

This is essentially system when it's not working properly that's often associated with touch issues. So it's not surprising we should see a high level of proprioceptive perception problems. Like all our systems, this goes wrong if this system is not used. It's important to get inputs coming through this system as early as possible.

When this sense isn't working properly, we see common outcomes. First of all, the children find it difficult to deal with gravity and they have a particularly strong dislike of being face down. So they often like to be on their backs on the floor or the bed but like being face down. Gravity squishes them down into the surface they are laying down and the face gets pushed into it. And has hard for them to function in that position. Very hard for them to bring their hands up and then extend the arms and push their body up in the way we would expect normally developing infants would do it. It's hard for them to feel the fingers, wrists, elbows and shoulders so they have very little control over them. And in the same

kind of way, we see an inability or reluctance in the children to wait there. They are not feeling the joints in the toes, the ankles, the knees and the hips. And also it's hard for them in that up right position to maintain the spine. That's another issue with poor proprioceptive. Maintaining it in a steady up right position. And does this prevent the ability to the children to crawl and walk? Yes, it's one of the many things that contributes to delayed crawling and walking. And controlled sitting in children with charge. Along with other issues. A main one of which is VESTIBULAR dysfunction.

These children do propping and leaning. It's hard for them to maintain muscle tone. So they develop strategies to lean against things and I forgot to say at the beginning. Although, you think I'm talking about people with charge syndrome. I'm talking about all of you and myself this evening. We're all on a spectrum of sensory function and dysfunction. We all have better sensory functioning when we're younger than my age. And we also have sensory function and per accept you'll skills -- PERSEPTUAL skills. And anticipation of something very present or very frightening. All those things are going to affect sensory perception. But in children with charge, these things tend to be much more marked and permanent of a feature of their development and behavior.

What else do we see? When the children are weightbearing, we see a foot stamping behavior. Stomp their feet on the floor when they are cruising along a couch or even if they are walking. If they are walking between two adults. You get this stamping on the floor. I call it feeling the feet. It's a way to make sure that leg and feet really is there and doing the job it's meant to do before you take the big risk of pushing weight forward on to that leg. And the children have learned the hard way that you need to make sure of these things because if you don't, you suffer. And of course these are children who fall and bang themselves again and again. So they know what the risks are. Sometime children who like to bear foot do foot stamping and walk with the knees bent and do that rolling. Sometimes some of the children when they are a little older go on to tip toe walking. They still like to be bear foot but right on to tip toe. If you do that yourself and think about your proprioceptive sense, you will find that going up on to tip toe massively increases the proprioceptive. You have a smaller area of your foot supporting your body weight. There's a lot more pressure coming up through the body, through the foot and up through the body. And the calfs and thighs and butt all screw up as you go up into tip toe. And I think the children develop tip toe walking as a functional behavior to help them feel their feet and feel their legs more affectively. We know children who have got high muscle tone and maybe cerebral palsy. They walk on tip toe because the muscles are too tight. That's a different kind of problem. Most children with charge have low muscle tone. And the tip toe walking is usually a functional adaptation to give their brain a better idea where their feet and where their legs are.

And what a therapist might do with this problem is increase the weight of the child. They might give the child a weighted vest, heavier shoes. You might give the child things to carry so they get periods of the day when they are walking with their heels down on the floor. Whole range of therapy ideas to help get

the feet down. Walking on tip toe for long periods of time will lead to contractions which will be basically physical malformations.

And I'm just reading, there is another question. Do children say hit themselves, bang their heads, kick their legs in search of stimulation because their sensory systems are lacking? I think those behaviors begin as a way of seeking extra proprioceptive input. Can become habit you'll habits -- HABITUAL habits.

Another issue is clumsy, poorly coordinated movements. Often the children teach themselves correction strategies. I've seen children who have learned if they bring their arm through space to reach for the glass of water on the table, they are likely to knock it over. If they first lay their hand on the table and slide it to the glass, they are more likely to grasp the glass affectively. And what they've really discovered is it's like flying a plane is more difficult than driving a car. A plane goes in three dimensions. A car only has to be controlled in two. And those behaviors if you observe them, you see all kinds of adaptations in children which often are misinterpreted to the point of being seen as evidence of mental retardation or some of the nonsense which is not acceptable in my opinion.

Another issue you see is it's hard for the children to grade their movements. So they either use too little force or too much force when they are touching, patting, grasping, pushing and pulling things or lifting and placing things. They may drop objects often because they are not holding them tightly enough or they may actually grip things until their fingernails turn white because they need to know they've got whatever it is. And the only way they can be sure is to get a really good grip on it. And sometimes the children are described as aggressive. I've seen a number of kids that before I met them have been described as aggressive. I've gone in and seen them and they are delight full children. Social oriented but they are having to use excessive force with their hands and feet because of this poor proprioceptive reception. Things like helping them to moderate the use of force and find ways of being more aware of how to control the force they are using so that they are not having these labels put on them.

And then a whole range of self stimulation behaviors where the children are looking for strong compression stretching inputs. Squeezing into tight spaces. Crossing or twisting the limbs around each other. Twisting a foot or a leg around the leg of a chair. Binding body parts with cloth or string or rubber bands. Pulling the teeth of the lower jaw downwards. Teeth grinding is a major source of proprioceptive stimulation. One of the most powerful you can give yourself anywhere in your body. Grinding the teeth. Tapping on the teeth with a hard object. Hand clapping or hand flapping. We all know children who hand flap. It's a major concern to many parents. I've worked with two parents in the last year and one of the biggest things they wanted from me was to stop their child hand flapping. I believe hand flapping begins as a functional adaptive behavior. When their children flap their hands. It's usually at times of

heightened emotion. It's when the arousal level gets high. The child is excited, anxious, frightened, upset, frustrated, in pain, hurt, all those kinds of emotional states and I think hand flapping is in origin a self regulation behavior. It's a way of helping you deal with a very very high level of arousal. Which has the outcome of bringing that arousal level down. Many of these behaviors are perceived as evidence of mental retardation. It's an indicator of either, for me of somebody slapping their hands. And I think before we try and stop these behaviors, we need to look at the child seriously and say what is this behavior achieving for the child? That's one of my main goals in this presentation is to get that message across. We see swinging or kicking, hanging from a bar, jumping up and down. Banging of the head.

Here's a young man who came to one of our family picnics in 2006. He has charge. He's completely blind. He's profoundly deaf. He's very low tone. Low affect. And his mom has walked him to a swing. And he cried and dropped to the floor. He mom walks and leave him and the boy brings his hand up and turns in this position. You can look at this and say the kid is nuts. You can say he's mentally retarded. He's autistic. OCD, ADHD. I look at this and I say why would he want to do this? What could he possibly be getting from it? And what I see taking a sensory perspective is deep pressure on his belly because his body weight is hanging over the swing. But it's stretching under gravity. Another proprioceptive input. And he has a habit of putting both arms in one sleeve. He also has a habit of putting both legs in one leg of his pants. To me, this is a child with so little perception of his body he can't see his body, he can't hear his body and he can't feel his body. He's finding ways to give himself extended proprioceptive stroke tactile stimulation to help him know where his body is and what's happening. And he's very much locked in his body and tuned into his own body. The external environment is not a feature for this boy other than it's a bad thing that keeps bursting in on him without warning.

My colleague MAURICE did some technical assistance visits for this boy. We recommended a change of program and the family got the boy moved surprisingly quickly into a much more affective program. We recommended an occupational therapist with integration training. I wrote a list of all the behaviors this boy showed that made us think he needed some kind of sensory integration therapy perspective and a program. And the therapist took the advice I wrote and called me in advance. She looked at the medical information on the boy and was anxious that he didn't look like the kind of child she worked with. And didn't look like the kind of child you could do a program with. And I allied a lot of anxieties over the phone. She went in and did a fabulous evaluation. Came up with a nice program of deep pressure and massage, brushing with joint compression and some pressure clothing. Here's the same boy exactly one year later at our next Northern California picnic. And you see a very different child. He's sitting up in the chair surrounded by his family. He's wearing a pressure vest. He's got spandex cups around his elbows and knees. We are passing an ice cream bowl and each child is being helped. They can shake the bowl for one minute and it passes on. This young man has had the bowl twice and his mom has covered his hands with the ball and shaken it. He's not just smiling but there's an audible laugh. And while he's waiting between times, he tends to sit slumped with his children down. The ball has just come to him. All his mom had to do was touch it and the boy sits erect, reaches up and bursts into a big smile and starts

to laugh. He's now learned that there's a whole world outside his own body which is worth tuning into. It can offer all sorts of valuable things.

Here's a young lady age 14 with charge. He's got little visual field in the lower field of the right eye. She's profoundly deaf. She's an American sign language user. Low toned, major medical and health issues. She's discovered that she can use fine vision to look at fine detail in picture books and she loves after she's looked at a picture for a long time telling someone what she's found and showing them what she's found. She has to get horizontal like this because of her VESTIBULAR issues. But has to put one ankle on the other knee. She has to exaggerate the pressure inputs. When she walks, she tends to stamp the feet and when she's laying down, if she wants to use fine vision, she has to bring that ankle up on the other knee because that gives massive proprioceptive information to her brain and what it tells her brain is your body is fixed, nothing is moving, everything is okay, you don't have to worry. YURN not going -- you're not going to fall. You can put that vision in the bod only of your right eye and look at detail in the book. And she's got a habit of pushing her lower lip against her teeth which seems to help her to stabilize the eye and maintain good visual fixation.

Here's a young man, it's a different picture. He's being tube fed. And he has to sit for about 20 minutes and he automatically brings one ankle up on the other knee as a way of helping him to relax and know that he's in a safe position and doesn't need to worry. I've seen children with charge as young as 10 months. Suddenly on the floor bring one ankle up over the other bent knee. It's not a posture you see normally in babies. But children with charge discover strategies for helping to put nem in touch with their bodies. Because they are not in touch with their bodies in my opinion the way regularly developing infants are.

Here's a wonderful young lady I had the privilege of meeting when she was a baby. She's as you can see wedged between accusations concussions -- CUCUSHION. I'm assuming I don't know this is not a family I work with. But I'm assuming this is general part of a whole program that's geared towards giving her proprioceptive inputs to help her to develop better body awareness and better posture control.

And here's a young man, different picnic who is like Greece lightning. He finds a bar he can hang on. You see my feet at the bottom of the picture and he has no objection for being photograph because he is in the highest bliss. He's hanging. At times he can lift his feet and hang with his full body weight giving himself that massive proprioceptive input which he needs. This is a boy who doesn't just walk but runs. But constantly is looking for pressure inputs and stretching inputs as part of this sensory diet that he needs.

I think there's another question. Do I think a ball pit would provide input? It can be helpful and terrifying to many children with significant visual impairment. Would need to be approached carefully. But I think a ball pit could be very helpful.

What can we do to help? First of all, occupational therapy preferably trained in sensory integration therapy, PT and adapted physical education teacher. All these professions have a lot to offer. And it's important that they don't do that withdrawal therapy. You don't want the therapist to take the child away and brings them back and says see you next week. Therapy is life and whatever they are coming up with needs to be fed back to everyone in the child's life so it can be implemented throughout the day, throughout the week between the therapy sessions. That's really important.

Things that the therapist might recommend deep pressure massage, brushing protocols, rhythmic joint stretching and compression are often parts of the program.

They might also recommend the use of weighted clothing, heavy shoes, heavy bed covers.

Acceptable binding or wrapping. Here you see a baby who has been swaddled. When my brother and I were born, we were swaddled. I have two much younger brothers. I have 18 when the youngest one was born. By then the fashion had changed and they weren't swaddled. And it's why I think my brother and I are mature people these days. So any kind of acceptable wrapping or binding in a blanket, tight gloves, tight socks something the therapist might recommend.

Specific exercises to improve proprioceptive awareness from the therapist. Chewing gum or chewy items. Many of you will already have some -- I can never remember what they are called. Chewables. Little rubber things. Often lime green or bright red. If you look at the catalogs online, you find a section on oral motor development. And they are quite helpful for many children to deal with problems with self regulation. Deep pressure is a calming input. Light touch is exciting and arousing. And sometimes if a child's arousal level is going up the ladder and getting a little concerning, something to bite on might be self recommending and might help.

Things like hydrotherapy, in other words, swimming. Being in water. Horse riding which is sometimes called hippo therapy. A crash mat for throwing yourself against. A climbing frame, a trampoline. And activities like wrestling. As long as these are not conTRO related. Particularly if they have

RETINALCOLIBOMA. So anything that's high impact, you might need to avoid because of the risks of a retinal detachment.

And it's so important not to judge. Respect the child. Respect the difficulties they are having. Respect the fact that what they are doing might well have a functional reason and it might be an adaptive behavior. And think about the confidence. They might be trying to raise their own self confidence through what they are doing.

This is a website. I haven't checked it for a couple weeks but I'm hoping it's still legit. If you go to this website, there's a very interesting 60 minute lecture about the proprioceptive sense. Tom JESSEL L is a neurologist I believe from England but based in New York. And it's a lecture he's giving for young medical students at Columbia. It's very accessible. I found the first 20 minutes a little confusing about neurology. A bit technical to me but he goes on to wonderful examples. If you are interested, I would recommend you watch it. It's entertaining and it will help flush out your knowledge of this. I'm really skating over the surface. And speeding up because I'm aware of time.

So now I'm going to talk a little more about the VESTIBULAR sense. Before I do, Amy has asked how often would you introduce a chewy or deep pressure or swaddling? If possible if you can get an OT involved, I would talk to the OT about and they are likely to recommend as part of the program the frequency. If not, then you might want to think about when is it likely to be necessary? And really the key is to observe the child, to get to know what the warning signals are and then if you have to administer these things passively to the child, do it. If not, encourage the child to learn it for themselves. Part of the educational program should be helping the child know that their self regulation is off kilter that their arousal level is too high or too low and need to do something about it. What is considered high impact? Well, throwing yourself against a crash mat. Bouncing very high on a trampoline. Canterng at speed on a horse. Diving into water head first from a diving board. All those things would be high impact. So might not be recommended for a child if there's a risk of RETINAL detachment. Children with charge often look for high impact inputs and go for strong inputs. And that's where you might need -- I'm jumping ahead to the end of this presentation but that's a situation where you might need to administer those sensory inputs in another way so the child doesn't need to be going for high impact stimulation themselves because of the dangers that it might involve:

this is the sense that tells us about head position and the pull of gravity. This tells us which way is up. It detects head motion. And it links very closely with the eyes and vision and the proprioceptive sense. I'm skipping slides just basically the quotes that I skipped say that this is the most important of all the senses in terms of what it does. Here's a quote from Jean AYRES, the OT who invented sensory integration

therapy. She says the 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.

this is the system that's more important than others. We know that in charge very very high proportion of the population have significant VESTIBULAR function.

But there are all sorts of other causes of disorder. Head and neck trauma. Chronic ear infections can lead to disorders. History of maternal drug or alcohol abuse during the pregnancy. Infection during the pregnancy. Certain immune deficiency disorders. Meningitis infection in an infant. Migraine. However you say it. Many of you yourselves might have migraines. So you might be familiar with that kind of VESTIBULAR balance issues you get with migraine along with visual disturbance issues. Metabolic disorders particularly if they are untreated like diabetes. OTOTOXIC drugs that are use today fight meningitis infection which can damage the inner ear and you don't then get a hearing loss implied but might also get VESTIBULAR disorder. Neurological disorders like cerebral palsy or hydrocephalus where fluid builds up on the brain and causes pressure on the brain. And these children often need surgery so that the fluid can drain away artificially. Certain dromos like WALLEMBERG, USHER and charge. POster I don't remember train -- POSTERIOR brain tumor. It's a very small statistically but needs to be added to the list of things that go wrong when the immaterial SPLANT switched on. -- implant is switched on.

I sadly had to give up alcohol because I have tinnitus. But I remember it can cause VESTIBULAR dysfunction if over indulged. Motion sickness or carsickness or sea sickness is when your senses are being over stimulated. And again , lack of use. If there are movement issues, fear of moving, horizontal in bed for long periods of time. All these things can lead to the sense and not working properly.

And here you see a diagram of what should be in the inner ear on each side of the head. At the top you have the thing like a snail shell which is the Cochlea. And below that you have the VESTIBULAR apparatus. There's the SACCULE and UTRICLE. And the semi circular canals. They are all hollow and filled with fluid and the insides of them are lined with nerve hairs. And as the head moves and changes position, the fluid swishes around and the way it moves and the way it hits those hairs sends messages to the brain about where the head is and what it's doing and what position it's in. The two bulbs are stimulated by, linear movement in the head. Like if you go up and down in the elevator, it's one of the bulbs which is stimulated. Even with your eyes closed, you know -- eyes closed, you know you are going up or down. The other bulb picks up in the horizontal plain. Moving forward or around the corner in a car, it will create the stimulation. The semi circular canals tell you specifically about head position

and head movement. One of them, they are at specific angles to each other. One of them tells you about the nodding movement of the head forward and back. One of them tells you about turning movements to the head to the left and right. And the other one tells you about diagonal movements of the head. And between them, the three of them and the two bulbs cover the whole range of head movement and this apparatus I can R is should be -- apparatus should be replicated. And children with charge, this might be missing or mal formed or present but not working properly. If a child has a CT scan and look at the apparatus, they may welcome back and say everything is fine. The apparatus is fine. We can tell just by looking at a child's behaviors and what they are having difficulty with and the way they are adapting, that the apparatus might be there but obviously isn't working properly. Even if it's intact, there must be some kind of neurological problem that's preventing it working. And I'm asks what about a child who is missing semi circular canals? If if they are missing them, they are going to have very significant dysfunction. And that carries with it implications. And Olivia asks with mal formed SSC cause TORTICOLLIS? I don't know how you even say the word. I don't know. I think of that as more of an orthopedic problem. But certainly mal formed or missing semi circular canals with cause very delayed head control so that the head is likely to flop down into gravity if a child is being held up right

And Amy asks is this the reason why my student may hold her head down? Yes, it's quite likely this plays a part. Might be due to fatigue or due to visual field problems and if you have vision field problems, you tend to hold your head in a particular way in order to use the visual field that you have. I'm blind in my left isomy head is always turned lightly to the left so what I call my good eye moves more into the center to give me a better view of the left side of my visual field.

There are strong links between vision and the sense of balance. And I'm going to talk about a reflection. This is the VESTIBULO--OCULAR reflection. And this is a slide I got from Jim at the Texas school for the blind. During normal head rotation, the eyes move in the opposite direction of the head to stabilize retinal image. If you look at something. Imagine you are looking at a picture on the wall. It's possible to fixate your gaze on the picture turn your head to the left but keep your eyes looking at the picture. Your eyes don't have to go with it. You can remain looking at the picture. We think that is -- we tend to think that is a visual behavior. But it's actually a VESTIBULAR behavior. If you are looking at that picture and you want to turn your head but keep looking at the picture, as your head starts to turn, the semi circular canals on the left side of your head which is the direction you're moving towards and semi circular canal that's triggered by horizontal movement cause that's the way you're moving, it gets fired and sends a message to your brain and says uh-oh the head is moving horizontally to the left so the eyes need to move horizontally to the right so they can carry on looking at the picture. And then when the head stops moving, that semi circular canal says to the brain very quickly, now the head's stopped moving. Don't move the eyes any more. Everything is stabilized again. And each of the semi circular canals on each side of the head is going to be sending this kind of information to the brain so I can look at a picture opposite me on the wall and I can move my head in all kinds of positions and yet my eye continues to look at the picture. It's not exactly comfortable but I can do it. If your sense is not working properly or is missing,

when you turn your head, your eyes go with your head. You do not remain looking at the thing you were looking at. And then your eyes have to search and find the thing you were looking at again because you've lost it. And if you look at people with charge closely, you will find they develop a whole range of strategies to stop their head moving specifically when they are trying to use vision. The children may MROP their head on -- PLOP their hand on the elbows. And they will hold if they are looking at a book or a picture or a piece of paper, the head will go down on the table and hold the book on its side and look at it this way. They will probably rest the book on the table as well to stop it moving. They are quite likely to get down on the floor and lay down or get on the couch and lay down. We are often when we're tired or need to relax. We lay on the couch, prop our head on a pillow and lay in that position. People with charge do it because otherwise it's difficult for them to use their vision, find vision to look at fine detail. And I think this is something that most teachers of the visually impaired don't know and don't get any training in. But it's very important. You saw the picture of the young lady laying on the couch earlier with one ankle up on the other knee. She needs to be horizontal because she's looking at fine vision. If she's not laying down with her head and body fully supported and one ankle up on the other knee so her brain knows she is stable and fully supported and if she can't then push her lower lip against her cheek to get some pressure to help her fixate her eye and stop it moving, if she can't do all that, she can't keep her trunk so her eyes focused in order to look at the fine detail. If her trunk moves, her head go with it. Her eyes go with it and no longer looking at the image. And Amy says CC please but I don't know what that means. I'm not too sure what that means.

I'm just going to skip through more slides that I've just talked about. Excuse me.

And so should you encourage a child to sit up and read when they prefer to lay down or should you let them lay and read? My child only lays and we are working on sitting and standing. Oh, closed captions. Thank you. CC means closed captions. Does that means the closed captioning isn't working?

It is now. Yes, I think it disappeared for a while. Sorry.

Back to your question, I think it's all about balance. Nobody wants their child going through life having to lay down on the floor in order to use fine vision and lead. But equally your child might never learn to read. They have to lay down in order to do it. The closed captioning is working now.

So it's about getting balance. This slide is about actual balance. So I'm not talking about the slide at the moment. I'm answering that question.

And let me just finish. Get the balance right between allowing the child to do what they need to do in order to use fine vision and working on more appropriate postures for reading. And it might be you can do propriety work. If the child gets more VESTIBULAR input or rigorous walking with a lot of proprioceptive input, maybe that will give the child better awareness so better control of their trunk and the shoulder and the neck and head so they are able to read and maintain a good head posture for longer. And ideally it's like that. So it's about getting a balance right. I think it's really important if the child keeps needing to get horizontal, they are doing it for a reason. It's not autism, it's not retardation. This is the need to stabilize the visual image coming on to the retina by stabilizing the eyes. And KATE BAELs 2. Sometimes I see children with charge syndrome who have absent semi circular canals but still seek spinning/rotation. I've attributed this to be being a source of visual stimulation. What is your opinion? I think sometimes it's a source of interesting visual stimulation. Sometimes the children have VESTIBULAR visual functioning and it's a way of giving themselves very strong input so they are able to perceive some of that. I think also fast spinning as they spin, they are giving themselves a lot of proprioceptive input. Strong proprioceptive implications. Think about the feet stamping and spinning around. Think about the fact the body twists so the shoulder is likely to be forward and the shoulder that's following is likely to be back. All these things are a part of it. So I think it could be a combination of visual stimulation, proprioceptive stimulation and some residual VESTIBULAR stimulation.

This leads into my next slide. There are three sensory systems that contribute to good balance. Input from the eyes or vision. Input from the muscles and the joints. And input from the VESTIBULAR organs. And here's the same things in this form. We call it the equilibrium TRIAD.

You have the visual sense and proprioceptive sense which is part of a very large sense of touch. If you look at this diagram, all three of these sensory systems are likely to be affected in someone with charge. VESTIBULAR function is the most common. But proprioceptive reception tends to be poor for the kinds of reasons I've mentioned. And also we know the visual impairment is often a problem. And I see questions in the chat box are jumping up and down.

So to someone with charge, likely all three of these sensory systems are missing or not working properly. The good news is that equilibrium and balance, that ability to stand and weight bare and walk is more than just a vestibular function. Developing vision and proprioceptive perception is a major contribution. Think about how it contributes to standing and weight baring and walking. I was persuaded once to do YOGA classes. I'm usually a nervous wreck. And a bit demented. And someone said do Yoga. I found Yoga stressful. I was hiding at the back of the class and at the end of the class we all had to stand on one leg and put our other heal up in our grown and bend our knees and I didn't know why. And in front of me I could see all those heads, the backs of the heads WABling -- wobbling all over

the place. And she said if you can't balance look at the clock and all of a sudden every head in the room stopped wobbling. People have brought that vision in as a way of holding on. So vestibular system was challenged by balancing on one leg and trying to do these contortions with the other leg. If you look at a fixed object it's almost like your eyes are holding on to it. And DHIRN with CHARN -- children with charge also use vision to know which way is up. Their vestibular sense is not doing that affectively. I think sometimes I see children who are walking and managing mobility fairly well in doors who have huge difficulty outside. Maybe they refuse to go outside. Maybe they drop to the floor when they are outside and revert to crawling. Or maybe they don't use a walker any more indoors but demand a walker when they are outdoors. And to me that would suggest one possibility is the ground is more uneven outside. Or maybe it's grass which is less stable. But it also suggests maybe they are using vision to help with their posture control and maybe we need to think about strategies to work around that particular issue. So any work you do to improve a child's vision and visual awareness could be a contribution to walking. Everything joins up. Everything joins up. So don't think that walking is just about PT and legs and feet. It's about eyes just as much as it's about legs and feet. And also about the proprioceptive sense. It's about feeling the feet. Feeling the spine and the rest of the body and maintaining good posture. I'm on my own tonight and the dog is going nuts. Please ignore her. She's very sweet. And Karen asks would you see difficulty with riding in a vehicle for longer than one and a half hours or so be a sensory issue? I think it could be a sensory issue possibly related to vestibular problems. But I think also there might be other behavioral features involved such as board only -- BORDOM.

And here's a quote again from Jean AYRES. She wrote when the vestibular system does not function in a consistent and accurate way, the interpretation of other sensations will be inconsistent and inaccurate. And the nervous system will have trouble getting started.

So this is a -- oops sorry. I'm going backwards. This is a really big deal. Carol, I have two quotes from her.

She says gravitational insecurity is manifested by abnormal distress and anxiety in reaction to falling or the possibility of falling. It is a primal fear. And then another quote from her book. Indeed, our need to know where we are in relation to the Earth is more compelling than our need for food, for tactile comfort, or even for a mother/child bond. So this is a major issue because posture security and gravitational security comes very high on the list of priorities, sensory priorities. And if you're trying to work on standing and weightbearing and using fine vision and awareness and responses to sound, if you are trying to work on language development, the child's brain might not be available for what you're trying to do because posture and security or gravitational security and poor feeling of the body has taken over. And that will jump to the top of their attention.

And ALLIE has written her daughter loves to ride in a car and cries when they have to stop in the traffic. Yes, there's no one rule fits all here. But the varieties tell us we need to know the child. And what's right or wrong for one person just because they have charge won't necessarily transfer to somebody else just because they have charge.

Vestibular problems are going to affect the way all sensory information is organized throughout all those sensory systems. Posture security and muscle tone will be affected. Use of residual vision will be affected. Perception sound and processing of sound is going to be impacted. Remembering auditory sequences will be impacted. Memory development, speech and language development. There will be a whole range of behavioral challenges. Bilateral coordination is likely to be delayed or even missing. Breathing, feeding, digestion and nutrition might be impacted. And social ability is likely -- sociability is likely to be impacted. Does loss of sensories cause a child to dislike being held or touched? The problems with sociability is these children being lifted through space is terrifying. They don't have the sensory feedback that they need in order to feel their bodies and get the feeling they have some control over it. So they tend to not like being lifted and then by extension they tend not to like being touched because they associate that with being lifted. Very early you get children who don't look at you, don't like being lifted. Don't like being hugged or moved and then don't like being touched. And this is clearly as you know I'm sure. I'm going to skip slides. I found it but a little late. So give me a moment. Sorry about the tech issues.

I wrote a piece that's in the American JORM of medical genetics. Early affects are poor or missing vestibular function in children with charge. Low muscle tone or floppy muscles. Poor head control and poor ability to resist gravity. Strong posture and security when held up right. Mark preference to being flat on the back. Delayed mobility and unusual movement patterns. And we know young infants with charge tend to move by executing. They lay on their back and push with their feet. And we move head first. We side wind or crawl very often. Two arms, two knees and the forehead. And they may go backwards. And with time may development forward movement. They are all strategies children development quite spontaneously because what we call normal crawling is too dangerous. They are likely to pitch forward and damage their nose, hit their face on the floor. Hit their head. So they develop these other ways that posture are much more stable and secure.

what is side wind SNG a child lays on their back and wiggles sideways. And the children often will use visual. They'll look where they want to go over the top of their heads or turn their head sideways and lay their body sideways and side wind. Or they'll look where they want to go. Put their head down and CRAWL towards it: And asks me to go back to an earlier slide. The vestibular issues tend to lead to low tone because gravity is frightening and very difficult. And the low tone often extends through the digestive system. Food is not being moved through the system. These problems also mean that being in

the up right posture is often not favored. So gravity is not able to play the part it normally does in moving food through the digestive system.

So there are reasons why vestibular function in an infant and younger child and going through longer through the age range is likely to have an impact on feeding and nutrition. Because it all joins up. Olivia says -- I feel like I'm juggling here. It's quite exciting. I don't know how much sense this is making. Olivia says do kids with vestibular dysfunction get dizzy? You can get dizzy because Disneyesque is over -- dizziness is over stimulation. I talked about usual movement. The children if they are on the floor and want to look at something or handle and mount something, they would the W sit where the lower legs and the feet are spread out to the sides to give them the more secure base. Of course, it's a terrible posture. It can lead to knee and hip problems. But the fact is, that the child might not be able to use fine hand control, hand eye coordination and fine vision unless they sit that way. And sitting cross legged or sitting back on the heels or sitting with the legs straight out in front, might not give them a secure enough base. And that security issue will override sufficient or auditory tension. And again, it's about a question of getting the balance right. You don't want the child in W sitting. Maybe they can sit up in a chair or on a bench or whatever the activity is. So then the W sit is not an issue. But I really think the W sit sends a clear message. There is a problem here with posture security. And the child has found a very affective way of dealing with it. So that they can concentrate on other things.

Children have better visual and auditory fine motor skills when they are in supine. When they are -- SUPINE when they are on their backs. This is a biggy for evaluation and assessment. I tend to evaluate children's vision and hearing when they are on their backs if that's where they like to be and that's where they are normally. There's no reason why a child has to be sitting up on their mom's knee supported of the hips for someone to do a vision evaluation or auditory evaluation. That's the kind of mythical habit that evaluate fors have got -- evaluators have got into. The child executing around on the floor under the bed and table.

And what you find is if you hold that child up right, they may well go blind and go deaf because all their attention goes on getting back down again. Rather than doing all the wonderful things you are trying to evaluate. They get bilateral coordination. Sometimes hand and eye dominance is complete. And they are almost one sided. Other times it might be missing and I saw a little girl recently very smart 8 year old reading, writing. But no hand dominance. So she's left and right-handed and left and right eyed which is a slight problem. Cause one eye has much less vision than the other. And fatigue. Trying to resist gravity for periods of time. Trying to do just about anything except lay on your back. When you have poor vestibular function it's difficult. In terms of emotional injury.

This is normal fewing posture. And -- normal viewing posture. It's normal if you have no vestibular sense. When you have no vestibular sense.

Someone is not muted all of a sudden. I'm hearing a comentry on what I'm saying. So again, here's a child who has learned entirely the way the children learn all by themselves. If I need to be up right and maintain my head and body in a stable position long enough to watch the whole cartoon, I need to get in this position. This way, gravity does all the work and I'm not fighting gravity. And it works for me.

Another good position over long periods of time, but functional. What can we do to help? Respect compen is a Tori -- COMPENSATORY behaviors. Minimize fatigue and stress. Remember that this is very fatiguing. Anything that improves the functioning of other sensory channels can help to make better of vestibular difficulties. And it's important to handle younger children to minimize stress so use anticipation cues. Use appropriate speed and direction of movement and provide a lot of physical support for the head and the limbs. Don't just put your hands under the head and under the butt. But maybe envelop the child in your arms.

This baby carrier might not be a great idea. It might be easier for the child to cope with facing the other way so the baby gets a sense of physical containment against the adult. And here's George Bush lifting a baby. This baby clearly doesn't have their stability function. If it did, it would be screaming and in panic by now. Lifting a baby through space with these issues is a no, no. And they tell you very quickly.

Make appropriate physical support available. Seating, tables, things to lean against, you yourself. This is a big one for mobility instruction for children with low vision. And allow periods of movement or repose as appropriate for reorganization of the whole body. Some children will need to go leaping around and running and bouncing and spinning. Other children might need to just lay down and KONK out and take a break. It depends on the individual and situation and the time and place and all sorts of other things.

And dawn says would I recommend vestibular stimulation such as swinging, rolling or bouncing? Yes, I would. If a therapist would be involved, that's way, way better. In California it's often hard to get therapy for children. So you have to do the best you can.

Reading. This is now out dating. A typo scope is a card that you cover a page of print and there's a hole in it that only shows one line of print. Now-a-days with computers and electronic readers, you can organize the software to do that online. Observe for indications of under arousal or over arousal and

know what to do about it. And I'll talk about that much more. And think about the total demands made on the child. I often see wonderful teaching programs that a lot of love and care and work and attention have gone into. Unfortunately people haven't thought about issues like posture security and gravitational security. The child is not available to learn what the person is trying to teach them because the child has the focus on those issues and the gravitational insecurity. And it's like all of us. If you are trying to listen to this in a cold room, you are not going to listen properly. A low temperature doesn't affect your hearing but it affects your ability to attend to watch your hearing. It's about attention and distractibility. If you're upset about something, you are not going to be listening to this as well as you might do and so on. And children with charge are just like us and we're just like children with charge. All those issues are going to affect them and have an impact.

And here's Jean AYRES again. After air to breath, POSTURAL security is our next most urgent priority. This is very very important and needs to be addressed. And I'm going to finish up talking a little about Jean and saying a little about self regulation because I think it's one of the big issues in the world of charge.

I want to talk -- I've mentioned all these things but I want to talk about them separately. Sensory modulation, enhancing sensory inhibition and hierarchies. All our sensory systems are working simultaneously and being stimulated all the time. And the information is threading our brains and we've learned to modulate our senses and learned to enhance certain things. That means we focus on them and concentrate on them and pay attention to them and we learn to inhibit other things. That means we tend to ignore them. We need to know they are there. You needed to know your left ankle was there 90 minutes ago. But you didn't need to enhance it. You needed to I object HIB it the information because you didn't want to be thinking about your left ankle. You wanted to be thinking about my presentation presumably. And that ability to focus on certain sensory inputs and ignore the others is a skill that we've developed as we've grown. And many children with charge don't do that very well. So they are highly distractible and everything comes in seems just as important as everything else coming in. It's quite hard for them to stay on task because any little sensory input that's unexpected is going to jump in and grab their attention. And we all know we are trying to focus on something and somebody walks past them and the person brushes the child's shoulder and the child instantly is completely lost the activity by that one little sensory input. It's very hard for them to enhance and inhibit in an appropriate way. Sensory hierarchies means which senses are the most dominant. Hierarchy is like a sequence from important down to least important. And I know children. I've worked with children who when they are well and full of energy tend to be very visual. They often use a lot to motivate movement and move around sometimes at speed SXCHLT they are very deaf. They function as if they are very deaf. Then when they are exhausted and burned out they lay down. They lay on the floor and are too tired to move and vision doesn't help them very much because all they are shown is the feeling. And suddenly they can hear things. And in their hierarchy their sensory hierarchy, when they are feeling full of energy, vision takes over and they kind of ignore hearing because it just is a distraction from using vision. When they are flat

on their backs and worn out, suddenly they tune into their hearing because hearing offers quite interesting things and vision isn't much use to them. The way senses jump to the top of the hierarchy is very related to energy levels and your emotional state and arousal state.

And let's think about sensory diet and self stimulation. Jean talks about sensory diets. Like you have a new FRIGS AI diet of -- nutritional diet of food and drink, you have a sensory diet. We all need sensory inputs. We all self stimulate. Self stimulation has a bad reputation in education. Seen as a bad thing. But actually it's a very good thing and it's a very important thing. And as I'm speaking, I'm self stimulating and you are all self stimulating but you don't call it self stimulation when you do it. We call it self stimulation when children with charge do it. Self stimulation means giving yourself sensory inputs that help you to function. Maybe they help arouse you and keep you awake. Maybe they help to calm you down. Maybe they help to make you feel more comfortable. Maybe they -- comfortable. Maybe they help you to listen. And look and see better. All these kinds of outcomes are produced through self stimulation. And if a child self stimulates, they are telling you a couple things. They are showing you what kind of stimulation they need. They are showing you what kind of sensory inputs they like presumably because they are doing it to themselves. They obviously need it. They may also like it.

Now, overtime, these behaviors can become habitual. If I do this somebody makes contact with me or if I do this, they go away and leave me alone. If I do this, I don't have to do the task they are giving me. But that's a different issue. In the beginning I think these behaviors start from a sensory need and they begin as self stimulation with a function and the function is the sensory input that is being created by the self stimulation. So the sensory diet a child is seeking for themselves gives you indicators about what you might be able to give them to build a relationship, to have them like you, to have them pay attention to you and maybe to have them function better in many ways.

and the last point I want to mention here in these three concepts is level of arousal. I have two questions to deal with quickly. Dawn says if the child is positioned in supported standing or sitting, are they able to attend to visual input? Or do they need to be SUPINE to attend to visual stimuli. The answer to that is you need to try it and see. And it's going to depend on the child and the situation. If the child is fully supported say in a standing frame or something like that, maybe they are able to maintain head control and use vision affectively. But you need to observe and see what happens and workout where does the child seem to be using their vision most affectively. What kind of position with what kind of physical supports. And then there was another question. Is in anyway to stop a child from negatively self stimulating such as hitting themselves or biting themselves? The behavior can come from lack of communication? I believe it comes from the need of proprioceptive input. And then overtime it becomes habitual and requires these other meanings such as I am upset or frustrated. I bite my hand or slap my hands when I'm angry or excited, for example. And the question how to stop children doing this, well, it takes time. It takes a lot of evaluation. It has to be quite skilled. And you do need help. It needs

some kind of team approach. But the beauty of the sensory diet idea is the sensory diet you give a child may well help to remove the need for the child to give themselves this kind of input. I'm just skipping through cause I see we only have four minutes left and I want to finish on time.

Here's a car too again. There's a little boy with his baby sister and swinging around and racing her in the cart. Giving her piggy backs and tickling her. And turns and says bedtime, she's all yours. And the baby is as high as she can be and the mom is looking dismayed because we know the baby is not in a good state to be going off to bed. And this brings me to levels of arousal and self regulation.

Here's a ladder of levels of arousal. At the top you've got the highest level of arousal and the bottom the lowest level. This is like a ladder that we all have to move up and down for different reasons. As you've been listening to me you began high on the ladder because that was two hours ago when you were excited and thought I would solve all your problems. And now you've moved down the ladder. I can't see any of you. I can't hear any of you but I'd be surprised if you haven't all moved down the ladder. I've moved up because I'm rushing more and more to get things in before time is up. But children with charge because they don't feel their bodies very well don't feel their arousal level very well. So first of all, you know where you are. If I asked you where you are you could tell me quite where you are. Children with charge tend to not know where they are. They don't even know about this ladder. If you don't know where you are, you probably don't have any idea how you can bring yourself up the ladder or down the ladder. We talk about waking up and calming down quite deliberately. We don't wake down and don't calm up. But how can you calm down if you don't even know you need to calm down? A lot of WOSHG with children -- work with children with charge and this comes out of the work with people like Martha majors and Sharon are doing and Pam Ryan are looking at self regulations. Looking at arousal levels. Helping children realize where they are on this ladder and exploring with individual children what strategies really help to bring them down the ladder or up the ladder. Should be an important part of the curriculum.

Here's a definition of self regulation. Self regulation is defined as the capacity to manage one's throughout, feeling -- thoughts, feeling.

I'm going to finish with two photographs. This is a young lady I know here in California. She's 9 years old. She's not walking independently. She has very significant medical issues. That have caused major delays in many skill areas of her development. She is a brilliant aDAP TER. -- adaptor. These are photos her mom sent me. This is one pretty amazing picture. This is a child with very low tone. Orthopedic issues, major nutrition and energy problems, breathing difficulties. Doing something that I would find something very hard to do. And here she's doing something I would find totally impossible to do. And

these are habitual behaviors she likes to do that look crazy. They look autistic. Mentally retarded, OCD. Again all these labels people throw around which aren't really helpful. I look at this picture and I take that sensory perspective and I think okay why is she doing this? While she's doing this, can she see better? Or when she gets down can she see better? While she's doing this, can she hear better? Or when she gets down can she hear better? While she's doing this, can she feel her body better? I'm sure she can because she's getting massive proprioceptive input. Her butt is completely off the couch so she's getting muscle tension and pressure from the posture she's in. When she gets down, can she feel her body better and weight more affectively and I'm sure that's a part of what she's doing. When she gets down, does she feel more stable in standing because she's more in touch with her body? When she's in this position, does it reduce pain? Is she in pain of some sort or discomfort and does this reduce it? When she's in this position, does her digestion improve? All these questions and any other you can come up with are legitimate responses to this kind of behavior. It's not enough to look at it and say this is weird, this is crazy, this is bad, we need to stop it. If it's dangerous, then it's good to stop it. If it's not dangerous and damaging, the first priority should be to say what is this doing for the child and where does this come from? In answering the question, you partially give the answers where to go with it and what to do with it. I'm making it sound simple because I'm rushing. It's actually complicated. I hope the messages you got from me tonight are first of all, children do things for reasons and those reasons tend to be functional and adaptive. Children have sensory needs just like all of us and children with charge have much more complex higher level sensory needs and we need to address those in different ways if we're going to go on and move them into more sophisticated higher level functioning.

And lastly, I think all the children I know do their best. That's really important point. And I don't need to tell you that. You're parents so you're programmed to believe that anyway. Though, there might well be times that you doubt her doing their best. But I like to think children are doing their best and what they are doing is feeding information I need as a teacher to know where to go and what to do with them. I'm sorry that was a rush. Like I said, it's a very complicated topic. I finished 4 minutes overtime but we did start a little bit. And I hope you're going away with a different way looking at your children and look at the literature out there. There's quite a lot of stuff I've children in the charge foundation, deaf/blind services website. If you check on the brain, there's 6 articles I wrote about proprioceptive perspective. All those things are there. Tim has written lots of things. The perk ins school for the blind website has information. Texas school for the blind. There's more and more out there now. You owe it to your child to get into the literature. If you are passing the literature on, might be a good idea to get a highlighter pen and mark it because all of us professionals are up against the wall at the moment. We're all struggling with impossible caseloads and if you can point people to what applies to your child that you want them to know about, they are more likely to look at the information. Thank you very much.

I was going to look to see who was online but I haven't had a chance. So I hope that was helpful. And you can always contact me. I'm sure you will if you have questions. And thank you, again, to the charge foundation. It's a sensational organization and anyone who is listening who hasn't joined and become a

member , please join. Because the foundation needs members. And it's well worth it because it achieves absolute miracles with what its got. Thank you very much.

Thank you. That will now conclude this meeting.

[Event Concluded]