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Sensory Integration Therapy.

Chantal Sicile-Kira,
International speaker, author and advocate

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Textual Transcription of sensory integration therapy.mp3

Speakers: Ernest Priestly
Chantal Sicile-Kira

Summary: In this web-based conference call, Ernest Priestly discusses sensory integration problems which affect people on the autistic spectrum. His guest, Chantal Sicile-Kira, offers advice and solutions for how to deal with a variety of sensory-related problems, as well as general tips on effectively dealing with autistic children and teenagers. Topics covered include sensory therapies, legal issues and how to get more help.

Full text below.

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Ernest: OK, everybody, I'm here. This is Ernest Priestly. How's everybody doing?

(Callers): Good, good.

Ernest: Good. OK, I'm going to mute the callers here and we're going to get started here shortly.

OK, everybody. I believe this is going to be our seventh conference call we've had so far. We're very fortunate to have, again, Chantal, who was with us the first time for the *Autism 101*. She's back, and she's actually going to replace the caller we had today; that individual was unfortunately sick, and was unable to participate. One of the things we wanted to do was introduce her, here. I have a pre-written script here that I wrote. Chantal is actually an international speaker, author and advocate who has been involved with autism spectrum disorders for over twenty years, as both a parent and a professional on both sides of the Atlantic. Chantal also currently hosts radio shows in English and French for *Autism One Radio*. She also writes in various publications, including the *Ask Chantal* column for *The Autism File*, and she also blogs occasionally, as well.

One of the things that's unique about Chantal is she is a mom to a son who has autism, and she has written extensively about this subject, and really brings to us, not only just the knowledge behind it, but the hands-on work that she's had to do over the years as she's raised her son, so it's a great perspective. Chantal, welcome again.

Chantal: Thank you for having me. I noticed that you didn't pronounce my last name because you were afraid!

Ernest: I was very afraid!

Chantal: I wish my last name was "Smith", but it's not, it's "Sicile-Kira". My name is Chantal Sicile-Kira, and I've written three books. I'm not an occupational therapist, but I do have a lot of experience with occupational therapy because of my son's needs. He's very impacted by autism, and a lot of it has to do with sensory processing, so he's received all kinds of therapies in that area since he was little. Also, I've done quite a bit of research for the three books that I've written.

The first one was *The Autism Spectrum Disorder*, the second was *Adolescence on the Autism Spectrum* and the third, which just came out, is *Autism Life Skills*. So I'm going to be talking about occupational therapy and sensory integration and answering questions. I'm doing it from research that I've done for those books as well as experiences from my son, but also – as an advocate – I've helped a lot of people in IEP meetings to get services and these kinds of therapies for their children, based on their needs.

Also, another new aspect I have is for my third book, *Autism Life Skills*. I interviewed people on the spectrum and I asked them what was important for them growing up. I wrote that book because my son was 17 – he's 19 now – and I wondered what was important to people on the spectrum growing up. The reason why I bring this up is because the number one factor that all of them said impacted their lives – and it didn't matter whether they were very impacted by autism, like my son, and could respond to interviews just by typing, or if they had Asperger's – all of them suffered from sensory integration processing difficulty. This really colored their world and colored growing up. I was really blown away by the amount of information that I received from these people about how it affected them. People with Asperger's that we don't think have any sensory processing issues, or very little, actually had some. It's just that because they had Asperger's they were able to compensate and learn how to handle themselves in different situations, which those that are more impacted with autism, such as my son, may not be able to do.

This is very insightful because it explains a lot the behaviors and situations that I didn't know were the result of sensory issues.

Ernest: Sure.

Chantal: Did you want to start asking me some questions, Ernest?

Ernest: Yes, I can do that. You saw the list of questions that we received initially – was there any on there you wanted to take right away?

Chantal: OK. The first one is someone from Florida, asking, "My son walks on his tip-toes all the time. We are constantly telling him to walk on flat feet but he still continues. He also has a very awkward gait. He is a very hard walker and moves his whole bottom half side-to-side when he walks. What can we do to help with this?"

The theory with toe-walking is that it has to do with sensory processing; a problem area in the vestibular. I'll explain a bit about what that is, for people who don't know that much about sensory integration challenges – or *sensory processing disorder* is the correct term these days.

It describes the inability to process information received through the senses. What this means is people either have too much information coming in that they can't screen out, or they have little information coming in. They may be mono-channel, which means if they're listening and using their auditory processing they can't use their visual processing. Most of us are pretty familiar with the fact that we use the senses of vision, hearing, touch, smell and taste. But there are two important areas that are challenges for people on the spectrum. One of them is called *vestibular* and the other is *proprioceptive*.

Vestibular has to do with where your body is in space. This means that where it is in relation to the surface of the earth. You know there are some people who can't stand the rides at the fairground, but other kids, like my son, are always seeking that spinning motion. That has to do with if they don't have their vestibular sensing mechanism working correctly. The proprioceptive area has to do with where your arms or limbs are in relation to the trunk of your body.

And why this is important – the theory is that somebody walking on their tip-toes is having a problem with their vestibular. They can't keep their feet flat on the ground because they're having problems figuring out where their body is in space. When we talk about kids on the spectrum who, perhaps, don't look like they have very many sensory processing issues, but you may notice that they're awkward, clumsy, or not very good at sports, other than the social aspect. That has to do with the proprioceptive, when they're not sure how to move their arms or legs, and where those are in relation to the rest of their body, which makes them clumsy.
It really affects our everyday lives all the time. So just telling somebody to walk on their flat feet is not going to be helpful. The fact that this person has a very awkward gait and moves funnily when he walks shows that he probably does have a vestibular challenge. I would definitely suggest sensory integration with an occupational therapist. It could be that once they do an assessment, they might say he needs physical therapy, because there's a difference between physical therapy and occupational therapy. But I'd start with an occupational therapist.

The thing that I'd warn listeners who are not familiar with sensory integration or occupational therapy about is you really have to be careful who you see. I have learned through trial and error. People may think that I'm so knowledgeable because I wrote all these books, but I always learn new questions that I should have asked the professionals working with my son. The thing you want to make sure of is: does the occupational therapist have training in sensory integration? This is very important, because many school districts hire occupational therapists, who just sit there and try and teach your kid handwriting. That's not someone who is going to help with the sensory integration needs of the child. The other thing is: ask if they have experience with autism. Not just autism in general – I once asked that question, and they said "yes". It turned out the woman had only experienced Asperger's syndrome; not with someone who had been impacted with autism like my son. So she was very ineffective with my son, but she might have been great with somebody who had Asperger's. Another question which comes up, and which people should ask, is do they have experience working with this age group? Sensory integration that you do with young children will look different that sensory integration you do with older children and teenagers. You want to make sure that the professional you have has experience in the areas, or at least the age area and ability level, of your child.

The other thing people should know is that occupational therapy and sensory integration are things that you should be able to have provided by your school district. If it's OK to jump ahead here – as I had read some of these questions – I'm going to try and find the question where somebody asked, "My son's too old for occupational therapy – what else can I do?" They're saying their child is twelve. I would bet $100 that they say the child is too old because that's what the school district told them, because I've never known a good occupational therapist to say that it's too old to do occupational therapy with somebody. Of course everything's better to do when they're young, but think of it this way: people that have strokes or that are in accidents and lose the use of one or two of their limbs; they go to therapy and they learn to re-use their limbs by using their arms and legs in certain motions that re-create the synapses in the brain. So it's never too old to learn and to work on the motor aspects of your body. But I'll tell you that when my son went from being in sixth grade in one school district, and transferred over to Junior High into another school district, all of a sudden he wasn't eligible for OT any more. It was like he was "cured" over the summer. This kid who was getting two hours of one-on-one a week, and all of a sudden, he doesn't need it any more. But really what they were saying was "we don't provide it any more." We started discussing it – because of course I had an assessment that showed he needed it – they said "we just don't provide it." You just can't say you don't provide it; there are laws. There are a lot of questions here that say "how can I have this paid for?" You need to get it through your school district, and what's really important is, if you don't agree with your school's assessment, you find an outside person. You can ask people in your area, whatever support groups that you have, if anybody knows a good OT. Then you interview the OTs, find someone who will do an assessment of your child, who you feel comfortable with, and the assessment will show whether your child needs therapy and what kind. Then it's up to the school district to provide. I just wanted to be really clear on that because this is something that should be provided by the school district. Don't let them say they can't help your child anymore, because they can.

Did you have something you wanted to say or ask, Ernest?

Ernest: I was going to ask you; people do struggle with their school districts a lot. It's an issue. Are there any tips you can give them? You kind of hit on it initially, but are there any other tips you can give them that might help them break the wall to deal with this issue?

Chantal: The first thing is just to base it on your child's needs. It's not just because your neighbor's kid is getting something, that you're going to get it. The school district love to do their own assessments, but you are allowed to ask for one as well. You have to pay for it; so that's where it becomes difficult. You might need to see if the assessment is covered by your insurance, or might be out of pocket for the initial assessment. But in the long run, if it's going to help you get the services for your child, it's worth it. But as I said, you want to make sure that you find the right professional, and you only get that by asking other professionals you trust, and other parents who have been in the same situation.

Once you have an assessment done, you have an IEP meeting, which you can request, and make sure the professional is there to explain his assessment and to make his recommendation. Then, if the school district doesn't agree with that recommendation, you have to start talking about either negotiating about where you're going to go on that, or if it's really an important issue, there's always filing for due process. It normally doesn't get to that for OT. You might disagree on the amount of OT they get, but the important thing for OT is to repeat things. Even if someone is working with your child, you want to make sure that either you or a tutor, or someone, knows what's going on so that you can repeat some of the things and use some of the tips.

That's the most important thing – have a really good assessment done. If a professional is saying that you child has a certain need, you should have that provided by your school district. So that's my tip on that.

I always tell people – in terms of IEP – it's really hard not to be emotional, but you have to think of a business meeting. What would you do if you were trying to convince your boss or your colleague of something? You'd get all the facts and information together, and then go to the table and say, "this is what I need, how can you help me with this?" You discuss it from the point of view that we're all in this together to help this child. That's the way I would talk about it.

Ernest: A lot of people seem to be confrontational at times.

Chantal: You get fed up after a while. I can understand that, but I always say, get that out of your system before the IEP meeting because you're not going to catch flies with vinegar!

I'm going to continue with a couple of questions here. Someone asked about auditory defensiveness, and does that play a part in a child's inability to process language sounds?

Ernest: Goerge from Texas, I think.

Chantal: Yeah. In other words, is the AD impending his ability to process sounds or is it just possible that he has both sensory integration disorder and APD? "We know for a fact that he has the sensory integration disorder and we are awaiting testing to determine if he also has the auditory processing disorder. Where are you located?" That was for the OT, I guess.

Yes, auditory defensiveness and also auditory processing disorder does affect the child's ability to process language, so this person's doing the right thing by having both the sensory integration assessment and also the audiology testing. Again, with the audiology testing you would try to find somebody who is familiar with testing kids with autism. All of that does impact the ability to process sounds; that's very important.

Someone from Houston says, "My son is 22 and does not want to wear any clothing. What can I do?" I would say move to Germany! There are many clothing-optional areas there! That's a joke, OK? I hope people have a sense of humor. I heard there was somebody from New York on the line, and I know people from there have a sense of humor, so I guess that's OK. It might be a little inappropriate, though!

This is a hard problem, not wanting to wear clothes. I think if he does not want to wear clothes, he's having a lot of issues with the feel of the clothing. The first thing I'd do is try and find really soft materials; there are some cottons now that are so soft they feel almost buttery. See if he can tolerate those kinds of clothing, and nothing tight or restructure, but very loose. I'd suggest wearing them, starting with a few minutes, and working your way up to longer and longer. But the thing is, it has to be very comfortable to him, otherwise he's not going to wear them. So that's what I would suggest, and maybe that's something that's already been suggested. If that's the case, I would definitely try and find somebody who has experience with the older teenage or young adult population, with sensory integration experience.

Carrie from Cody – “We have a teacher who gives my son a big bear hug just after P.E. to help calm him down after all the excitement. We have another teacher who will just lean in heavily on his shoulders during work time. He pretends he’s just checking on him, but uses the chance to give him a little sensory input. The care educators and other teachers are looking for ways to help him; do you have other ideas?”

My first thing is I would like to know how old this boy is, because it may not be appropriate for him to be having a big bear hug from his teacher if he’s older or a teen. We do have to be careful about those things because of the mixed messages that we could be sending our teenagers about appropriate and inappropriate behavior as you get older, in terms of touching adults. But I can understand why he’s giving him the big hug. Also, talking about leaning heavily on his shoulders; that’s a good idea. The thing that works really well for a lot of kids is wearing a backpack which has a certain number of books in it. You have to figure out how much weight the child wants to feel as sensory input. We have found that works really well for quite a few kids – the backpack. They can wear that most of the time and it looks really appropriate in a school setting.

As the kid gets older, you want to try and teach him himself to be giving himself his own squeezes and a bit of massaging. Again, not knowing the age of the child, it’s hard to suggest that. Some kids can end up teaching themselves how to do that – to squeeze their legs, arms or shoulders, which can help. I suggest these things but my son is the type of person that has not been able to learn to squeeze himself, but I know other kids who have. I know some of these suggestions can’t help everybody; they can help some.

Another question from Albany, New York. “What is the difference between occupational therapy and sensory integration therapy? Aren’t they one and the same?” A good question. It’s not the same thing. Sensory integration therapy is usually done by people who are trained in occupational therapy, but occupational therapy is more about how you use your hands or your body in functional ways for practical things. For example, for working on fine motor skills like buttoning your pants, pulling up your zipper, or anything that’s fine motor with a practical use – strengthening the fingers so they can pry open and close lids of containers, so they can get food out. For the gross motor skills, it could be anything that’s going to help them function - to strengthen their arms for lifting things, or to strengthen their legs for walking. Some of the gross motor stuff also crosses with what physical therapists do, but the difference is that with OT the goal is a functional one. You’re not just talking about the strength of the leg or the arm, but a goal. For example, in my mom’s case, she’s getting occupational therapy because she’s now in a wheelchair. Her goal is to be able to move the wheels of her wheelchair with her arms. She might be getting some arm-strengthening exercises from the physical therapist but also from the occupational therapist, who is working on how you move the arms to actually move the wheelchair.

Sensory integration, on the other hand, is how to get all those different senses that I named – auditory, visual, feel and touch, smell, vestibular and prorioceptive – integrated together so that the person is processing through all those different channels. Why is sensory processing so important? It’s because that’s the way – as babies – we discover the world and figure out what things are. When babies start crawling, they’re looking for things, put things in their mouth, touch and feel – this is how they identify the world around them. If their visual or auditory processing isn’t working, or is too sensitive, then you have a real problem because they aren’t able to make sense of all of that. When you can’t make sense of that, the world loses meaning for you, and that’s when some of these kids shut down, because it’s too much information at once.

The thing that I learned a lot from adults when I was interviewing for my book, *Autism Life Skills*, is how much this really impacts everything. For example, social relationships. We always think of that being a problem because they don’t understand social skills or parameters, but a lot of them explained to me that they had problems – and I’m talking about the ones who are very verbal; high functioning autism and Asperger’s. For example, this one gentleman, he had a terrible time meeting new people because of the smell, the new smell he had to deal with, and the new visual he had to deal with. He can’t process the visual with the hearing at the same time. He’s mono-channel, there’s only one channel that works at the same time. So he's meeting a new person and focusing on their face, trying to learn their face so he can recognize them again, and he notices their mouth is moving and their eyes are blinking. He can't hear what they're saying. I mean, he can hear but he can't process it, so then he's lost that conversation, and whatever he responds is out-of-sync. So that's one area.

The other area is… sometimes it's overwhelming to be in social situations because there's too much noise or too much light. That is very, very tiring and taxing to people on the spectrum. Here's a perfect example of how sensory processing affects people on the spectrum in ways that I didn't fathom, at least. I'm sitting in the hotel lobby interviewing a person with Asperger's, and we're sitting together talking. All of a sudden, her cellphone goes off and all of a sudden she leaves. She comes back 20 minutes later, and I ask if everything's OK – I thought maybe she got a call from home or something – and she said, "oh yeah, when I'm out in public I get overwhelmed by the new sounds and the new different lights around me, and I forget to use the restroom because I can't feel my body. I cannot feel my body in situations of sensory overload, so I always have to set my cellphone to remind myself to use the restroom."

I was blown away, because my son still has toilet issues at 19. Sometimes I get the feeling professionals think I haven't followed through on my behavior plans, or I'm not doing everything I should. But at the end of the day, now that Jeremy can communicate by typing, he has said to me, "I didn't feel it coming, I couldn't feel my body." He will not go in certain stores with very sharp, high-voltage, fluorescent light, and will say "too much light." When he was younger, he used to wet his pants as soon as he entered a store that had a lot of fluorescent lighting. So I've always been made to feel like this sensory issue has to do with being on the less-able end of the spectrum, but it doesn't. I thought, "OK, maybe this is a one-off incident", but I asked other people that I interview, and a lot of them said they had the same situation. They said, "when I leave my house, I always set my cellphone to remind myself to use the restroom – I can't feel my body, and the situation's overwhelming, and I don't know if I'm going to be overwhelmed or not if I'm going to a new place." Isn't that amazing?

Ernest: It is amazing, it really is.

Chantal: So it has nothing to do with intelligence. It has to do with whether or not you can feel your body. This is really helpful for me, because now I thought… I usually remind myself, or the tutors remind, if Jeremy doesn't go, we have to prompt him to use the restroom every couple of hours. So now we're getting him a watch that we can set for him, and we're going to train him over the years to use the restroom, and eventually he can set it. But you see how having information for those on different ends of the spectrum can be very useful. I was amazed at things like this.

I should probably answer more questions – I can go on and on for hours here!

Erenst: It's OK. We've gotten about 20 more questions since we've been talking. People are really vibing off what you've discussed so far. We can continue on and pick up some new ones, too.

Chantal: Here's another one from Renee in Minnesota: "Are there any other types of therapy that a teenage boy can do? He has done years of OT but he is now too old. Any suggestions? Clothes, food, soaps, etc.?"

First of all, OT is not too late for a teenage boy, but maybe she's saying that it's plateau. She mentions clothes, foods, soaps, etc. – is that maybe because the child is having sensory issues? I don't know what kinds of sensory integration this person's been doing, but I know it doesn't sound like vision therapy is something that would help her. It's something you can do at any age, when you have children who have a problem processing through their visual sense.

Another thing that is useful is auditory integration training, which is for people who are having problems with their auditory processing. The reason for having good visual processing and auditory processing is because this is how we learn, especially at school. This is a little bit of a pet peeve of mine – we always hear about how children with autism are helped mostly with visual reminders, and told everything should be visual. That's how most of them are learners, visual learners. I don't think that's true. The ones which we have been successful with are visual learners because we – most of us – are visual learners. So we have adapted the way that we teach them through visual prompts.

Also, hearing from people like Temple Grandin, who is very well known, she is a visual person. But people like Tito and my son, who are very impacted by autism, visual schedules and things like that have not worked for them. But auditory reminders and auditory schedules have worked, and that's because they're visually not processing but their auditory processing is working well. That's another thing you have to be careful about – knowing which processing set is working the best, because that's going to be the way they learn.

Again, Judie from California said, "Can a child of any age still benefit from this treatment? My son is almost 12 and still has sensory problems although the autism has improved." Again, yes it can help. But what you do have to start thinking about when they're teenagers is what kinds of ways can you accommodate for this child, because certain things are going to be harder for them and meanwhile they still have to live in society while they're getting these issues taken care of. It's important to work on the sensory problems, but sometimes we do have to accommodate for them.

Ernest: I have an interesting question here, if you don't mind. It's from Lewis Bryant from Arkansas, and his question is: "Who is qualified to teach sensory integration? The person in our school is not trained. Should they not get training from a specialist before they implement a program for our kid's IEP?"

Chantal: Yes, that is a very good question. There are schools which offer sensory integration programs, but you want to be careful. I would specify in the IEP that someone that has been trained in sensory integration and also shows a working knowledge of sensory integration techniques. It depends on the age of the child, but you should have that mentioned. For example, my son was in junior high, and I had it written in his IEP that the sensory integration had to be done by someone who had sensory integration training, but also experience with adolescents. I put in that stipulation because the person that they gave my son, as an occupational therapist and for sensory integration training, was straight out of school. Yes, she had the training, but didn't have the working experience, and had not learned how to work with teenagers, and gave my son rug burns. Front and back. She was using a technique that they do with the little kids where you pull them around on a mat by their arms or their legs, and they love that feeling. It helps them with some of their sensory processing.

Ernest: You're getting back to your point before, where it had to be age-appropriate.

Chantal: Right. And so that you can't do with a teenager. The other thing is, when she was pulling him around on a rug, and hadn't noticed that his T-shirt was pulled up, so was just getting rug burns everywhere. Very, very painful. He came home and I said, "what is this?" I went to the doctor, and the doctor said, "oh my gosh, those are rug burns." You want to make sure – and I say the same thing for aides or care professionals, when we're talking about applied behavior analysis or any kind of training – I don't say that they must be trained. Some of these school districts, they give your kid's aide two hours of training, and say "she's trained." I put in – and I learned this from an attorney – I put in that the care professional must show that they have a working knowledge. They must demonstrate a working knowledge of whatever it is – ABA or sensory integration. There are schools for sensory integration. There are programs that OTs have to follow, and that's what they should make sure is in the IEP as well.

Ernest: Do you want to pick up another question on your end?

Chantal: Yes. Sarah from Holstead: "I have so much trouble with my son misunderstanding things and over-reacting. He is so inflexible in his beliefs of what happens to him that I can't reason with him. Any ideas?"

Again, I wish I knew how old this child is, because some of this behavior happens when kids hit puberty. Regardless of whether they're on the autism spectrum or not, you start getting children that become non-compliant and start over-reacting. But the mis-understanding thing and over-reacting could be that he can't help it, and the sensory overload is making him over-react.

One of the things that I learned from everyone I interviewed is how any kind of transition was a very difficult area for them, because of the sensory processing. Once they get used to routine, if the sensory processing issues are painful for them, it's OK because they get used to it. They know that every day at this time I'm going to have to go down this crowded hallway that's really crowded and noisy, and I'm going to feel all these people touching and brushing up against me, but they can handle it for a certain amount of time, because they know that it's going to happen so they psych themselves.

With my son, he knew that he was going to the dentist, so if I told him a week ahead of time, he could prepare himself for the fact that he would be in that situation. At first, he didn't like to go – and he never really ended up liking it – but it got to the point where if I forgot to tell him and put an icon up a week ahead of time, if I just told him the day before, he was OK with it. Over time, he got used to the fact that he could psych himself into putting up with it. But, if you have constant change in routine for kids who don't understand what's happening next, a lot of it has to do with they're afraid of having sensory overload. So they say that the best thing you can do with any child for autism – if you only did one thing – was to make sure that you worked on their transitions; telling them ahead of time what was going to happen next was something that really helped. This helps their behaviors, because you didn't have somebody over-reacting, because they knew what was happening next. So that's an area, like this person, it might not be that he's mis-understanding things; he could be over-reacting because he's overwhelmed. And that's why sensory integration is good, because it helps people become aware of what it feels like when they're reaching overload.

For example, if you have a child who can't tolerate certain noises or noisy situations, you can observe this child and know when the tipping point is, but they don't. You watch them, and take notes on it – and don't tell them then, because they're too upset – but when they've calmed down at another time, that's when you have a little talk about it. Even if you don't know how much they understand. For example, with my son, I didn't know for years if he understood us or not, but I always talked to him as if he understood. I also showed some visuals, too. But you explain to them, and try and ask them, "What did it feel like before you had that meltdown? To me it looked like this… and you started hyperventilating, and started flapping your arms, and I knew that you were going to have that meltdown."

So eventually, they learn to recognize by figuring out what's going on with their body, before they get to that tipping point. Then you can teach them to tell people they need a break. My son has a break card, because it takes too long to type things out. So, always on his desk when he's mainstream, sticking out of his binder, is a break card and a restroom card. If he needs a break, he just hands the card and walks out the door, and he'll go and do a walk around, and that's what helps him. Other people like jumping on the trampoline, other people just need to play with something in their hands, but that's helping them be in control of their behaviors by giving them control and understanding of what's going on to their bodies. Is that helpful?

Ernest: Yes, very helpful. I've got a question here. It's sort of a two-part question. "What is auditory integration training?" I have not heard that one.

Chantal: What's the second part of the question?

Ernest: "We considered auditory integration training for my son, but he's only three years old. Could this benefit someone this young, or is it best to wait until they are older and can respond better?" From Linda, New Jersey.

Chantal: That is an excellent question. First of all, I'll explain about auditory integration training. Yes, it helps young kids, but I don't know about the age of three. My understanding is they'd have to be able to sit relatively quietly, but I can tell you that I know a very good auditory integration therapist whose name is Terrie Silverman. I'm going to try and find her email, because that's a good question for her. If the person is listening they would be able to contact her by email, and say that I gave them it. I'm looking up the email now, because that's the kind of question you want to ask an occupational therapist. They may say that three years old is too young, but they may say that's fine. Then let me explain what auditory integration is.

Her name is Terrie Silverman, and here is her email: *terries@execpc.com*.

So what is auditory integration training? It is a method where you try and teach or train the child's auditory processes to focus in on different things. For example, someone who gets easily overwhelmed by too much noise – the reason they do that is because they can't filter out different sounds. Let's say we were talking in a café, Ernest. There's a lot of noise around, you can hear people moving their chairs, you can hear people talking, having their own discussions, people pouring and making coffee, but because you're not autistic and don't have sensory integration issues, you can look at me and focus on my voice. All the other noise is in the background, and is filtered out. But people with auditory integration difficulties can't filter it out. It's also as if they were on a tuner for the radio and they couldn't find the right channel, so they're listening to all the stuff in between but not getting the clear sound.

When you go for auditory integration training, they have a special machine. You usually do it twice a day for a 10 day or two week period. You listen to music that's been filtered through this machine. I've listened to it along with my son to see what it was like, and it's kind of irritating, to be honest. You usually try and do auditory testing before and then after – if they've been able to do one before, then they know what areas to work on, but if not they usually can tell what the type of child you have, and the way your child reacts to certain noises. My son hates high pitches, but things like vacuum cleaners don't bother him. Other kids, it's the complete opposite. So the person doing the therapy will be modulating the music based on that.

Afterwards, your child should be able to process auditory sound more easily. It's funny – we've done it twice with my son. Once when he was four or five, and that was the first time he ever started reacting to noise. Before he just ignored everything – I guess it was too painful – but once he had auditory integration training, if he heard me open the oven or refrigerator door and was hungry, he would come running into the kitchen. That was the first time when I said his name, he would look at me. He never did that before. This past time, we did it over Christmas. My son was sitting down watching TV which he rarely does – he usually watches the same thing over and over and won't sit down and watch with us. The first thing that he typed to me when I said, "How's your day going?" he said, "Today is the first time that I can actually hear all the different voices on the TV, and it makes sense." This is why – and I know a few people asked questions about their kids listening over and over to the same thing, and not wanting to hear certain tapes – a lot of the times they listen or watch the same things over and over is they know what's going to happen next. They know what the sounds are and they're going to recognize the sounds. Whereas, if you put something new in, it's more work because they have to try and understand everything and filter things out, so it's not an enjoyable past-time for those who have visual and auditory processing issues. Does that make sense?

Ernest: It does. This is a lot of good information, and the questions are still pouring in. We're up to 84 so far. I don't think we're going to get to all of them.

Chantal: I don't think we will. Some people can also mail me at *Ask Chantal* for my column. That's *chantal@autismfile.com*.

Ernest: Great. We've got one that just came in, based on something you'd talked about. Her name is Lisa from Illinois. Her question is, "Regarding telling your child ahead of time about what to expect, I've found that with my son, if I tell him in advance what to expect, or what to do, that he frets constantly until the event takes place. I guess OCD has taken over. Any ideas?"

Chantal: That's a good one. It's right you get rid of one problem and then have another one. So what do you do about someone who obsesses? That's a good question – I've heard of these situations but I've never helped anybody with that. There are some kids that "OCD" on the same things over and over, and what we have done in the past is make it so the child or teenager can only do or talk about that certain thing for a certain amount of time that day – like, half an hour. I would say the same kind of thing. You have a time of day when you're going over the schedule or what's happening, and that's when you talk about it. You don't talk about it at other times. They do assess on that, some of them. One thing that Temple Grandin told me – people called her "tape recorder" when she was little because she would repeat the same things over and over. The reason why she would repeat the same questions over and over is because she would like to listen to the answer. Not the answer in terms of the context of what it was saying; but the sound of the voice. The sound of those particular words.

Ernest: I have a question here from Sonja, and her question was: "My daughter chews everything and will put foreign objects in her mouth. What tools can I use to get her to stop?"

Chantal: Eating things that are non-food items is called pica, if you want to look it up on the internet. There are various reasons why pica exists. For some people, it is that they're looking for sensations, so it's another sensory things – they need to be chewing on different things. One of the men that I interviewed for *Autism Life Skills* said that he did that all the time when he was little, and he was able to replace it when he got older with chewing gum. He needed to be chewing on something all the time, and that's why he would start putting all these things in his mouth.

I have heard that some children who have pica are missing something in their diet, or are having other kinds of issues that some biomedical therapies can help with. The first thing I would look at is if it's happening all the time, or only with certain materials or objects. I would consider trying to get them to eat chewing gum if they can.

Ernest: So many questions here. Is there one you want to take up?

Chantal: Here's one that has to do with haircuts. "My son has sensory issues as he screams whenever he has to get his hair cut. He doesn't even like to pretend so that I can de-sensitize him. Any ideas as to how I can get through this, or at least to the point where he will not scream uncontrollably?" First of all, I don't know how old the child is, but secondly, he doesn't even like to pretend. Your child shouldn't have to think that that's what you're doing. Of course, it all depends on what the situation is, but, for example, if you have some kind of home program, that can be something which can be put in. If you have a certain number of hours in the afternoon that you're doing work with him, that's just part of the program. He sits down, and then you have to do a task analysis of all the different parts of getting a haircut. Take data on which parts seem to be most difficult – is it a problem getting him to sit? Is it a problem with the scissors? Is there one particular aspect that's a problem? If it is, then you start with that.

The first thing is, maybe you want to start with having him sit. Then you start with the scissors sound near the ears, and see how far you get with that. But the point is, if the child knows that you're just pretending – whether they're autistic or not – you won't get very far. You have to make it like "this is what we're doing now", and then reward him. Add a couple of minutes at a time until they sit through it for a while, and they get desensitized. But it shouldn't be an option.

It's funny, because my son has two part-time aides at school, and now one of them has good communication with him. With the letter board, she's able to get him to spell things out. She constantly is asking him questions about how he's feeling, and now that he's figured this out about her, before he goes into science class and doesn't want to go, he'll say "I feel sad". Then she starts having a discussion with him about feeling sad, and he misses half the class. It's like I'd do for my 16 year old daughter. She can tell me she's said, and I could say "OK, let's talk about that later, because right now it's time for class. You have to go to class." Then you go back and talk about it, but when people are getting out of work because we're having all these long-winded discussions with them, it reaches a point where, like with neuro-typical kids, you have to say "right now is not the time for this." But of course, you have the behaviors to deal with, but they will lessen once they know you mean business, and it's something they don't have a choice about.

Here's one from Norma Drew from Holland, Michigan. "How does sensory integration tie in with autism spectrum disorders?" Here's what I want to explain to people. To have a diagnosis of autism, there are really only three characteristics that have to be involved. One is problems in communicating, the second is problems in social relationships, and the third is obsessive attachments to objects or topics. Having a sensory integration problem is not part of a diagnosis of autism, but I have yet to find a person with autism who doesn't have some form of sensory integration problems. Does that make sense?

Ernest: Yes, it does.

Chantal: Bob from Warren has a 17 year old daughter on the spectrum who has no serious verbal issues but seems to lack the desire to be with peers. She prefers to be alone with a TV or computer and is only comfortable around adults. Could this be a sensory issue?

It could be a sensory issue, but I would also look at if she has been taught social skills. Does she know how to interact with other people? If not, or if she's also been bullied or made to feel uncomfortable in how people are interacting with her – like, maybe she's been left out or doesn't feel like she belongs – then that could be why she prefers the company of a TV or computer. Or, she's more comfortable around adults, because they're pretty predictable. With teenagers, your peers, are not predictable. It could be a sensory issue but it could also be that she's getting teased or just feels very uncomfortable in not knowing what to say. With those kind of things, you could do a lot of social stories or scripting, where you practice appropriate conversation, or appropriate ways to interact with peers. I would look at the sensory things, too.

Ernest: Can you talk to us a little bit about cards, for example, a bathroom and break card. How did you arrive at that for your son?

Chantal: That's a very good question, and I have to say that a lot of the things that work with my son that I've taught him – with the help of the school – have taken a very long time. My son is the type of student who it's very hard to teach anything to. People usually give up, and I'm the one who usually finds the way.

I've worked very closely with occupational therapists in figuring things out for my son. But here' what we did with the break card. I recommend this whenever I speak around the country – I do a lot of speaking and like to give practical information out. I always teach about giving the use of a break card. The reason why you want to have a student be able to ask for a break is that when they get older, they're going to be more non-compliant, just like any teenagers who are non-compliant. You have to give them more choices, and a little more control of their environment, in preparation for adulthood, as well. That's one area.

The second area is that if they're going to be needing breaks, you don't want them just getting up and bolting out of their chair. They have to learn that if they need a break they can have it, but it has to be asked for appropriately, and it's not just to get out of work. Here's how I suggest teaching the use of a break card – and you can do this with any ability level; you can adapt it.

For example, if you're a teacher or parent, and you're working with your child or student, you might notice that he always jolts out of his chair and tries to get out of work after 20 minutes. 20 minutes seems to be the cut-off point. That's what you need to do, after a few days, is analyze the amount of time. If you're certain it's 20 minutes, the next thing you are going to do is make yourself a break card. This is really easy – I'm all for low-tech stuff. You just get an index card and write "break" on it. If you want to use a stick figure, they have pictures which show someone sitting on a chair with a clock in the background. You can get a break one where the stick figure is breaking a piece of wood in half. But anyway! You have this card. You're going to carefully watch the clock, and at 18 or 19 minutes – before this kid is going to take off from this table, you prompt him to give you the break card, and you say "time for break" and let him go. Then you get him back a few minutes later. He can go and do whatever he wants for a few minutes. You do that and after a few days, the student is going to realize "if I hand over this card, it means I get to get up". Then you can give him control, leave him the break card, and every time he gives you the card, you're going to let him go. Of course, what's going to happen is he'll give you the break card every five minutes now, but that's OK. Now you're working on giving him the idea of the break card.

When you know that he's understood that it's a break card, and he can have a break when he hands you that, you're going to take back the time, and say "OK, we have an hour's worth of work every day, and you know that for 20 minutes you can tolerate sitting." Now you say, "I'm going to give you three break cards for the hour, and whenever you want a break you hand me a card."

In the beginning, he's going to hand the cards over pretty quickly. But you're going to have to make him stay in that chair and work for an hour. He's going to realize after a little bit of time that he needs to not use up all his break cards right away. Then, he will know that he only has those three cards and can use them whenever he needs them. That way, it gives him control over it, and he knows that when he needs a break he is going to get it. That's a good way to start teaching how to use a break card.

Ernest: OK. I think that's very helpful for people – they can easily try that, it's low-tech, and they can write out the cards as you mentioned. It's something parents can try and see if it works for them.

We have a bunch of more questions here – we're up to 92. We have Julie here, who's been pretty persistent. She's from Canada, and asks, "I have a nine year old son who has been diagnosed with Asperger's syndrome, ADHD and SID. He has issues coping with certain sounds, volume, etc. and tends to try to mask that sound by making louder sounds of his own. This is disruptive, especially in the school setting. Any suggestions?" I guess that's fairly common, I think.

Chantal: Yeah. Can you repeat that one more time? He gets upset when there's certain sounds?

Ernest: Yes, certain sounds and the volume specifically. The higher the volume, he speaks louder to try to mask that sound. He's nine years old.

Chantal: So here I think is what's going on. There are noises that are very painful to him. It sounds like he could benefit from some auditory integration training. It's hard to teach someone to change their behavior when the behavior is trying to deal with pain. If the sound is too loud for them, that's painful to them. Temple Grandin says you have to differentiate between bad behavior and behavior that's due to sensory issues. Those kinds of behaviors that are due to sensory issues, unless you take care of the sensory issues, the behavior is going to continue. Another thing I'd suggest that has been successful with some kids is wearing headphones, either with white noise, or which block out some of the sound. Also, people can listen to music very quietly through iPods. Of course, it necessitates being able to tolerate something on your ears or on your head. Often, those kinds of things have been very helpful.

Ernest: We've got a couple more.

Chantal: I've got one by Christine Nell. It says, "Our six year old, Max, has Aperger's. He has trouble almost every day around one o'clock. It doesn't matter what he is doing, even if it is a favorable activity, where or who he is wish. He becomes extraordinarily emotional, angry, lashes out, complains he is tried and will not do his school work or anything he is asked. This has been going on for about a year. We had him tested for low blood sugar; it was negative, and make sure he has adequate snacks throughout the day. We feel so helpless and frustrated that we cannot get him through these rough times. Thank you."

Here's the thing. It sounds like to me – just from this paragraph – if you've tried all the medical issues, which you have, is it sounds like his tipping point is one o'clock. So if he's been holding it together all that time, then it sounds like he's not getting the breaks that he needs from his sensory environment. He's having major overwhelm, and it's around one o'clock because – I don't know, if he's been in school since eight, maybe after four hours, it's too much for him. I say this because many of the people that I spoke to for my book said that they can't work 40-hour per week jobs. If it's typical 8-5 jobs, because they get sensory overwhelm. Unless they're allowed to have their own breaks when they want or need them, they have a hard time. We see this pattern in schools, usually not one o'clock, but this is a six year old. What we usually see with teenagers is that they hold it together all day, the Asperger kids waiting to get home who have been mainstreamed, and when they get home they're so wiped out they don't want to do anything else. Or, they have a breakdown in the late afternoon at school, at the end of the day. It's because they're overwhelmed with all the sensory input they've put up with all day. They need a break.

I have helped in situations with job coaches, who placed people with Asperger's in jobs, and they call in sick after a month or so. I talk to the person with Asperger's and I find out that he can do maybe two days in a row of really long hours, but after that he needs a day off. We figured out what his pattern was, and with the job coach, we approached the hotel where he was working and asked if they'd be open to having a two on, one day off schedule. It worked out, because this guy knew that after two days, he was totally wiped out and couldn't handle, and needed a day to just vegetate. I'm thinking of this for this son, because it sounds like he's been in there for a long time, if it's one o'clock and he's six years old.

Another question. April G, I guess she's talking about sensory integration difficulties – "How do we get this diagnosis for our daughter? No-one seems to take us seriously. We are still looking for an autism diagnosis, too, but everywhere we go we are dismissed. Emma is four years old; will occupational therapy help her?"

OK. I understand that no-one takes her seriously. That seems to be the case unless you have a child who's so out-of-whack. If somebody has autism and they have sensory integration problem, they automatically take it as being a problem because of the autism. But you can have sensory integration difficulties and not have autism. So, occupational therapy by someone with sensory integration training can help the person. Autism diagnosis is a bit difficult – that's a separate thing, even though if they have sensory integration issues they may have autism, it can be separate. I would focus on trying to find a good occupational therapist with sensory integration. In saying this, I don't know, in terms of an IEP, whether that's enough – sensory integration needs – to be accommodated by the school. It may be something you have to pay for. I'm not sure it's a qualifying condition for an IEP. It doesn't sound like it would be unless there's other stuff going on.

Ernest: OK, I have a couple here. This is an interest one. A mother from Orlando who asks, "How do you go about finding a good auditory training person or facility? Our son is five years old with high-functioning autism and lately it seems worse with sound, and he is holding his ears more than ever before." It sounds like she's definitely needing some help there. Could you repeat the advice you had before, one more time?

Chantal: I will name this person, even though she's not in Florida. She might be able to help. While I'm getting it back on my screen, it's very good that this mother is asking questions, as she does need to make sure she has the right professional. Again, I'd look in your area for any *Autism Society of America* chapter, or *TACA – Talk About Curing Autism* – they have chapters around the country. Find out what professionals other people have used and if they're happy with them. That's how you choose the right professional.

Don't just listen to one parent, and try to find parents whose opinion you trust and who may have a child with a similar type of situation. But just by talking to people, you eventually fall on the right person who can give you information which is logical.

I feel terrible about this, but I put off having vision therapy for my son for many years. I've been wanting it for about four or five years, but it's mostly been about the fear of not getting the right professional. I have asked around, and I got the names of a couple of people, but they did not instill in me a feeling of being the right people who would be able to help my son. What happened is now I have this really great occupational therapist, working with my son who used to work with him a long time ago. He wrote to me and said, "Have you thought about vision therapy? I know a really good person." Since I really trusted this professional, I followed his advice, and of course I checked up on the practitioner, but I've never met someone as good with my son who doesn't have a specialty with autism. He's a vision therapist and does children and teens with autism, but treats a lot of other people as well.

Terrie Silverman is at terries@execpc.com.

People might also want to look on the *Autish Research Institute* website – I'm not sure if they list auditory integration therapists, but it would be a good place to look as well.

Ernest: Did you want to take one?

Chantal: Yeah, I'll look here. "My son is in therapy for social purposes, and for some reason it has not helped him. He is in the tenth grade and is having a hard time socializing with other kids. In fact, he is rude to them and not sure what to do. What other types of integration can there be to help him cope with others in school?"

It would be interesting to find out what kind of therapy he's in for social purposes, because if it's not helping, then it's not the right kind of social therapy for him. Maybe they have not worked on generalizing. Here's another thing that's very important – teaching generalization skills. Just because a child or teen understands something and can act it through in one environment, doesn't mean it will immediately transfer to another environment which has all the sensory components attached to it. I would look at different kinds of social therapy. Also, she said he has a hard time socializing and is kind of rude to other kids. I don't know her son, but I get this a lot from parents who have read – and I've seen it myself – that some people with Asperger's, because they have a different way of speaking, their voice can be a little monotonous, and they don't understand the metaphors, or hidden meanings behind things. They take things at face value. And so to other people it may appear rude, but it's not necessarily so. It's just, again, he sounds like he need a lot more social help.

Some of the things which help is not just role-playing and therapy, but it's what are people teaching him? Are they teaching him about the hidden curriculum? There's a book out there called *Hidden Curriculum* – it teaches things that we, neuro-typicals, take for granted but someone with Asperger's or high-functioning autism would not. We have to teach them. For example, if my daughter's picking her nose, I'd say "Rebecca, don't pick your nose!" She, being neuro-typical, would think "I don't pick my nose in public without a Kleenex." She could still do it in her room or the bathroom, for all I care, but when I say "don't pick your nose", it just means don't pick your nose in public. If I said the same to my son who had Asperger's, he might think "never ever pick my nose, so what do I do when I have a problem in that area?" You have to be very clear in teaching these children that there are different meanings to expressions. Not everything is literal. That's one thing you want to make sure they are learning in social situations.

Also, there are books out there which teach about different metaphors. There's one called *The Asperger's Dictionary of Everyday Expressions*.

Ernest: They can perhaps purchase that on *Amazon*. Speaking of which, could you talk a little about your latest book that talks about life skills?

Chantal: Yeah. I've been talking about the short title, so I'll tell you the long one. It's called *Autism Life Skills, from Communication and Safety to Self-Esteem and More: Ten Essential Abilities Every Child Needs and Deserves to Learn*. There's 10 chapters – one's on making sense of the world. One's on communication. Safety. Self-esteem. Pursuing interests. Self-regulation. Independence. Social relationships. Self-advocacy, and earning a living. All of these are things that people should be starting to think about when their kids are little, and there's practical tips in there based on what the adults told me, on how you can instill these abilities in your child. Basically, it can start at any age. But it's always better to start sooner than later.

Ernest: Very good. This book, you can purchase it directly off your website?

Chantal: Yes, people can go to my website and it links to Amazon, or the Penguin website. Any major bookstore has my book anyway. It should have all three of my books. I want to encourage people to go to my website as I do have a lot of information on there. I know not everyone's got a lot of free time to read, but the other thing I have, if older parents are interested, is you can get, as a free download from my website, a self-employment guide for developmentally disabled individuals. It's like a workbook for people like my son, who want to have their own business.

The reason why a lot of people are going this route now – and I've worked on a couple of grants in here San Diego area – is that so many of guys don't have work when they get out of school, but may have a special interest or can provide a service that they can earn money from. It's about how you look at what people are interested in, and how you earn money from that, either through a special interest or through a service they can provide. If people who are interested maybe want to download that from my website.

The website is just my name – Google my name and you'll get the website.

It's www.chantalsicile-kira.com .

Ernest: At the end of the call, I'll send out an email with your link to the website so that people can actually go to the site and download the free workbook.

Chantal: The workbook is free, and I have a lot of information on the website.

Ernest: There was another site which you quoted – *The Autism File*. I'll send it out to people after the call.

www.autismfile.com

Chantal: Here's one from Rebecca in Pennsylvania. "My four year old daughter was diagnosed with PTD, OS and sensory integration disorder and has an issue wearing winter coats." Move to Florida, that's my answer! "She will take off hats and gloves, and will refuse to keep the coat on. It has been very cold and windy here for the past few days, but we can't get her to put on the coat. I've even given her choices of several styles – one even pink! She will wear some sweatshirts and one very lightweight wind breaker occasionally. I've resorted to putting her older brother's sweatshirts over her own. This issue has been ongoing for the past few winters. She also refuses to wear jeans or any other pants which don't stretch. Are there any tips I can try which her which you'd recommend. She did have an issue with getting dressed in the past, with screaming fits and wrestling matches, but we were able to overcome those. She also has some postural and reflex issues. Thank you so much – these conferences are amazing; thank you for doing them."

There you go, Ernest, that last thing's for you – thank you.

Ernest: Oh yes. Definitely answer her question, just so people know, the more good things you say about us, your questions will be answered!

Chantal: This is a perfect example of sensory integration disorder to touch. Her mother's really smart here, because her mother has time to figure that out, and she talks about how she did have an issue getting dressed in the past, but has been able to work through that. That shows the daughter has been de-sensitized and doesn't scream as much any more. The mother is on the right track here by putting on different clothes. But this girl is four, which means you can do a lot more sensory integration techniques. For example, one thing you can do at four which doesn't seem as useful when they're fourteen is the brushing. This is where you have a little brush that you hold in your hand, but it's a special plastic brush, and you do it not lightly, but firm pressure all over the body, on the arms and legs. Again, a sensory integration trained therapist can help with this. Over time, they will be able to tolerate more clothes. I would suggest until then the mother should continue with what she's doing in terms of wearing the sweatshirts and the light wind breaker. I know it's hard, as you want her to be wearing a nice heavy coat, but until you get her able to tolerate it, it's not going to be possible. So think about the brushing. I don't know if this person has an occupational therapist with a sensory integration specialty, but it would be really helpful for this girl.

Ernest: Someone here asked about weighted vests. "How can a weighted vest work for a child with autism while doing the required one hour of homework every day? How is the amount of weight determined? What is the frequency and duration that they wear it to be effective, and what should you do during each break during that hour?"

It's a detailed question. I've heard about the vests being used before, maybe you can talk about the reason why.

Chantal: Remember when I talked about the backpack earlier, and I said that a lot of teens wear a backpack with a lot stuff in it? A weighted vest is used often to give that deep pressure that they need. It's usually just used inside classrooms, as it's not very appropriate to have out in public, although some of them look better now. It's hard for me to answer that question. I would think that the person would need to talk to th person who is providing the treatment – the occupational therapist – as I wouldn't want to contradict what they're saying. I don't know how you'd determine the amount of weight – that is a therapist question. Regarding the frequency and duration – I think it depends on the child. And what should you do during the breaks in that hour? Again, I have no idea what the therapists would say. In my mind, I would say just to keep it on because it's giving you that continual pressure you need, but again, check with the therapist who's helping you out.

Ernest: A person is asking, "Where can parents implement sensory integration training themselves? Is there a place where they get a class on how to do that, or exercises they can do on their own?"

Chantal: A good question. I don't know if there are classes you can take, but I do know it should be individualized for the child. I would say to go for an appointment to a sensory integration therapist. I don't know if someone would give you an appointment without having the assessment, or at least some sort of an assessment about your child. But they can teach you a lot of these techniques, like when I talk about the brushing and deep pressure – those are things which have to be done every day. And so, the sensory integration therapist is going to say that you need to do this every day, and they're going to have to train somebody.

I would say if you can find or afford to have someone show you what to do with your child, that would be the best thing. You don't want to be doing something that's not effective with your child. When I talked earlier about using a firm brush, if someone had a different type of sensitivity issue, it would have to be a light touch with the brush. So you have to make sure it's the right thing and you have to have the specialist look at your child.

Here's a question from Cynthia in Florida. I'm doing a six-hour seminar on adolescent issues, on November 6th or 7th – I can't remember – but if anyone wants information, contact me. But here's the question: "Will giving a child a trampoline outside only decrease the need to jump on and off the bed, couch and furniture? If so, what would be the duration and frequency required to meet that need?"

OK, definitely a trampoline would be a wonderful way to decrease the need to jump and off the bed. They're transferring that input they're getting, and it's so much better to get it off the trampoline. I don't know the duration or frequency required to meet that need – that's an individual thing. I think the trampoline is such a great idea, because obviously you need to have some kind of safety around the trampoline, but it's such a good way to get people's engines running at the right speed.

That's something I wanted to bring up. When you look on a scale of one to five, on how your state of body is, three is what most people are best at. Your engines are not running too low, and not too high. So try and keep people around a three. When they get older, and you're trying to teach them self-awareness and regulation, you want to have a couple of minutes, especially in the morning when they're settling into school. What speed are you feeling? Is your engine low today, or is it high? Obviously if you have kids that don't have that much communication, you can at least talk to them about what you feel that they're feeling. If you see someone who is very hypotonic and is falling asleep, you know his engine's really low.

And if someone's really hyper, then his engine's high, and you can talk about those kinds of things so they recognize what they're feeling. They become aware of themselves.

Ernest: I have a comment from someone in Kansas; Johnnie – she says, "I am not sure about the vest but the blankets are supposed to be 10% of the body weight plus 1 pound. We have made several blankets for ourselves and for the kids in our groups. I've read that the time limit to leave these on is about 20 minutes on whenever they move, and replace it as needed."

Chantal: Really good for them to share that. I did want to mention those weighted blankets because a lot of kids tend to – even at night- seek that sensory input, so it's a good thing to have.

Ernest: We have a few more coming in.

Chantal: OK, how about Sue Denton, about toilet training. "Hi, my name is Sue. I have a wonderful nine year old son with autism, and a having a really hard time potty training him. My son still wears diapers, and my mom and I have tried everything. He does not understand when he has the feeling to go to say "potty". Please help if you can. Thank you."

I hesitate to say anything because it sounds like she's tried everything, but again, it would be interesting to figure out if this little boy – well, he's nine years old – can feel his body and feel when he has to go. First of all, does he understand that he's supposed to be using the potty? That's the first thing. Once he's figured out that using the potty, then it's a matter of getting him to use it. So, for somebody like him, you'd have to take him. The first thing I'd do is look at the diaper situation – how often is he wet? You're going to have to time it for a while to see how often he's wetting. Then you're going to figure out if he stays dry for a fifteen minute period of time, or a half hour, or an hour? Whatever it is, that's the time that you're going to use to start training him, putting him on a schedule, and taking him to the restroom every fifteen minutes or every half hour. Eventually, you hope to decrease the prompts, and he will go. But remember when I said that a lot of the adults say that they have problems feeling their bodies? You still use all that information I just said to help them use the bathroom, but they might still always need the prompt from a parent or a tutor, or a watch when they get old enough to figure that out.

Maybe it's hard for him to say "potty" – maybe it would be easier for him to actually go there. But it's really just about taking him at timed intervals. It does really depend on styles. My son who is 19, nearly 20, we still have toilet issues, for a variety of reasons. Mostly because he can't feel his body at a certain time, but the thing you have to realize is that often for families, it's touch-and-go with toileting. You can have a period where the child is not having any accidents, and all of a sudden, boom, they start having accidents again. A lot of it can do with anxiety, changes in programs, or changes in what's going on in their life around them. If that's their sensitive area, that's going to be the thing that goes first – the toileting.

You can't get disheartened, as you can always get them back on track. If you've managed to do it once, you can do it again, and again, and again!

Ernest: Right. A lot of people don't understand the struggle that it is. Could you talk about that? A lot of people might not understand what that's about – the toilet training.

Chantal: I never thought I'd be talking about toileting issues when my son was 19. For some kids it's not a problem at all. I know some kids on the spectrum, they were out of diapers day and night as fast as could be. These are usually the kids that are a little bit on the hyper end, and are physically very active. They seem to have a good sense of feeling in their bodies, and seem to be in control of their movements more. But for other people, it has to do with being able to feel when you have to go to the bathroom, and understanding where it is they have to go. It's true that if they can't feel their bodies then you're not going to be able to train them to use the restroom. So you have to keep an eye on that.

Ernest: Right.

Chantal: I have one from Donna in Woodberry. I don't know if I can answer much of her question, but it's important, because it shows what all of us have to do when our kids get older, too. "What type of financial, medical and educational help is there for children who are in their late teens and have a much milder form of autism, but are unable to function socially outside of their own home? Our 18 year old son has not left home in two years except for doctor visits, and wasn't diagnosed until four or five years ago. Also, we will be moving to North Carolina, if you have any information or contacts for that area, it would be greatly appreciated. Thank you."

I'll tackle that last part first. North Carolina has a lot of good resources, and I strongly suggest that you look up the North Carolina ASA chapter. Hook in with families there to find out more, specifically. It is really hard, I know, and it depends on the state, to get help for children after their late teens who have a milder form of autism. Usually, it's based on functions. If they're functionally able, they don't have access to certain services. But, you can continually have assessments to help counteract that not getting help when your child clearly needs it. In terms of financial, I don't know if this person is considered handicapped if he has a milder form of autism. If he's considered disabled, he should be able to have some kind of financial SSI. Often, at least in California, SSI also kicks in with Medical, so they have medical coverage and some money coming in. Education help is something you have to get on your own.

Its difficult, because I'm finding that I meet a lot of families where the kids are older, have Asperger's or high-functioning autism, and they work so hard to get their children through school, through the academic, and because there was so much work, they never had time for all the other stuff, like the social skills training, the OT, any kind of therapies that could be really helpful for real life issues or preparing for adulthood. What happens is when you graduate from high school, if you have a diploma, it's over in the terms of help you can get from special education under IDEA – the *Individual with Disabilities in Education Act*. That means you're on your own after you have a high school diploma. There's community college, but if they're unable to get help and are unable to function outside the house, that's really tough. I would look to see if there's any way you can get some kind of coaching for your child. It's pretty scary when I hear that he hasn't left the house in two years. I've known two or three people who never left their house. There's a psychiatric disorder or name for people who are afraid to leave the house. These people were not on the spectrum, so it's even harder if you have someone on the spectrum, because it's all those areas they need so much more help with.

Obviously, he feels much more comfortable at home than out in society. Something must have happened so he feels uncomfortable. Or nothing could have happened in terms of him having a terrible time in school, missing friends or feeling lonely, and he just feels more comfortable at home. But I would really be concerned about who is following that child or teenager in terms of medical care, or psychology. There should be some kind of job coaching available, and maybe that would help with some of those other areas like education. I wonder if he isn't leaving the house, he can't go to community college or vocational school, but is he able to learn things from the computer? There are things available from outside classes that might help him or provide a connection to the outside world.

Ernest: I've got a couple of questions here, and one of them is one from Pam in Dartmouth, Massachusetts. Her question is, "Can a high school, such as a vocational or agricultural high school, deny admission to a student because a student has a demanding IEP? My son has Aspeger's and requires one-on-one aide for writing notes, and I was warned that schools could refuse admissions because of that. Not that they will admit it is a reason, but he is a straight-A student with no history of behavioral problems."

Chantal: I'm not sure what school district this person is in, but technically speaking, if you move from one district to another, that district has to honor your IEP. Also, it depends on were those schools are located. For example, in our area, if my son wants to go to any of the schools in this district, he is eligible. But the thing is, he would be eligible for ones closest to his home if it's not for a specific program. For example, his school is Tory Pines or Carmel Canyon Academy. He is at Tory Pines. But, if he were someone who is not mainstreamed or integrated, he might have to go to a school that has a specialized program for him, which might not be the neighboring school. We're talking about a student, though, that is a straight-A student, who needs some accommodations. The thing is, I don't know from what the person is writing, are those schools within his school boundaries – within his right to go to those schools. If it's his right to attend, in terms of his address and if he's living in the correct school district, then there's no way that they cannot honor his IEP. Again, you have to know about whether the schools are located within the same area that he is allowed to go to, geographically speaking.

I know, sometimes it happens in school district, they're going to try to get out of something or a school's going to try to not have your child because of certain things. You just have to get through that and I would definitely check with the protection advocacy in your state to find out more. You can find out more about that particular school district in that way, too. Every state has a protection advocacy. It may not be called that, but you can start looking with those two words first. What that does is gives you free information about anything having to do with disability rights, or educational rights, and so they can answer that question.

Ernest: I have another quick question, a little off-topic, but it sounds like she really wants to know. She wants to know if you have any seminars scheduled in the St. Louis, Missouri area, this year?

Chantal: I worked in St. Louis two years ago! I keep getting asked lately about speaking in different places, and there is an organization which organizes seminars. They have two people back-to-back, one six hours one day, one six hours the next day. And that's how I'm going to Tampa – somebody heard me when they sent me to Orlando, and a few people from Tampa wrote to me and asked, "are you coming into this area, can you help organize something?" I don't have time to do that, but what I did was I handed the information over to this organization because they're very good, and respectful of the audience. Usually, the parent organizations and school districts are great, but I've had other companies like this send me places where they don't care about the comfort of the audience, and they're not very good about the person they bring in – you can tell they're just doing it for money. But this organization are the grandparents of children with autism and that's why they do this – to provide the best training for parents and school districts. They provide, also, the educational units. I'm going to tell you their company name.

It's *Spectrum Training Systems*.

Ernest: I've got another question here, maybe the last one. Jenny from Elgrove, California. Her question is, "My eight year old son has just been diagnosed with Aspeger's. We have had no problems with bathroom issues except for him sitting as opposed to standing when using the restroom. Is this common? Should we accept this or work towards standing? Thanks."

Chantal: He's sitting, and is eight years old. To be honest, I don't think it's that much of a problem. I'm trying to think of the future as well as the present, but maybe it doesn't really matter because when he goes out in public, as he gets older, there's always stalls with doors that close. It's maybe a nicer thing to learn than just standing up at a urinal. I don't think it's a real problem. If the child feels comfortable doing that, it's fine. In fact, I would feel more comfortable if I knew my son was using a stall instead of a urinal, but I've never heard of that being an issue for anyone. I know guys who are not on the spectrum who never liked using urinals and would always use the stalls. Maybe you have comments on that, Ernest!

Ernest: I don't! None whatsoever.

Chantal: I can hear you blushing on the other side of the phone, there.

Ernest: I have this other question here. It's a little off-topic but I figure we should cover it. Her name is Lisa, and she's a police/fire dispatcher for a police department. She feels that the police need better education on children with these issues, e.g. high-functioning autism. They are trained to be 90% on the defensive. Any ideas for training to be more understanding to approaching children and adults with special needs? Thanks."

Chantal: Absolutely correct in that this is an area of need. It's an area of need not just for recognizing children with autism and adults with Asperger's in terms of potential suspects for something, but also for victims. I've been in the system – someone I know was a victim, but even as a victim, he was not getting the full rights that a neuro-typical child would have because of the autism. What I suggest we did on a state-wide level, we managed to get it written so that the police are supposed to get more training, but who knows when that's going to happen with the way the financial situation is in the States.

There are people who go around and do training. Dennis Debbault is a good resource. He goes around and does training, and used to be a security officer himself. But the police love him, so they do training. But he also makes videos that he sends around – training programs. I would contact someone like that, and if you're already in the organization, either in the police or in the firemen, it's easier to get it in as a parent of a child with autism. For example, here in San Diego we have as a member of our ASA chapter, a fireman who has a child with autism. He is the one who convinced the firemen and police department here to bring in Dennis Debbault and do training. There is a lot more training available, it's just as this person knows from working, that firemen and policemen, and all these kinds of people who are there to protect and help us, they're over-worked and over-booked. It needs someone who has a passion for it, like a parent who is in the forces, to bring in the training.

Ernest: OK. I've seen things written, such as cards for kids, where if the police officer sees the card, it instructs them as to what to do and what not to do.

Chantal: If you go to the *National Autism of Society of America* website, you can get those from them.

Ernest: Yeah, I think you can print them off from the computer or even send for them.

Chantal: I wanted to name the company: it's *Spectrum Training Systems*. So you can always write to them and ask if they're going to have me in St. Louis.

Ernest: We're coming up on about three minutes here. I'm going to extend it for a few more minutes. Maybe you can pick one, there's just so many here.

Chantal: Here's one from Carrie in Knoxville. "My son is three years old and recently he has got where he doesn't like to see or hear his videos or songs for kids, but he does in his class at school. He is in an early intervention program, and gets very upset if I try to play his music or video. He scratches me on my arms. What should I do?"

This could be a couple of things. It's interesting, because normally they like to hear the same things over again. Maybe he's fed up with them and wants something new. I'm not quite sure if the son is still tolerating the same videos or songs at school, it's just that he doesn't want them at home. Or is it that certain videos or songs for kids that he doesn't like at all, anymore? Maybe it's bothering him – a certain pitch. But that's no reason for scratching someone on their arms. I'd suggest that the music and videos are the things which should be optional for someone, and it's not worth forcing someone to listen to that if it's going to make them scratch you. But obviously the scratching is trying to communicate that there's something he doesn't like about that. I would try and find other tapes and videos, and maybe he's just all of a sudden sick of them.

Ernest: That could be. I've got one last question, and I'll take it because I think it's pretty topical here. It is, "I'm new to this. What exactly is involved in a sensory integration evaluation? What happens after the results are received?"

Chantal: Good question. In a sensory integration evaluation, the occupational therapist who is trained would be observing your student or child, normally in a variety of environments. So visiting them at school, or at home, possibly. If they have a clinic, they probably would also see them at their office, but would have to see them in at least one other environment to see how the person reacts to what's around them. I can't say exactly what kind of things they do, but they look and see how their fine and gross motor skills are, and their reaction to noises and light, by observing their behaviors. If they're verbal, they'll ask them questions. They'll also interview – usually very thoroughly – the teacher and the parents, and ask them to respond to questions on a form, so they can answer what they see the child acting like in certain situations. That gives a lot of information, as they may act way in one environment and one way in another because of environmental issues.

Once an assessment is written up, the assessment should say what areas the child is having challenges in, and then it should come up with the conclusion of what can be done to help, in terms of how many hours of therapy, or does the person need sensory integration, does the person need auditory integration training? Whatever types of things the person thinks would be good for the child, and recommend them. Then, there should be an IEP meeting to go over the assessment and then a plan put together of what's going to be provided by the school district for this assessment.

Ernest: OK. I think that ends the call tonight, but before everyone goes, first step is I want to thank Chantal once again for giving us this great talk. This has been a wonderful call on sensory integration as well as answering generic questions about autism. What Chantal has done is handle this call really well for us, and I certainly appreciate it. We all thank Chantal for taking the time to do this.

Secondly, I need you to do something for me. I know you've heard this call for two hours, and would really appreciate your feedback. Often, we need to get new speakers, or convince other people to come in and join us. We'd love to have you tell us what you liked about the call, what you'd like to see different. Is there any subject you'd like to cover that we didn't cover tonight, that we could put on a future call? Just tell us what you liked about it. We'd love to get your feedback and your testimonial. Is there anything that you heard that was an "aha!" moment that said "I'm going to do this, this is the takeaway that I have". The feedback that I want you to give me, you can give to me directly over the phone.

The number is 877-211-0212. This number, you dial and you'll hear a message. Press one, and you can go directly where you can record what I just asked for. Tell me your name, your email address if you can, and what you thought about the call – what things you liked about it, was there an "aha!" moment for you, was there something you can say that you would say to someone to recommend this to someone else, for example? Just give me your feedback, I'd love to hear your testimonial.

The number again is 877-211-0212.

That's the call tonight. That's it come to an end. We have one more call this month which is on autism and insurance. We have a woman who is going to be talking to us about how she was responsible for Ryan's Law. Her son is named Ryan, and she fought the legislator in South Carolina to get the insurance companies to cover certain types of treatments in autism. She's going to tell us stories; it's very exciting. It turns out that Chantal is going to be the moderator, so it should be a lively call. Two great people just talking about autism and talking about how they were helpful in getting this rule passed for her child.

Once again, Chantal, thank you so much. And to all, goodnight.

Chantal: Thank you. Goodnight.

Ernest: Goodnight.