



Autism and the Holidays: Lessening the Stress and the Expectations, while Maximizing the Enjoyment

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Moderator: Chantal Sicile-Kira

Guest Speaker: Esther Hess, Ph.D.

Chantal: Hello, and welcome to the *Moms Fighting Autism.com* webinar. This is Chantal Sicile-Kira, your moderator, and I am happy to announce that my guest this evening is Dr. Esther Hess, and our topic is, **Autism and the Holidays: Lessening the Stress and the Expectations, while Maximizing the Enjoyment.**

Dr. Esther Hess is a Developmental Pediatric Psychologist, working in the areas of Child, Adolescent and Family Therapy and Developmental Delays. She's an expert in her field and she has over 30 years of experience. Welcome, Dr. Hess. How are you?

Dr. Hess: I'm doing fine, Chantal. How are you?

Chantal: Good. You have a very impressive resume, or curriculum vitae. I wanted to hear a little bit more about your background. You have over 30 years of experience. You have quite a bit of academic experience as well. I understand that you studied under Dr. Greenspan?

Dr. Hess: Yes. Dr. Stanley Greenspan is my mentor, and has been-- I've actually been his Senior Clinician on the West Coast, for about 30 years now. I actually was introduced, by Dr. Greenspan, through my father, Dr. Leon Cytryn, who himself is a Child Psychologist in the Washington, D.C. area. How I got associated with Dr. Greenspan, is there was a period of time when, way back when, my dad, who is considered the-- I guess at this point, the grandfather of childhood depression, said, "You know" (when I was trying to decide what area of expertise I was going to go into formally, after I got my Ph.D.), he said, "You're very good with kids." He said, "I foresee the next kind of main and onslaught of childhood issues being autism." This is before it sort of hit the papers. And he said, "I have a wonderful gentleman, who at one point in his early, early career was one of my students, Stan Greenspan. He's somebody to really listen to and follow. So if you can take the time to go back to Washington, D.C. and follow him, it's worth your while." So my dad has always been, I guess my original mentor. And I followed his advice and met with Stan and his partner, Dr. Serena Wieder and they became both friends, colleagues, and certainly mentors. I became an expert in the field, using a method of intervention for kids with developmental and regulatory disorders called DIR/Floortime.

Chantal: And for those listeners, who are not familiar with that, would you like to explain a little bit about that?

Dr. Hess: Sure. Floortime is a developmental relational approach that asks you to think about three things when you're dealing with a child. First off, most of the kids that we are working with are young adults, even at this point. They are often younger than their chronological age, so that you join a child, or an adult, or an adolescent, not where they are necessarily chronologically, but where they are at that moment developmentally. So that's 'D' for DIR. Then you have to ask yourself, "Okay, well, what is the 'I,' the individual neurological difference that could possibly be fueling some of the complex issues that are making the development not at its optimal level?" So then it's our sensitivity to be aware of things, such as sensory processing issues, for example. Then through our 'R', through our Relationship, we have to support those individual differences and thereby helping the child, or the adolescent, or the young adult, move forward, in terms of moving them to the best place that they can be developmentally. So that's DIRI. Once you figure out where a child or a young person is, then what you could do is you start-- You could start the involvement, the play, and that's Floortime.

Chantal: Great. You also have a lot of experience in other areas, not just with autism or developmental delays. You have divorce issues, with lots of different areas. And, in fact, you're now the Director of the Center for the Developing Mind, in fact?

Dr. Hess: Right. Exactly. About a year and a half ago. Well, I have been sort of the speaker for the Center for the Developing Mind for more than 30 years that I've been here in the Los Angeles, California area. My families have continuously said to me, "Dr. Hess, can't you help create a one-stop wellness? Because we are constantly schlepping from interventionist to interventionist to interventionist all over the city. Not everybody talks to each other or they take days to get back and forth. Can't we have one cohesive place where our kids can get help?" So we listened. With my husband and business partner, Allen Samson, I created the Center for the Developing Mind, which is just that one-stop wellness, that cohesive treatment facility. It's a multidisciplinary treatment facility for kids with developmental delays, as you had suggested, but also kids with regulatory issues and other concerns. We treat kids with Attention Deficit, with Bipolar Disorder, a variety of different learning issues, trauma. We have a specialty for children who are burn survivors. We have

kids who come in because they have concerns associated with, as I mentioned, parental divorce.

I also have a secondary specialty, that happened about 15 years ago, called Selective Mutism, which is an extreme form of social anxiety, social phobia. We treat all those through myself, as a mental health interventionist. We also have occupational therapists, physical therapists, speech and language, educational support. We have a home-schooling option; a vision therapist; a neuropsychologist, a feeding specialist, a Geneticist onboard now. Basically, you name it, and we have what it takes to make both the child and the family feel that they're getting as much and the maximum amount of support possible.

Chantal: And that brings us to an important point, in the fact that autism is autism, but it's not just a concern for the child. It affects the whole family, so your practice is really looking at the whole child. I know that you don't deal just with autism but the fact that you do deal with divorce and all these other issues, as well as children who have other types of challenges that they are facing makes a lot of sense. There's a lot going on in autism families.

Dr. Hess: Right. Our Center, we treat from birth to the age of 22. But as you very accurately suggest, I have never met a child who lived alone. To myself, it just didn't make sense not to deal with the family as a whole. Certainly when you have a child who has as profound a disorder as autism, it absolutely impacts everybody in the family. I just felt, and after working so many years with children and their families, that we had to create a cohesive package.

Chantal: Right, which kind of leads us to our topic today, about **Autism and the Holidays: Lessening the Stress and the Expectations, While Maximizing the Enjoyment.** Just talking about holidays, in general, without even thinking about having a child with special needs, or with autism. Holidays are stressful because of all the inherent expectations that people have about getting together, about the gift-giving and all these other things. Do you want to talk a little bit about the stress of holidays? Not even thinking of the autism aspect.

Dr. Hess: Oh, absolutely. Absolutely. I think first off, whether you're following the media or you have your own kind of homespun memories, or ideas, or wishes. I think we all have expectations that often are not very realistic, in terms of what the holiday is supposed to present.

Then you get together with family and oftentimes all these expectations, which are often unrealistic, sort of come crashing together and people feel, at worst, disappointed; and at best, sometimes they just feel that they can't believe that the experience happened and they don't know kind of what went wrong. It just can really start off-- It can make the end of the year terrible and start off the beginning of the new year in not the best of ways. So I like to really help my families prepare appropriately. I mean, I start talking about holiday time really around the time of Halloween. Because for a lot of our families, starting about Halloween all the way through the beginning of the new year can be a very stressful time.

Chantal: Right. I actually was speaking with friends earlier this week, in saying that there should be a way to change things so that Thanksgiving, which is actually my most favorite holiday, happens like three months before Christmas, so you have time to like recuperate.

Dr. Hess: Right. Right, right, right.

Chantal: Then you can actually enjoy all the things that you should be doing, or need to be doing before Chanukah or Christmas or whatever season that you're...

Dr. Hess: You know, Chantal, I think you can enjoy it. I think really though, what it takes is a different kind of planning. This is when I go ahead and I share with my families. You know, regardless, in terms of why children are having the issues, I try to get families to understand what and why the child is struggling and then how we can sort of circumvent that by us thinking ahead and planning differently. Then, even the fact that there's only about a month between Thanksgiving and Christmas, I think we can really plan for some really wonderful times together.

Chantal: Great. So that's why I'm glad you're here, because we have plenty of questions.

Dr. Hess: Okay.

Chantal: I'm going to start asking you some of them, if that's okay. But before I do that, I would like to ask you, do you have a website that people could go to for more information about your practice and find

out more information about yourself, and also speaking engagements that you may have?

Dr. Hess: Absolutely. You're welcome to go onto my website for our Center for the Developing Mind, and that is *www.CenterForTheDevelopingMind.com*. And you can see the upcoming presentations. We've just actually returned from Utah and Colorado. And in the first part of January, we're actually going to be going to the state of Florida. Then, actually before the end of that month, we're actually going to be going also to three cities in North Carolina.

Chantal: I noticed that you're going to be in San Diego.

Dr. Hess: I will be in San Diego, as a matter of fact. I will be in San Diego through the University of San Diego's extension program, both in November of 2010 and January of 2011.

Chantal: Oh, okay. So that's a little ways down the way.

Dr. Hess: It is. It is. We were actually in San Diego just this past September. I'll be talking about DIR/Floortime and as it impacts sensory processing disorder.

Chantal: Right. And that's a big part of the holidays. We're going to talk about that as we go along, I can tell, from many of the questions that we have. I'm going to get started, right now, with a question from Carrie in Saginaw. "What can I do to help my son, who is a 9-year-old Asperger's child, deal with the break from school? Because this is a less structured time, we seem to have a lot of outbursts and screaming that goes on. I also have three younger children: twins, who are 6 and 5, who do not like to have the downtime to do what they want." [Actually they do like to have the downtime.] Here this mother has the concern, because she has three younger children, including twins, who like the downtime. Then you have a 9-year-old Asperger's child, who does not deal well with the break from school. Any suggestions to this poor mother?

Dr. Hess: Absolutely. Well, first off, I have to give a lot of validation and empathy, that you are experiencing a very real problem. Because what fuels your three younger children absolutely is the antithesis for what makes your 9-year-old comfortable. The problem oftentimes in families, where you have both typical and atypical developing kids, is a lot of times, the world does go around the child who is not typically

developing. So what I like to do is, first off, keep in mind this sort of philosophy in DIR. In other words, and particularly, you know, even though your 9-year-old is chronologically 9, because of his Asperger's, he's probably developmentally somewhat younger. So I say to myself, "Okay, so what is that I? What is causing him to have that problem?" There could be a multitude of issues, in terms of sensory processing, delayed auditory regulatory issues, visual spatial issues, which we can talk about. But really, I think to myself is, "transitions are really, really tough." And what you state in your question is that the break from school is hard is because the rhythm and the structure, which are so important for our kids, who are on the spectrum, is missing. Consequently, their anxiety goes up a lot. So one of the things that I'd like to do is first, I'll try to understand what's going on, and then how do we go ahead and create both a structure for your son, so he can feel better? But at the same time, still acknowledge that there are three other sibs who have different needs.

So one of the things of what I would like to suggest is to go ahead and create a calendar, a very concrete calendar with your children, with all of your children actually, but particularly the child who is the 9-year-old with Asperger's, about what to do during the holiday time and how we're going to break down the hours. However, in those hours, we're also going to have a special time where we can have free time that can be included, where the younger children can do what they want to do as well. Now if that particular time is too difficult for the 9-year-old to join (I don't know, again, what the resources are in this family's home). Whether there is a sitter, or an aide, to go ahead and lend support, whether he needs to be home with a sitter, or could he come with somebody who could give him physical support while mom gives attention to the other three. But what I find, if you create a map, particularly a visual map. That that gives a lot of support to our kids on the spectrum. Then I even like to add another piece. It's sort of a kinetic portion, that sort of validates and gives proprioceptive input, which actually helps reduce anxiety.

I have a place where the child sort of clicks off. You know, like sign off, check off, or erase. What is the item that we've just accomplished? So let's say we have a program that we run from say 7 in the morning till 5 in the evening, which includes the activities that we're going to do. And the only thing, it doesn't lend itself to be with some spontaneity, although you can sort of build it in, like "From 3-4:30, one day, we're just going to have free time that can be decided by brother and sister. During that time, you can do X, Y or Z." Once a child sort of has a

physical representation of what the schedule is going to be, they usually calm, because the anxiety is reduced by having that sort of concretized, predictable kind of element to their life. They're pretty good about following the routine and tolerating, even when they are doing things they might not often appreciate, like giving credence to his two younger brothers and sisters free time activities.

Chantal: Right. Do you suggest in there, because I've always found, especially when you have numerous kids, that sometimes things happen that you can't control. You know, like the schedule changes?

Dr. Hess: Sure. Sure.

Chantal: I think it's a good idea when you have schedules, to always-- I always suggest to parents and teachers at school, on the bottom of every schedule or planning, is the comment, "Sometimes the schedule has to change" or "Sometimes the schedule changes." Because you don't know. Things happen.

Dr. Hess: Exactly. As a matter of fact, Chantal, I would even add to that. If the parent can even take one extra step, what I like to do and for many of our families, I like to have them construct a social story, you know, with their child before the holiday starts. Like something doesn't have to be very long, 4-5, 6 pages maximum. Basically the title can be, "We're about to take a break for Christmas" something like that. School is going to end and you're going to have a little calendar on December 14th and then I'm going to have two weeks off. And he's got another picture with a calendar, and again, somewhat, "Mom and I are going to make a schedule." Then inclusive, exactly what you've said. "Sometimes, even when we make schedules, things change" (and here's the most important phrase) "and that's okay." This is sort of based off of the work of Carol Gray, who came up with this idea of Social Stories. Again, when she found that kids could participate in the creation of their stories, and with the understanding that things, life does change. If they could see it already and kind of anticipate and have something concrete to hold in their hands and to visually take in, they were able to sort of calm their bodies and relax and feel things are a little bit more predictable. Because even change was something that somebody had talked about ahead of time.

Chantal: Right. That's right. It's really all about them getting used to the idea, or preparing themselves mentally and emotionally for what's going to happen next.

Dr. Hess: Exactly. Exactly, which is somewhat, which you were talking about how basically from Halloween on, we've got a lot of changes going on for us as well. One of the things, besides from [you don't have to be on the spectrum]. Kids take their cues off mom and dad and mom and dad are feeling too stressed because there's a lot of money that goes out for the holidays, or the parents feel that they have to have enormous kinds of expectations or the kinds of foods that they have to prepare, or their house has to look a certain way. They are stressed and can't sort of keep it together. The children pick up that underlying unconscious cue and they kind of get as riled as the parents. So one of the things I talk about also is the parent self-care and kind of lowering your own expectations for making whatever that means, "a perfect holiday."

Chantal: Right. A good point. Okay, here's another question from Sandy in Wisconsin. "I have a young adult that stresses majorly over the holidays, with the questions like: 'Who is coming? How long will they stay? What are we going to do? Then what?' Other than medication, what can I say, as I don't have specific answers to all of her questions?"

Dr. Hess: Okay. Well, first off, I want to acknowledge the fact when it comes to young adults, we have been working for multiple years on helping children, young children with autism. And then people have discovered, 'Well, you know, all these young kids that we've been helping all these years, they still need support.'" So now there is a larger push to go ahead and get individuals involved to help with the transition issues that young adults have to deal with. As a matter of fact, I was asked to be on a Task Force by our Governor for autism and related disabilities. My specific specialty is early identification and early intervention. My husband, Allen Samson, who I mentioned, is also my business partner, with our Center, is actually a specialist in adults with developmental delays. He's on the same Task Force but deals with these transitions, particularly for adults who have moderate to severe forms of autism and helping them find the next stage of their journey, in terms of both getting help and finding appropriate transitions to creating an optimum world in adult developing.

Getting back though to the actual question, what I see here, again, is that this young adult is stressed over the holiday, again, because things are different. So consequently, their anxiety is up. I'll go back to my DIR format. 'D,' even though this young man is-- The question is that this is a young adult, meaning that he's acting more childlike. Because when

anybody has an anxiety, they all tend to regress. So I have to sort of respond to this person, not like maybe a young adult of say 22 or 25, but maybe kind of a younger person, who might be more like 14, 15, 16 and give a lot of support for that anxiety. So again, what I'm doing-- I appreciate the fact that this parent doesn't want to necessarily go through the medication route. Again, what I like to do is create a more sophisticated, a social story, about the fact that things change over the holidays. When things change, I have a lot of questions about what's going to happen, and sometimes I don't have all the answers, or mom doesn't haven't all the answers. Again, the buzzword is, "and it is okay." But what we try to do is say, "Let's figure out as many questions as we can." We write them down together. In other words, we'll go ahead and we'll say, "Well, who's going to be coming over?" And put that answer. "And how long are they going to stay," and so forth. Then that's concrete.

We'll put that up maybe as a visual map, someplace comfortable, in the individual's room or perhaps in the kitchen. Then when the person becomes to persevere a little bit, because oftentimes, obsessive-compulsive issues often go hand-in-hand with autism. This, again, is a reflection of just anxiety. We can go back and say, "You know what? I think we have some of the answers. Let's see if we can find them." It takes a lot of extra patience on the part of the parent, because again, we have to have a lot of compassion for the fact that really what's talking is not incessant questions, but it's a reflection of the underlying anxiety. Then, when the person sort of does see the answers, usually, again, because they have that visual tracking, they can begin to sort of calm and organize, once they see it in written form.

Chantal: Right. And it's something they can refer back to as well.

Dr. Hess: And often as they need to. Exactly. In fact, that's what I often do. I say, "Well, let's go back to-- Oh, look. You know what? That's exactly question two, that we answered before." Again, and I reference it. Say, "This is something that you can look at any time you need to, in case that question comes up again."

Chantal: Right. Good point. Okay. Another question from Bonnie Sedan, in Brigham City, Utah. "How do you minimize the 30 days of harassment? 'Can I have a present early?'" That's the kind of question this child-- I don't know how old this child or teen is. "We don't put presents under the tree, because he cannot leave them alone. We don't keep

presents in the house." What suggestions do you have for minimizing the 30 days of harassment?

Dr. Hess: Ah-hum. Ah-hum. Again, these are all reflections of very similar questions. Kids get very anxious when there's change. Whether or not you don't want to-- You know, I have families who used to put their Christmas trees up right after Thanksgiving, and now they may put it up two days before Christmas, because it was just too hard for having all that stimulation in the house.

Chantal: This person's focusing on the presents actually.

Dr. Hess: No, I understand. I understand. But you see, the point is though, I'm not sure child-- However this child is, they're making the association with the presents. I don't know, for instance, if there's a visual stimulus, like a tree already put up.

Chantal: Right.

Dr. Hess: So one of the things I would suggest is perhaps to wait, you know, as long as you feel comfortable doing so, not to put up the tree. Because that might be the cue for the child, "Oh, tree means presents." Then what I would do, again, is-- A lot of our kids get great comfort out of that visual map I'm talking about. So come up with a big-- You can go to Staples or any kind of office or party store and come up with these big wall calendars. Go back to, "Here's 30 days. Here's from Thanksgiving to Christmas." Then to say, to actually mark the days down and say, "Let's take a look when we're going to start getting presents." And go, "Oh, look." You know, again, whatever the holiday tradition is, whether you do it-- You open presents Christmas Eve, on the 24th," or do it on the 25th; or if you're Jewish. You know, "Here, this week, you're going to be doing Chanukah." I don't know, again, if you're going to get a present a day, or one present for all the 8 days, whatever. This is something that you, as a family, decided, "This is the day." And then somebody says, "When am I going to have it?" Say, "Let's go back to the calendar."

Again, this is something very similar to what we just answered in the previous question, that the person can reference as often as they need. And if somebody says, "Well, when's presents?" Say, "Well, let's go check and see when is presents?" It may not make the question stop, but I think it'll start-- The person has a different way-- This young man, or a

young woman, has a way to have some sort of organizational cue, by being able to say, "Okay, fine." They can even check off the day. You know, have a marker there. At the same time, you can also be self-reflective. It's really, really hard to wait.

The other thing is a lot of times, there are kids who just like the experience of like tearing off the wrapping paper and this kind of thing. So one way that I-- I have, as I mentioned, at our Center, we have different categories of occupational therapists and physical therapists. They have taught me, personally, that to be really sensitive of the fact that a lot of times, it's very hard for our kids to wait and they're experiencing a lot of anxiety. One way to organize is to give them different kinds of pro-preaffective activities. I like to-- There's a catalog company that I like to get-- There's a variety of different koosch balls [K-O-O-S-C-H, I believe is the spelling.] The company is called Oriental Trading Company, and it's not a diversion for this company. They just happen to have a variety of different koosch balls that I like to give. They're out of Los Angeles, California. Sometimes I will say, "You know, it's really hard to wait." But when I squeeze a koosch ball, and different kinds of pro-pre-- I have this input when I'm chewing gum, or when I'm sucking on a lollipop, these are different ways to sort of calm my body and organize. When I'm visually looking at my calendar and maybe I'm chewing some gum or squeezing my koosch ball, I can-- And I'll work on deep breathing, different kinds of relaxational techniques. It's just a little bit easier to wait until the day we can have those presents to open, but it doesn't mean it's going to make it easier. We're basically teaching tools to wait and to help with tolerance.

Chantal: I find that the opening to presents, from the people that email into me, written on this topic, has to do with sensory stuff, as you're talking about. But also the fact that the sensory aspect, where they just want to twiddle with the ribbon, so they stop from opening the present, which can be a very big disappointment when you're out with relatives. So other suggestions, as well as taking care of all this sensory stuff, is to actually practice unwrapping presents, so that they know that their much favorite object in the world is actually wrapped up in that box?

Dr. Hess: Right.

Chantal: They're going to keep going till they get to that object. If you practice that a little bit before going, that also can be helpful.

Dr. Hess: Absolutely.

Chantal: You know, if they're getting stuck on the ribbon, they'll need, as you say, all that sensory stuff.

Dr. Hess: Absolutely. I think that what you're reflecting Chantal is really to go ahead and do role-playing, which I think is a huge piece to all the questions that are being asked this evening. A lot of times I'll have different experiences with families that come into my office and we'll practice opening presents or waiting, or what it's like when you first have all the rhythm of school and then that stops, or the rhythm of work and that stops. How do you tolerate different transitional issues? And we'll practice different strategies, what to do when. That is actually is a very organizing, because then a child can kind of, again, go back into their minds and say, "Oh, now I have sort of a script to know what to do."

Chantal: It's important to remind people too, that a technique may seem like it's not working because you're not getting immediate results, but the point is that even if it doesn't work 100% this first holiday season, if you begin the next time, they'll remember back from the last time. Over time, it does become a strategy that works.

Dr. Hess: Right. I think this is also as much for families as it is for the individual who's impacted. Because the truth is, I think parents often feel helpless, especially when the children are in the middle of a meltdown or whatnot. Basically we're giving alternatives to giving them the actual tools, to say, "You know, you can do this, that and that." You can do role playing. You can create visual maps. You can go ahead and give pro-perceptive input, all these things so that there are active strategies for parents, themselves, not to feel so helpless in the midst of a child's meltdown or incessant questions or intense anxiety and so forth.

Chantal: Right. Now I'm going to switch more to another question, which has to do with actually the behavior of the child and the expectation of other family members that are around for a celebration. But before I do that, I'm going to read a little something from what I wrote about the holidays, that parents in the autism community, we often joke that we become more religious during the holiday season because we pray our children will behave while we are visiting relatives. We will pray that they will show interest in their gifts and not just the ribbon. We pray that they sit at the dinner table. We pray that they don't hit the relative who tries to kiss them. And above all, we pray that we all have the strength to politely ignore that judgments happen less to misbehaving children. I

guess we all do become a little more religious during the holidays. So here is a question from Julie in New Baden. "How should we go about letting family members, who aren't so close, know why our son may be behaving in a certain manner? Also, is it appropriate to ask family members to lower their voices when speaking to our son? It's such an overwhelming sense for him? You know, such as at a family reunion or a dinner with lots of people present during the holidays?"

Dr. Hess: Sure. Well, first off, I want to applaud. I love your religious reference, because I think we do pray a lot. I think parents of children with disabilities pray all the time, and particularly to try to-- You know, everybody wants to have a feeling that this holiday season, my child will act a certain way. This sort of leads into how to deal with extended family. One of the things I'm recommending, again, is that for me, spontaneous does not work. You know? Meaning that you really have to-- We're talking here and now about helping to prepare a child for the upcoming holiday season. What I'd like to do is also prepare family. One of the things is that you have the right, as a parent, to choose the kind of events that you will expose your child to. If the event is too large, you (A) have the right not to go; or you have the right to leave in the middle, if it feels to you that it's becoming overwhelming, (A). (B) I like to go ahead and either phone call, or meet, or email the families I'm going to be getting to. Sometimes I do just a universal email to the families that are going to be at a certain event. I explain to them, well ahead of time, what's going on for my child, which is a big deal. Because I do have families who, so to speak, who have never come out of the closet, in terms of the issues for their child, and either don't take the child at all, and sort of hide that feeling; or have never shared this. So the child will act out and parents, you know, the family members will point, or whisper or want to know what's going on, and then the family feels terribly humiliated or embarrassed and so forth.

Again, I'm a big believer to alert people to what's going on. One of the difficult pieces is sometimes family members don't believe that an issue is there, or have a hard time. What I say to my families is, "That's not really your problem. You know? If a parent, a grandparent, you know, Great Aunt or something is saying, 'No, no. You just have to be tough around this kid.' Or 'You know, when I was raising children, there was never such a thing as autism,'" and so forth. Certainly, we are better diagnosticians now than we were say 50 or 60 years ago. It's very likely that no one talked about the word autism when this Great Aunt or somebody was a parent themselves. But along those lines, is that's not

your problem. Your problem is to explain the situation to the extended family and then also give active suggestions (kind of your own wish list), how you would like the evening to go. It is absolutely okay to say, "My son, aside from experiencing autism, is experiencing something called Auditory Processing Disturbance, meaning that loud noises really bother him. I may ask you to sort of lower your voice when you speak. Speak a little bit slower when you're speaking to my son, because he'll appreciate that. He may not like it when there's a lot of people kind of making an onslaught for him, because it'll feel kind of overwhelming."

You do have to be an advocate for your child, giving them those kind of parameters. Usually I have families who will tell me after the holidays, that their extended family really appreciated the heads-up and were trying to be very, very respectful. When I have families who just absolutely won't listen, what I say to the parents is, I say, "Well, then you have the right to leave." And you can also share that before that's going to happen, and say, "If I feel that my child is in a position where he just not that comfortable, we may leave early. I want you to know it's not because the food is not good or we don't want to be with you. But my first job is to be an advocate and protect my child." And so I think if you... Huh?

Chantal: I'm sorry. Go ahead.

Dr. Hess: No. That's sort of a longwinded answer to a short question. Basically, you have the right to protect your child. I think if you give enough information ahead of time, then it's up to the family to decide how much they're going to take in. But you've done your job, in terms of being the best advocate that you possibly can be for your child.

Chantal: Another suggestion I always make is to ask if there couldn't be like a quiet room, that's childproof? If the child needs to retreat for some quiet time, you know, to escape from the commotion, the noise.

Dr. Hess: Absolutely. It's a great idea. Yeah, absolutely. As a matter-- In fact, I helped a family create that because they-- We actually went to the grandparents' house ahead of time because they were planning on making the big Christmas tree and all the decorations. The mother was afraid that that would be just too visually over-stimulating for the child. So what we ended up doing with this particular grandparent is that we also had a safe room for the impacted grandchild. And that when things got a little bit too over-stimulating, then that child was given the

right to go out, with adult supervision, at this particular time, to get comfortable and then when they felt able, they were able to go back and forth. There were no problems, because everybody had sort of been cued in as far as the kind of route this young man would take, so he could feel comfortable and still participate to the best of his ability into the party celebration.

Chantal: Right. It's important to note, also, you know, you talked about it earlier. About how we think a lot about the kids, but we need to be thinking about the teens and also the adults as they are growing up. Sometimes these sensory challenges can get easier as they get older, but sometimes they still impact them in some way. Some of these suggestions or things that are going to be useful or need to be carried out even when they're older.

Dr. Hess: Oh, absolutely. I mean, if you think about it, Chantal, we all have regulatory issues. You know? We just mask them a little bit better. If you go to kind of a boring lecture, people will tolerate it by maybe taking a walk and getting a drink of water and coming back. Certainly people smoke as a way to get a different kind of oral input, and sometimes it's a way to kind of negotiate a difficult time. You know, for child and adults, who have issues, sensory issues for instance. It's not that these issues are going to actually go away, but we have to sort of make it socially appropriate for them, so that it becomes also developmentally appropriate. Can I give you an example? It has nothing to do with the holidays. It has to do with being an adult.

Chantal: I think these sensory things are very important and going to make comments again after this as well. But please do.

Dr. Hess: Okay. So I share a story often. I mentioned, you talked about my upcoming presentations. I speak both nationally and internationally on Floortime. In part of one of my lectures, I mentioned recently a very pertinent example to what we're talking about, as far as the young adult. I had a very high functioning individual, who I had seen for many years, all through her high school. Now she was about to go on to a university. She was a very bright young lady. Now, she had organized, by hiding her baby blanket in her backpack all through high school. She felt somewhat ashamed by that, but she also realized that she needed that sensory input to feel comfortable, particularly when she got stressed. You know, social situations were very challenging for her. So what we decided to do together is she brought her baby blanket into the

office and she-- It was really an honor, because she allowed me to be the keeper of the blanket basically. What we did is we cut up the blanket in 40 different squares and we contacted this Oriental Trading Company and asked for key chains. And we made basically key chains, like I think Koosch balls. I gave them the ideas because they have koosch balls on key chains. I took the baby blanket and we put that in the center of the key chain. Basically what happened is we created a sensory repertory device, not unlike say a rosary, where any time that this young woman would get stressed [-- and she did often in a university. It was challenging in multiple levels --] she could go ahead and rub it between her fingers, and that really calmed her. Now, she could also have, attached this key chain to her belt loop or her backpack and then every time the blanket piece would get worn, and it often did, we would go ahead and interchange the next piece that we had. She was successfully able to navigate Junior College initially and then on to a regular university program.

Chantal: Well, what's going to happen when you run out of the 40 pieces?

Dr. Hess: Well, we were able to train-- That was the nice piece. The point was this. This is a need for her, and so we sort of sophisticated that. After we started getting though about half of the pieces, she and I went shopping together. We decided it was okay to have something that felt like her baby blanket, but something that she could use at other times. Eventually, what we were able to do was to find material in a like a fabric store. She was able to-- We worked on this, because she had initially some small motor issues, and these are things that she, herself, could make up later on, on her own. Meaning this. Her sensory needs didn't necessarily go away, but she was ultimately able to do things to help herself, so that she could regulate in a world that did oftentimes cause her a lot of stress. We don't discount the fact that these sensory needs exist. We want to create different strategies that are more age and socially appropriate, so that it lends support to these individuals, so that they can succeed at their optimal level of development and capacity.

Chantal: Yeah. And you know, this is a little off the topic, but again, it relates to our kids, whether they're young or they're adults. But that California Task Force, that you were talking about, I'm actually co-chairing the Task Force for the three counties here: San Diego, Inland and Imperial. So one of my big concerns, or thoughts about the transition and the training and employment, that's one area where they're not really

taken into account yet. The sensory issues, and so I think that's a real important piece that I hope that this Task Force, the workgroup in that area can help remind people of, because it is-- As you say, it doesn't just go away as they get older.

Dr. Hess: Right. And we have to just sort of help people understand that these issues do continue to exist, but then, you know, be more creative in our strategies that are age appropriate.

Chantal: Right. And also, that's part of the whole issue with employment.

Dr. Hess: Ah-hum. Exactly. Exactly.

Chantal: I've helped some individuals, where they have Asperger's and they love their job at a hotel, but they couldn't work more than two or three days in a row. They needed like the day to recuperate and people thought that they were having a bad attitude. But once you go in and you explain to them that they actually needed that time to recuperate from all the sensory sensations and the overload that was really taxing them, they had the best employee ever. You know, they were able to work out a schedule...

Dr. Hess: And... I'm sorry. Go ahead.

Chantal: ... that was able to accommodate this young man, in that situation. It's just another example of how sensory issues can create a situation where people can't work somewhere. But sometimes when people know about these things, they can work it into the situation.

Dr. Hess: Right. And this is what I'm talking about, going back to the holidays thing. When I have a lot of situations with families, and once the extended family is sort of told about this, they generally are more, than less, accommodating. Because they go, "Well, now, at least we know what to do-- what's going on." Then generally the next question is, "Well, what can we do to help support?" So some of the things that I have to do is help my families get comfortable with the telling of that something is going on for their child.

Chantal: Right.

Dr. Hess: And I think that's part and parcel to, you know, how to go ahead and make the holidays a positive experience for everybody.

Chantal: That is a very good point. Because a lot of times, people do not feel comfortable telling. But you're right. You have to be able to feel that confidence that you have a right to make these points.

Dr. Hess: Ah-hum. Absolutely.

Chantal: Okay. Here's another question, and this one's from Jerry, in Orlando. "The holidays are always a time of stress, but especially since our adopted autistic son joined our lives. One therapist suggested we not decorate as much for Christmas, since the disruption is probably causing the negative behaviors. We include him in the decorating and explain the reasons, but is there more ways of helping him cope without changing our tradition? His brothers love helping to decorate, and we'd be disappointed if we changed."

Dr. Hess: Okay. Well, we began to sort of address those issues. The first thing I would do is sit down with brothers, because there's a lot of different pieces that are going on. One is the fact that this family has adopted an autistic child. I don't know if they knew the child was autistic before they adopted the child, or if that was a discovery along the way. It sounds like they also have other children, who were not adopted in the family. I think there's lots of different issues that are going to be addressed here. You know, one is the adoption, and one is the fact that the brother that we adopted is autistic. I'd like to explain to brothers and sisters, based on their level of capacity to understand what's going on. Because oftentimes, children are not taught, you know, the typically developing sibs, and that leads to a lot of confusion and resentment. When I've talked to parents, they said, "Well, you know, of course there's change. Our brothers and sisters should have just known." No child just knows. Sometimes you have to take the time to explain the differences. And again, the same thing. "This is what we can do. This is the best way we can support our brother and sister who's having a tough time."

In terms of actual concrete suggestions, one of the things that we just discuss is the fact that oftentimes, the Christmas tree is in a room that's sort of right kind of in the middle, the dining room or the family living room. The tree takes sort of a major center stage, which is appropriate in terms of what the holiday means for most families. But as you have suggested earlier, if the child has a safe room within the house;

or if it's another family's house that you're going to be going for the holidays, that they can retreat to when they become overwhelmed. Because oftentimes there's a lot of over-stimulation that can take place in terms of visual stimulation. Sometimes if you buy a real tree, a natural tree, the smell, the pine smell, which makes it smell so good to you, could actually be noxious to our child on the spectrum. So again, they need a place where they can just go to decompress from a variety of different stimulations. Now sometimes the children don't even realize they're being over-stimulated. So here's when they need parental support. No one knows the child as well as the mom and dad. Usually you know the signals when their children are being too over-excited and unable to sort of keep it together themselves. That's when a parent has to intervene and say, "Do you know what? I think we need a few minutes." And let's call the room something special, "Our Time Out Room" or something like "in our quiet space," so it doesn't sound like it's negative. And have it like it's really kind of cozy and a special sensory quiet place. Sometimes I suggest a beanbag chair, or a comfy blanket. Something that gives this child a comforting place.

And I also, most importantly, have a clock. If the child can't tolerate the sound of the timer going off, there are several clocks that don't have timers. Just are ones that you'll see when the minutes are passed, that there is no more red color to the timing, so you know that it's time to return. Because the most important thing is sometimes our kids get too comfortable leaving the scene, and our families get too comfortable not having the child there. I really want to say, "We're going to have a few quiet minutes and we're going to take five, or seven, or whatever the time is that you feel is appropriate, and then we want you back." So we have to help the child sort of get used to being part of it, but also say, "I respect the fact that you need a few minutes to yourself."

Chantal: Right. Okay, here's a good question from Louise and Oshella(?). "I want to enjoy the holidays but they are just so stressful. When we go to any event or family gathering, we seem to always spend the entire time chasing around after our two young daughters, who both have autism, and we aren't able to relax and chat with friends and family members. Then we end up having to leave early. It's so overwhelming for the kids and us. Any suggestions about how to have a more relaxing holiday? How do we make it through and remain sane through all the events and craziness of the holidays?"

Dr. Hess: Okay. Great questions. What I'm hearing is that there's not one, but two children who have autism.

Chantal: Right. They're young. They were just-- Even if they didn't have autism, you'd have two young children.

Dr. Hess: Two young children, who are having a hard time navigating. The first question I have is-- It sounds like this family goes out to the event, to the family gathering. I'm going to make a suggestion. The parent has to share with me whether that's appropriate or not. Because I don't know. Sometimes it's actually more comforting for children to have the event at their house, like kind of their turf. So I don't know if sometimes that could be ever arranged. The family would be the people that would be hosting. So they could have actually a little bit more control, in terms of how long the party is going to be; how many people are going to be at the party and so forth.

The other thing is, which I think is so important. Families cannot do this by themselves. Okay? Whether it's hiring a neighborhood child as babysitter or looking to the State-funded program, the Regional Center for some respite time or something. You have to sort of decide what you want from the evening. If it's time where you would like to also visit, then you have to be able to create an extra set of eyes and a pair of hands to be with your children. That might be either yourself, or your partner, or your spouse. To say, "Okay, you know what? I'm going to sit here and socialize with friends for half an hour, and then you're on." You know, so you take turns. Or you have-- You bring your aide, your sitter with you, so that you can have someone who can help you do that. Or you just sort of make a decision for yourself, saying, "Do you know what? I know that my kids really need me right now. I probably won't be able to socialize as much as I would like, when I have my kids. Maybe we need to make a different kind of date to do so when the children are occupied another time."

Because, again, even if you didn't have kids with special needs, children who particularly don't see family members very often, or they're out of their own environment and get in different transitions and different tensions. They don't always behave the best. One of the ways that children tell us that they need to leave is to create kind of a turmoil, until finally the noise or the kids get so loud, the parents go, "Okay. I have to get out of here." Then the parent gets frustrated, but really the child

who's been asking all along, in their own special way, "I need help here. This is overwhelming."

Chantal: Right.

Dr. Hess: What I'm saying is I think sometimes the parents have to sort of decide for themselves what kind of event this is going to be. If they, themselves, need some social time, they have to create the environment that's going to allow them to do so. So in other words, they're going to have to bring some help along, so that they can do that, if they also want to bring their children. The other thing is instead of coming to a party, you know, midstream, sometimes it's helpful if they come to the party first, so the child has a way to scope out the area. Then they can say, "We're going to be here for an hour or so, because that's what our children can tolerate." Then say to the families, which are coming after, again, "Either we're going to go home and put our kids down with our sitter and then come on back." If that's physically possible, in terms of the proximity of the holiday and the distance between homes. Or "We'll make it another day, another time, which will be an adult time for us."

Chantal: Right. Yeah, those are all options. I have to say though, as a parent, that is particularly difficult around the holidays to have help. I mean, I have at least 8 people fully trained to be support staff for my son, and there are certain days, you're not going to have anybody.

Dr. Hess: And believe me, again, the holidays, it's really tough. But you know what? Sometimes, like for instance, I also-- At our Center, we have people who work as interns, and one of the first questions I say to them is, "Tell me when you can work and when you can't work." And I will say to them, "This family particularly needs you on the weekends." Or "This family particularly needs you on Christmas." Even before we started the relationship, "What kind of availability do you have?" You know, not to say the course they're on surprises. Some people have different changes and schedules. But I also try to create as little surprise as possible. Because I hear what you're saying and you do need support. Sometimes things happen and parents are on their own. Of course, that happens. But I try to also create an environment and hire people who might have that flexibility in their schedule, because this is the kind of flexibility that our families need.

Chantal: Right. It was kind of a running joke in my house for quite a few years, between all the different sitters, and respite workers, and tutors and support staff, about I had to have certain people from all different religions, so that all the religions were covered.

Dr. Hess: Absolutely. I know this is a joke. I, a hundred percent. I will tell you that support staff ranges-- We come in all different flavors and sizes, so to speak, and religious denominations, particularly because I have a Jewish guys and gals, who have no problem working on Christmas. And in contrast, I have those individuals who have followed different religious observances and they have no problem assisting on Jewish holidays and so forth, to my families. Absolutely. I specifically ask those of my screening questions, in terms of, "What are your sensitivities? And when could you work, and this is what our families particularly need." But yes, absolutely.

Chantal: Okay. Here's a question from Tina Moreno, in Tahoe. I'm sorry if I'm not pronouncing the cities correctly.

Dr. Hess: Okay.

Chantal: "How can I take my son anywhere? He doesn't like to go where there is a big crowd. Then my nephew starts him up and I can't control him. What to do?"

Dr. Hess: Okay. Okay...

Chantal: This is for like on the spot, what can you do when someone is kind of setting up the person, in a big crowd situation, where already that child is feeling overwhelmed.

Dr. Hess: Okay. Well, first off, you can leave. Okay? I mean, this is thing where I think so many of my families don't understand or feel embarrassed and so forth. One of the first things you sort of have to give up is this sort of sense that you are going to be embarrassed. Because basically what I'm asking them to do is to be the best advocate for your child. Oftentimes, many-- Yeah. You don't have to be autistic. Many kids get overwhelmed in big crowds. Okay? If you can't control it-- Suddenly, you're in a situation, somewhere where there's a lot of people, you can do lots of different strategies. One is you can leave. Okay? If people say something, that's too bad. It's the other people's problem, not yours necessarily. The other thing is that you can go ahead and take your child

and excuse yourself, "Let's go to try and find a safe spot, in this area, that you're going to feel a little bit more comfortable," and see if your child can't calm down. The situation, it seems like, in addition to the big crowd, there was a nephew who started him up (whatever that means). I'm not sure if this is sort of a situation where the nephew knows, "Oh, if I just do a couple of things, I can get my cousin to kind of get jazzed and that's sort of funny to see him act out." In which case, I need to meet with the nephew at another time and say, "Hey, you know what? That's not cool. Let me tell you exactly what's going on with your cousin."

And have that child's parent around as well, to have sort of, enforce kind of the rules. And "that when your cousin is here, this is the way we have to be." Especially, I don't know the age of the child, but to sort of lay down the rules. If that parent is there as well, so they emphasize that this is really serious stuff and it's not a game. Because a lot of times, children don't understand, if they sort of see the child kind of rev up and go, "Well, that's kind of funny. I can kind of get that child to kind of jazz up a rather boring afternoon, if he's going to have a meltdown." And it doesn't feel good. It doesn't necessarily feel good to the parent. It doesn't feel good to the children. And as I said, that parent has the right to create the safest place for that child and remove themselves from the situation. It can be temporary or it can be just the rest of that day.

Chantal: Okay. Those are some good suggestions.

Dr. Hess: Thank you.

Chantal: I'm looking down here, at some other questions. Okay. This is a question from Esera(?) in Norway. Actually it's two question. I'll start with one of them because it explains more about her son. "I have a 3-year-old boy. He has autism. I have a problem. When I have visitors and my husband is not around and he goes to the visitor's personal space and asks them for attention. If they ignore him, he gets angry and upset and he starts throwing objects at their faces. What do you suggest I do? I have another child, who's 5 years, and a 10-months-old."

Dr. Hess: Okay.

Chantal: So that's the first question. And the second question is, what do I do-- when they're in a gathering and her 3-year-old boy finishes his food but yet interrupts the guests and is screaming and asking for

their food, although she thinks he's definitely had more than enough food to eat. Two types of gatherings here.

Dr. Hess: Yes, okay. Well, I'll tell you the common theme in both questions that I'm hearing, is that this child, even at the age of three, is a pretty smart little kiddo. Because he had learned that if he screams, he probably gets what he wants. You know? Whether it is more food or attention. So we have to do a couple of things here. One of the things we have to do is try to understand what is fueling this little guy. Again, to understand that even though he's three years old chronologically, he's probably developmentally a little bit younger. So I have to approach as a younger child and figure out what is his underlying Individual difference, that neurological piece that I (in terms of the DIR profile) and then through my Relationship, help regulate him and move him and help him get to the place where he can move forward in the most developmentally appropriate fashion.

So the first thing, I'm going to go backwards. I want to talk about the food issue first and then we'll talk about the attention. The first thing, in terms of the food, what happens with children who-- It's interesting. It sounds like this child eats his food and then screams because he wants more. I usually have situations where children have a lot of feeding concerns, because they don't like so many foods because they are orally defended, again, because of sensory processing issues. But the one of the things that we have at our center, is an Occupational Therapist who specializes in feeding problems and she actually works hand-in-hand with a Nutritionist onboard. Because not only do we have to work on the actual feeding problems, but we also educate families, because a lot of my families don't know how to regulate the intake of food for their children, or if they have a family dinner, how to really feed their children to begin with. But in contrast, this little boy who screams for food because he's never really full, one of the things to realize with kids who are autistic is all autistic children also have a regulatory disorder, meaning they don't take cues from the environment, like you and I might. So that this little boy is not reading his body correctly. He doesn't ever really know when he is full.

So secondary to this actual problem, one of the treatments that might have to go on is having him work with an Occupational Therapist and perhaps a Nutritionist, to help him understand what full and empty actually mean. They can do it visually, for instance like playing with balloons and filling it with water. When the balloon is really swollen, that

means full, just like the tummy is full after it eats and we have to wait for a certain amount of time before the tummy is empty, and again, teach them how to use a clock. "This is how long we have to wait." And again, have a clock with or without a bell, depending on what the child can tolerate auditorally and say, "After this amount of time goes by, then we can eat something else," in terms of tolerating how long it takes to be able to digest and empty enough to get more food.

The thing I would not do is actually support the screaming because if this child goes for food, I guess, on plates. I guess the question that can't really be addressed here, because I'm not speaking to the parent in person, is does the same kind of screaming goes on when there's not a guest? Because one of the things that makes my ear perk up is like-- and this goes into the second question. That, when, if I remember correctly, this mom's husband is not around. This is when the 5-year-old-- Excuse me, the 3-year-old acts out. So my question is, is this acting out just simply for guests, both in terms of taking food off of the plates of guests and throwing objects and gets fits when they come to visit? Or does this happen to everybody in the house? So one of the thoughts is what is it about having guests in the house that causes this particular child so much upheaval? Again, is it because it's new? Is there a transition? Is there a thought that when guest come, you know, sort of mom and dad's attention leaves me, and that causes me too much anxiety? And if that's the case, what I would do is, again, help him with the social story and in anticipation of the guest who's coming.

One of the things that we can do is if you have pictures. If the guest happens to be a family member or somebody from the office or whatever, is have pictures ahead of time and almost create a story book. "Tonight, we're going to have company and the company's name is Mr. and Mrs. X and they look like this. And we're going to have dinner and then...". You know, and sort of really go ahead step-by-step and create the evening for the child, so he should know. And then also put into place, in the social story, what we're going to do and what is not allowed to do when you have guests. "When you have guests, you can come ahead and you can say, 'Hi, my name is.... And would you like to play with so and so, a toy of mine or something?' What we don't do is we don't take food off somebody's plate. We also don't hurt anybody's body." Again, address all those issues ahead of time that the mother has seen happen when this child has to deal with the anxiety associated, I'm guessing, with visitors coming to the home.

But I don't want to ignore the fact that there is a 5-year-old in the house, as well as another 10-month-old. So the mom sounds like she's pretty overwhelmed with already three kids, one of whom has special needs. Again, you can't do it by yourself, so I'm wondering whether or not-- Sometimes it might mean to have a set of hands, a sitter, an aide to be able to actually navigate the 5-year-old and the 10-month-old so that she can create these kinds of social stories with her 3-year-old. And actually if the 5-year-old is up to it, have him part of scenario, so he can also help and plan and maybe give suggestions, "What are the different things we can do when the company comes?" and so forth.

Chantal: Very good. It does sound like he has a mind of his own.

Dr. Hess: I'm sorry. Say it again.

Chantal: It does sound as if he has a mind of his own.

Dr. Hess: He does sound like he has a mind of his own but it also sounds, between you and I, Chantal, is that the screaming has worked for him.

Chantal: That's what I mean. He's so smart, like you said at the beginning...

Dr. Hess: Yeah. So one of the things that we have to do is we have to renegotiate this situation, where he's not being rewarded. Because basically if he screams and the parents eventually just give in, because they don't want to be embarrassed or they're just too loud or chaotic in the house. Basically he just learned to just turn it up to that octave.

Chantal: Okay. Here's a great question from Lindsay James, in Freeport.

Dr. Hess: Okay.

Chantal: My son likes belts and strings, but he already has too many of them for me to buy him more. I never know what to buy him for Christmas or his birthday. He doesn't really play with toys but he loves to watch movies, mainly cartoons. But that still only limits me to belts, strings and movies to buy him. Do you have any suggestions? This is a great question because I know this is true of most people with children

with autism. Because you think you should buy these educational toys that would really help them out, but when it comes down to it. when you have a stemmer, my son, there's a few things that really make them happy.

Dr. Hess: Yeah. No, and I can appreciate that. Again, one of the things-- I guess the first thing I keep, and I don't mean to sort of beat the issue until it's kind of dead in the face, or blue in the face rather. But I really want families to understand, kids do or don't do something because it feels good or bad to their body. In other words, they'll do something because it feels really good, or they won't do something because it doesn't feel good to their body. There's a reason why children stem, you know, off of belts, or strings or anything else, because it really feels good. So one of the things I'd like to find out is can we do one of the basics tenants of Floortime? Can we go ahead and follow the initial motivation of a child, but expand and extend on those elements. Meaning that-- You mentioned that he likes belts and string and movies. Okay. So the question is, you've got to kind of-- I think what happens when you have a child with special needs, they ask you to be sort of more than creative.

As a matter of fact, in Los Angeles, and if anybody ever has the opportunity-- I know that they have this in other cities as well. But we have wonderful theater. Particularly, there's a theater company called "The Groundlings," which is improvisational theater. I think what happens when you have a child on the spectrum, it sort of behooves you to become an improvisational player, meaning you've got to take what you've got and then sort of almost as if you're taking from nothing, make it into something purposeful and meaningful. Meaning if your child goes ahead and he likes belts and strings and movies, and particularly cartoons, is there a way to combine it but make these different elements socially acceptable? Let me give you an example, that just sort of popped into my head. There's a movie, that came out fairly recently, called "Up." It's one of the latest Disney movies. And in that movie, there's a character named Russell, and Russell-- You know, there's an element when there are strings are in there because he's sort of holding balloons or balloons are attached to the house that he and the gentleman are a part of. They're having an adventure. So what I'm wondering about is if there a character in the movie that the child really would identify with? That somehow that could be part of the Christmas gift, that could also like strings or belts or something like this. So that you might be associated with a figure or a character that makes sense, rather than simply stemming on a belt or a string by itself? Does that make sense?

Chantal: Yeah. No, that makes sense. You're associating it with something that he admires.

Dr. Hess: Someone he admires in the movie, that he really finds-
- But it also has to do with belts, with some kind of whatever stimulation or pleasure he's getting out of belts and strings. You know? Again, because sometimes, also, it's about just holding something in their hands, to get organized as a way to reduce anxiety. And so can I replace that item? I'll go back to my young woman, who replaced her baby blanket with basically this key chain. It's kind of the rosary key chain. Can you replace the same kind of experience that a child has with a belt or a string with something else that is more socially appropriate that they could just hold in their hand, as a way to stem and organize? Because, again, I don't want to take away something, because it serves as a purpose to help reduce anxiety. But if I can change it around, so that it becomes more of a socially appropriate object, then I'm still allowing this child to get his sensory needs met. But at the same time, I'm putting him in a situation, which allows him to be part of a more appropriate reciprocal relationship.

Chantal: Right. But I guess the question is, when it's Christmas, or Chanukah, or their birthday, you're trying to give them something that they like already, and not something that is going to give them more stress or that he hasn't yet attached to perhaps.

Dr. Hess: Again, you start off with what they're interested in. So let's try to figure out-- It's something that-- In other words, if a child likes the string, can we-- How can we update it? So I'll give an example. This is just sort of, again, spontaneous. It comes into my mind. If somebody likes string and so they're just giving him string, could we give him a yo-yo as an example? In other words, and that's kind of hard thing, especially for small motor. But it can be taught and it is a way to sort of making it more socially appropriate. Does that make sense as well?

Chantal: Well, my son loves patterns. Like on the rugs. He likes patterns whatever. I found a great book at the bookstore that was a book on patterns and it actually also had a DVD in it that had patterns, so you could actually print them out. We still haven't printed them out, but the patterns on the book pages also had an explanation of where they came from. So then it also became-- He could actually-- We could read to him about where the patterns came from and why they had those patterns and whether they were wallpaper patterns, or rug patterns, or what kind of patterns they were.

Dr. Hess: Now, that's a beautiful example of Floortime. He liked patterns and you found a socially-- You took his initial motivation but then it was your creativity, your improvisational skills to extend and expand something that he loved into something socially appropriate. So that's what I'm asking to see for Christmas or a birthday present.

Chantal: Maybe there's books that have pictures of belts and strings or something.

Dr. Hess: Ah-hum.

Chantal: I'm just thinking that way because, also, my son loves to carry something. He needs an item to transition with and I have no problem with that. But I don't like it when he is constantly wanting to stem. Because I can tell when the stem is helping him and when the stem is not helping him. So if he's in a high school mainstream class, I'd much rather he find another way than stemming on a string, because that usually becomes something that gets lost in. If you know what I mean?

Dr. Hess: That's the point. Right.

Chantal: That's why I sort of transfer it to books.

Dr. Hess: Right. Well, that's what I'm saying. Is that we're looking for socially appropriate ways to acknowledge the fact that the need is there but not to create an escape.

Chantal: Right.

Dr. Hess: Right. Exactly.

Chantal: Maybe she could find things that have pictures of belts and strings on them or that they're a part of something, like a yo-yo, as you said. You know, like some backpacks or bags have those kind of belts.

Dr. Hess: Right. Exactly. In other words, and again, or again, he can have-- There's a certain kind of clothing that also has, like cargo pants and different places that-- You can create a more age appropriate type of extension of an original stem. But now it's actually a socially appropriate method of getting him into a reciprocal relationship with you.

Chantal: Right. Like I'm thinking about-- Here, hoodies in California. I don't know where Freeport is, but the hoodies in California, they also have strings on the hoodies. That is the greatest emergency string ever. Because they're on the hoodie.

Dr. Hess: There you go. There you go. Exactly. And you know...

Chantal: When I first started buying hoodies for my son, when he was picking out his clothes?

Dr. Hess: Yeah.

Chantal: He was focusing on the string and on the pattern.

Dr. Hess: Right.

Chantal: Now, he focuses on the whole thing. He started out with the pattern and the string as being why he likes the hoodie.

Dr. Hess: Right. Right. The other thing is to take string, again, and make it a social-- What I want is to have a relationship with that child, but I don't want the stemming. Because a lot of times, the stems are very self-absorbing. Okay? So I want to say, I'll go ahead, and "I'll do the string with you, but I want to go ahead and make a game together like Cat's Cradle." So you're working on small motor skills, which is often difficult for our kids, as well as the fact that they have to do it with another person. So this is too, to do things that are difficult for our kids, but it's still having to do with strong. Again, taking an idea that is initially, originally your child's even if it feels like very innocuous and then have to be creative to figure out, "How am I going to do something that going to take this original idea but make it complex, while still keeping the basic theme of the child's interest and text?"

Chantal: Remember when we used to make those potholders with those like stringy...?

Dr. Hess: Sure. Sure. That was part of everybody's camp experience.

Chantal: Things like that, I mean, that are more-- There's more up to date. I'm sure any teenager could say what they do in camp now that involves strings. But things like that too could...

Dr. Hess: Surely. I think actually you build it on a loom, which I know they still have at any craft store. Exactly. So this is an idea. To go to a craft store and say, "You know what? My child likes string, what...? And they may have small motor issues, so what do you have that would be not too hard for my child to learn how to do, but still would be embracing the fact of the theme that he loves string?"

Chantal: Right. Now here's very good question and I don't know if you can help this person. This is Jane Tipton from Long Beach, California. "Are there programs to help low-income families on the spectrum during the holidays?" I only know of one off the top of my head and that's the TACAN (Talk About Curing Autism Now). If you look up their website, I think that they have, because I know they routinely ask all of us, in the autism community, to donate what we can so that they can help families who need help during the holiday season. Again, that's Talk About Curing Autism Now.

Dr. Hess: Ah-hum. And I would actually add a few more different, large agencies, that I've seen. For instance, because of my association with autism, I get a lot of emails from major support groups, like Cure Autism Now, the Autism Society of America, Autism Speaks. These are different organizations that do offer, oftentimes, low-fee or free support groups. One of the things, I think you can actually also Google is different programs for families who have children on the spectrum, that are no-cost, low-cost or no-cost. See what-- Oftentimes, even local organizations. Like, for instance, in Los Angeles, there's the Foothill Autism Society and they often have low-cost or no-cost events. The parents are welcome to come to. Also, again, I don't know exactly if you've reached out to Regional Center. That's a State-run agency that can offer different programs, and they usually have programs associated with, again, low-fee or no-fee kinds of programming for the holidays.

There's also, again, I don't know in terms of religious affiliation. I know, for example, that for the Chanukah holiday, the Jewish Family Service has a program in Los Angeles called Hamarcaz (H-A-M-A-R-C-A-Z) as well as the Friendship Circle, which another Jewish organization, Chabad (C-H-A-B-A-D) runs, in terms of special needs. These are very low-fee or no-free kinds of special programs that are run on weekends

and on holidays. Particularly for both children of special needs and their families.

Chantal: Those are all good suggestions. I would also reach out, yes, to the local Autism Society of America chapters and see if they have any resources in your area.

Dr. Hess: Exactly. Exactly.

Chantal: Okay. All right. Here's Sylvie in Ottawa. "Hi, my 9-year-old daughter, with ASD, always gets really stressed for about one month prior to Christmas and then it's affected for about one month following. She has it in her mind that she is Santa and so she plans; makes sure and tries to get the perfect gift for everyone she knows. She puts a lot of pressure on herself to get everything perfect. She obsesses about it and this is all she wants to do. She even wakes up before sunrise in order to have more time to prepare the gifts. When Christmas comes around, she pays special attention to everyone's reaction to the gifts she gives them, and then she puts herself down when people don't appreciate them."

Dr. Hess: Okay, yeah. Well actually this mom sounds like she's pretty high functioning, that she's really thinking about Christmas and sort of, and planning. Consequently, I see a lot of times, with our very high functioning kids on the spectrum, they do get stressed for Christmas. One of the things that I'm noticing is that she gets stuck. She believes in her mind that she is Santa and that she has to make a perfect gift, as you mentioned, for everybody she knows. Often, what goes hand-in-hand with children with an autism spectrum disorder, is actually an obsessive-compulsive disorder. And again, these are ways to deal with tension and with anxiety. Everything has to be just right and just so. One of the things, if it really gets out of control -- and again, I'm not an advocate for medication. I'm an advocate for kids. But if I find a child's functioning really is-- A child is unable to function during part of the year, as a consequence or the transition just gets too great, this is when maybe I'll work with a parent to suggest, you know, what are the parental feelings about medication and have they thought about that as a direction if, again, the child is really stuck and needs some help, to sort of help calm them and sort of regain their ability and composure.

But without necessarily going the route of medication, if that's something the families choose not to do because, again, with all, certainly Western traditional medications, there are side effects and the parents

may choose not to do it at all; or don't want to go through a homeopathic or Eastern medication as an example. One of the things, again, what we can do is create what we've been talking about many times tonight, which is to create a social story ahead of the game and before this one month prior to Christmas and say, "You know, Christmas is coming. Let's talk about presents, for instance, and how I always think that I'm supposed to have a certain present for everybody and it has to just be so. But my mom told me that that's not my job. That I'm 9 years old and my job is to [you know, whatever a 9-year-old is appropriate to do] and if I do want to give a present, I can give a present to so and so, and so and so. But that it doesn't have to be perfect. Because I don't know anything that's perfect." Again, having a 4-6 page story, where the child is sort of relieved of the-- Talks about it and relieve the anxiety to have to do something exactly so. Then you can also talk about the fact that, you know, the people's expectations may be this way or that way, so she doesn't have to-- You know, and "Even if somebody doesn't like my present, that's okay too." So that's one piece, an active suggestion that I would give.

Chantal: Very good. It's all about expectations too for the holidays. Aside from this young girl, a lot of things that I'm hearing from people and also from your answers is that parents have expectations. The children have expectations, and the relatives have expectations. I think that as parents, we have to be so careful to not try to live up to certain expectations that we may have put there, that perhaps are unrealistic.

Dr. Hess: Oh, absolutely.

Chantal: Trying to keep up with everyone else's expectations of, and events.

Dr. Hess: Ah-hum. Exactly. I think, you know, too often, in our minds-- When you talked about Thanksgiving and "I wish it was many months before so I can have some downtime to kind of get ready for Christmas." I think we all have this image in our minds of the perfect Normal Rockwell painting. The reality of most families is it's far from that idealistic situation. So it may even start, not even in terms of our children with special needs, but what is the parents' expectations of the holidays, period? And then add into the mix, the child with special needs. How do you maneuver within that?

Chantal: But I think there's an aspect that we're not-- we haven't brought up yet or discussed yet. Is that for many people, who the holidays are a special time, and it is a time to be together. So when they're having all these concerns with their children, it brings about a deep sadness and a sorrow because even though, you know, we have these hard situations, even if we didn't have kids with autism, where you have expectations that can't be met. But the fact that your child is not enjoying the holiday the way everyone else is. The fact that you are not free to enjoy the holidays, the way you normally would? You know, as you say, you have to think about having a respite person come with you or you have to think about leaving early and coming late. After a while, it gets-- It's really sad, because those are the moments that you cherish and you're always supposed to cherish with your child.

Dr. Hess: Right. Right.

Chantal: So what sort of advice do you give parents in dealing with those...?

Dr. Hess: Well, what we're talking about is acceptance. You know?

Chantal: It's not acceptance. Because it's also feelings of sadness that people have.

Dr. Hess: But that's part of...

Chantal: Because meanwhile, you can be going towards the acceptance, but you still have those feelings of sadness.

Dr. Hess: Oh, no question whatsoever. No question. But that is part of acceptance. In other words, when I think of acceptance, I think that it's a process. And the process, first off, has many, many elements in it, including being very sad and very angry and maybe blaming and denying and hiding and there's no particular sequence to finally getting, to coming to terms with this. And it doesn't mean that you don't go back and forth and you think, "Okay. Finally, I'm accepting this," but a situation happens where I get horribly embarrassed or I had hopes and it didn't happen and I feel sad and depressed again. Or I have come to terms with my teenager, who has autism, but then I see my sister's children, who are smaller and 2- and 3-year-olds, who are doing things that my 17-year-old will never be able to do, and I get thrown back into depression. There's no

question that the sadness, this coming to terms, is an ongoing life process. Because as you hit certain milestones, and certainly holiday time, when you have other family members and you're going out of your own routine, so that you can sort of see contrasts, that sort of puts everything right back into your face.

I think it is also about giving the opportunity for parents ahead of time, to reflect in their own minds, "What are their expectations?" And talk about the feelings of loss and sadness and frustration and anger, you know, that they have. Because they would just have to be able to go to the holiday like everybody else, or not have to plan so extensively. All the different elements that we've talking about. The fact that really we can't be spontaneous with the holiday and we can't take time off to say, "Okay, tonight. Just don't be autistic for me. Would you, please?" It doesn't work like that. So one of the things that I offer to parents is something about self-care, because I don't think we talk about that enough. I mentioned that briefly, that parents themselves tend to get overwhelmed by their own personal expectation of the holiday. What ends up happening in those situations is tends to exaggerate and exacerbate, I think, the situation. So what I offer also is that, within all these groups that we've been talking about, there are parent support groups. Other families, who have done the journey, who are willing to sit down together and talk about holiday time, and just hear another person kind of say, "Yeah, I had the same experience. This is what I did." Or "You know what? There's no answer. It's just crummy." You know? And just to acknowledge and validate that experience. That makes the parent feel, I think, a little bit less alone.

The other thing, which I think is really, really important. There's got to be a time when you're not dealing with your kids. Again, I don't believe in super moms and dads. I don't believe in perfect moms and dads. I don't think there is such a thing as "perfect" and "super." And I think that that sometimes gets our own expectations and it sets us up for exhaustion and failure. Parents, particularly in holiday time, have to be able to pencil in for themselves, downtime on an individual basis, as well as a couple of times for themselves and their partner. So they can get away and just not have to deal with the overt stressors of the holiday and having a child on the spectrum and having other kids that they have to negotiate, and just take care of themselves and have a little bit of downtime, fun time, quiet time, whatever it is that they need, so that they can do some self-care and recharge their own batteries. So that they can be available for all the demands of the holidays and thereafter.

Chantal: A good point. It's not always so easy to do, but a good point.

Dr. Hess: No. No. A lot of my parents, they find it nearly impossible to do, because they are such good parents and they just-- It's like, "I can't take downtime." I said, "You know what? You've got to take downtime. How are we going to pencil that in for you?"

Chantal: The reality of the respite people and the babysitters. You know, as the kids are out of school for two weeks. I don't care how well organized you are, when it comes to respite people. But people who work for you, they want down time too. When your kids are in school, you can do the self-care. When they're not in school, it is very hard unless you're a wealthy person with a live-in, who's going to be there during the holidays, to take those times.

Dr. Hess: Is it. But you know, this is like I shared with you, about "The Groundling" idea, in terms of, asking you to be sort of extra creative. What I have found, for instance, in Los Angeles County (I don't know if in San Diego), there are-- Almost all the high school students, that I've worked with, in regular high schools. They have 30 hours of community service that they have to commit to. And so what I do is go to the-- I go to the school counselors and I said, "Listen. I have a lot of families who could use support. Can this count as their 30 hours towards community service?" Then what I go ahead and do is I will train a high-schooler.

Chantal: But there are people, like my son, that I could not leave with a high school student. He has toileting issues. That's not something that you're going to leave.

Dr. Hess: No, no, no. I understand that.

Chantal: It seems like-- You know, if there's-- And I know a lot of people like me, who are very resourceful. You know, it's just hard. I have a daughter who's almost 18. I can leave her at certain times with my son. But I can't, certain times of the day, when I know he might possibly have a toileting accident. The toileting accident is a sensory thing, again.

Dr. Hess: Sure. Sure. There's no question. I don't mean to minimize and say there's an easy answer for all these tough situations.

Chantal: But I'm putting it out there, because I didn't want people out there to be listening to say, "Oh, no." Because for some people, there are options like that, and those options could work. Like my daughter does work with a boy, who's 11 and has Asperger's, and she's perfect with him and that's a perfect fit. She could help a lot of people like that, but...

Dr. Hess: Okay Let me... Let me... No, no. Okay, no. Chantal, and I don't mean to cut you off at all. And I appreciate the fact that you're putting out-- You know, it's not just...

Chantal: I don't want people listening to feel like if they have a child like-- Who can't be left, that they're like, "Oh, my gosh. Am I the only one with this?"

Dr. Hess: They are certainly not. But what I want to share with you, and I'm really addressing one part of your initial question. Was, for instance, like the holiday time. So I want to share with you that there are children who have different religious schedules. So that if you have like two weeks during Christmas and you have other schools, who are not taking their breaks because of their religious affiliation. It's not a holiday time, so they can-- So they are available to go ahead and do something. What I'm saying is-- This is where I'm asking to be creative on that level. Okay, meaning-- We joked about having different, you know, in terms of different religious affiliations. You have to be that creative at times, but you do find people that are more available than you imagine. Okay, because that particular holiday isn't something that they identify with, so that they would be available. But at the same time, I don't want to minimize situations (as you're suggesting, like your son's, which really you need a specialized person to be with him). You just can't just leave somebody who is a well meaning high-schooler to sit and provide respite.

Chantal: But I do have to say, those high school people are really wonderful for-- Even for people like my son. They may not be able to baby-sit or be alone with him. But they're great for the socializing and hanging around, under supervision even.

Dr. Hess: Right. And the reason I bring that up, again, is because I don't think you have to break the mind. Meaning a lot of families are saying, "You know, I don't have the money for a sitter." So I offer this as an option because it doesn't cost-- You know, it doesn't cost families

anything. And also, what happens is that, is the advantage of the student, because they get the 30 credits that they need anyway, in terms of going ahead and providing services. So that's really...

The other piece is also to do cooperative babysitting, where-- Especially with other families who have special needs, who are familiar with dealing with difficult kids and can certainly tolerate and know what to do and are a little bit more savvy because this is their life experience as well. And they'll be happy to help, because they know, themselves, that next Tuesday, they get their night off, so to speak.

Chantal: Right. And also, they know exactly what kind of things to look out with for your child.

Dr. Hess: Exactly. Exactly. But I did want to thank you, because I did not want to reflect at all, that there's one blanket answer for everybody, without a question.

Chantal: Also, in these times, it's getting harder. Even in the State of California, where we have Regional Centers, the Regional Centers are cutting the respite and they're cutting the social programs. Well, you know, from being on the Task Force, to what extent that's happening. So we all are having to be creative.

Dr. Hess: Exactly.

Chantal: Which you have the Task Force, and so individually, we also need to help each other more, just like everyone else has to in this economy.

Dr. Hess: Exactly. Exactly.

Chantal: Trying to look at the bright side of the economy, is that I think, especially around the holidays, people are being more thoughtful about what kinds of gifts they're giving to people and they're giving more of themselves. Going back to that, what we used to do in those days.

Dr. Hess: Exactly. Exactly. And here's another answer. In other words, if somebody's trying to say, "What can I give to your family, or to your child or something?" They might say, "You know what? I need some babysitting time. I need somebody to come in and give me-- You know, you want to do something really-- Commit five hours, over the next

month, to come in and-- And not even deal with special needs kids. Help with my typical developing kids, because I feel really guilty that I never can take-- You know, here's my 5-year-old twins and my 6-old-old. I don't know. During the holiday time, it's going to be really tough for me. Could you take them to the zoo, or something special that they want to do? That would be wonderful." As an example.

Chantal: Good idea. So here's a question from Diane in Burnt Hills, New York. "How do we get our son, who is 6, with PDD and NOS, to settle down and enjoy the here and now, as a holiday, and not focus on what is next?"

Dr. Hess: Okay. Again, we have to sort of understand what is going on. Usually what happens to our kids is because, again, of this individual neurological differences, they have a lot of anxiety. Because they don't get the reassurances that typical kids get, from just watching their mother's body language or hearing the message, because they might have receptive language problems, where they can't quite understand the message from their parents. They're always sort of on edge. They're always not sure what's the next step. So consequently, I see my kids get very anxious, "What's next? What's next?" Because they're always anticipating, because they just don't get a sense of reassurance. So what I like to do then is use, as I mentioned earlier, a visual map of, "This is what's happening" and create a schedule. And if a child goes, "But what's next?" I go, "Well, here's what's happening. This is what's happening from 4-5." "Well, what's after that?" "Well, this is what's happening from 5-6." "What's after that?" I say, "Well, we decided only to do a calendar up to 6:00" or whatever it is, and then you have that social story that sort of supplements the visual map to say, "And it's okay."

Chantal: Right.

Dr. Hess: So one of the things that I think parents get involved with is they sort of follow-up with, you know, the perseverations of the children, without the understanding that this is just a form of anxiety. So we have to support with our relationship, that individual neurological issue, by the visual maps, by the social stories, by maybe having a child in our lap as we're reviewing this because that's a pro-perceptive input, which automatically comes and helps a child feel more grounded. And usually that'll be enough to have the child just sort of tolerate the fact that sometimes in life there's a lot of ambiguity.

Chantal: Yeah. You know, in the last book that I had published by Penguin, which was called "Autism Life Skills." I interviewed adults on the spectrum from all, people who are just typers and non-verbal, to people with Asperger's, impacted but not perhaps as severely or differently, I should say. The one thing everyone said that was the hardest was the transitions.

Dr. Hess: Ah-hum. Absolutely.

Chantal: What's happening next? What's happening next? It creates all this anxiety because they're not quite sure if they're going to be handle what comes next and so all...

Dr. Hess: How to navigate. Sure. Ah-huh.

Chantal: These visual maps and these explaining what's going to happen next gets rid a lot of that worry.

Dr. Hess: Right. Correct.

Chantal: They said if there's just one thing that you could do to help them is to prime them, to let them know what's going to happen next and to get over that fear of worrying about what's going to be happening next.

Dr. Hess: Right. And this is why I really love, you know, all kinds of variations of Carol Gray's work with social stories. So you can sort of plan it and then that person can have a whiff, and a lot of times I like to laminate the social story, so that you can use them again and again. And then have a marker, where the child sort of checks off, "Okay. We did this." "So that's done. Okay. Now we can move on to the next thing."

Chantal: Yeah. And also, I think it's important to say here that it's not just for people who are verbal...

Dr. Hess: Oh, absolutely.

Chantal: Yeah. With my son, when he was younger, we didn't know how much he could understand or not. And we said-- You know, he wasn't able at that time to participate in the creation of the social story. But our social stories are about rules of behavior, like going to the library, because he loves going to the library. But there were like three sentences, of the three rules, stated positively. You know, like what was going to

happen in the library and what was going to happen if he didn't act in those positive manners and actually leaving the library. It was to get him-- Because he was at a point where he's ripping books at home. So he'll rip books in library. That's just not done. And it was funny, because that's when we figured out that he was actually understanding what he was hearing, and not just visually. Because people started to forget to bring the paper with them. You know, the laminated card. So they would get there and they would just tell him, and you know, he got to the point where he just knew what he was supposed to do or he just needed a...

Dr. Hess: A prompt.

Chantal: ... a verbal reminder.

Dr. Hess: Yeah, sure.

Chantal: It's really helpful. And so for people out there who think-- who are afraid of try things because they think their child doesn't understand, you don't know. You can never assume that they don't understand.

Dr. Hess: No. As a matter of fact, I have a lot of children (as you're suggesting) like your son, who initially are not verbal. And eventually they are able to access verbal skills or through augmented communication means, they're able to let us know what's going on. They will tell me that they remember exactly what happened when they were younger and it was very frustrating for them because they couldn't communicate. It didn't mean that they didn't understand. That they heard but they felt frustrated because they didn't have an access to letting us know that they knew what was going on.

Chantal: Right. Now, I have a couple more questions and I'm sure you're going to think, "Well, I've already kind of answered those." I know that by hearing it, it might make you think of another way.

Dr. Hess: Okay, sure.

Chantal: This is from Jason in Kato. "My son now enjoys unwrapping the gifts." So I guess they had to work on that. But "How do we get him, now, to understand that there are ones for him and then there are others that are for other people, so that he-- and try to keep

him interested in the items that we got him." So I guess he really likes the unwrapping part now.

Dr. Hess: Ah-hum. Ah-hum. Ah-hum. Well, it sounds like again, to some degree, what we've been talking about. The unwrapping obviously creates a lot of sensory input for this young man. And so, again, you can practice and role play. There's lots of different things. First off, to help the family understand, he's not doing this activity because he's selfish, because he's narcissistic. He's doing it because it feels good to his body. And so there's some degree, we're just going to have to practice role-playing, you know, wrapping of presents and unwrapping. "This is yours and that's okay. And this belongs to Jim, and this belongs to Jane." And what we have to do is sit and watch and say, "Okay, so let's open a present. Oh, good. Look at what you got." And so forth. And you practice these, you know, step, by step, by step skills multiple times. So that when the actual unwrapping of Christmas morning comes, there's a tolerance. Because, again, he's experienced it.

You also can supplement by a social story again, of what's going to happen, and create a story with pictures, in terms of his family unwrapping. You can have the other family members come and play act, so you can actually have a story that he can look at. And he can also have written down, the same kind of visual map. "This is how we unwrap the present and then we wait. We go inside and we say, 'Oh, look.' And we say, 'Thank you' for the present and we wait for Jim's turn, and then we wait for Jane's turn. And then, we open the next present." So you actually break down the fact that, "Yeah, it does feel good to your body. But in our family, we give everybody a chance."

Now, the most important thing. I don't know if you were listening to sort of my, the way of my tone of my voice. What I've been really focusing on is not to get tied into the turmoil that can be associated with-- sometimes our kids starting to meltdown. The most important thing is if you get caught up in the craziness of the moment, as a parent, that's just going to aggravate it and accent the whole problem. Really what I do is when I begin to sort of feel some agitation going on, I really slow down my actions. Because a lot of times what happens when kids meltdown, it's because they haven't been prepped appropriately or we're moving too fast. And so I try to really slow things down. I give very definitive boundaries. Sometimes I'll say, "Do you need a special time away to have a breather before"-- Again, I begin to see, like the water boiling, but it hasn't hit its pitch, because it's much easier to stamp out embers, than it

is a raging fire. So you have to get, to some degree, have to get good, to sort of anticipate and give a chance for kids to take a break. But if you prep them with enough time, usually what ends up happening, and practice, that the opening of the presents can be stressful but not to the point where they can't participate. And ultimately, it could be something that's enjoyable.

Because also, we sometimes forget to really acknowledge our kids on simple gestures, which is so-- which is such a big deal for them. Like, "Wow, you were able to sit and let Jane and Jim open up their presents today. That's really great." You know, then you acknowledge how hard it was for them to do something like that. Because all kids like to be acknowledged. And for our children what appears to be simple gestures, is enormous, because it means that they're one step closer to being a reciprocal member of their community.

Chantal: Speaking about that area, here's a question from Carrie in Michigan. "My son is 9 years old and has Asperger's. His biggest deficit area is social skills. Normally, we celebrate Christmas Eve at home, but this year, we're going to my mom's house. So how can I prepare him for this and keep his anxiety level down?" I know you'll talk about the mapping and so forth. But is there a way that he could role-play with the social skills? Things that he might be doing at his mom's, or his grandmother's house?

Dr. Hess: Sure. Absolutely. This is when you're going to have to have grandma's help. You know? And again, I don't know where grandma lives, in the sense of if it's in the same town. So they can sort of practice going over to the grandparents' house. Or it's out of town, so it's more difficult. But I think what it is now, and it might be helpful in terms of saying like, you know, "Mom, could you send me pictures of the different rooms, so we can actually create a book?" And say, "We're going to go into this room. And then we're going to go to this, this and this, and really kind of role-play and break it down to what's going to happen." And ask grandma to really be kind of sensitive that, "We're going to go over to your house, mom, but we want to try create an environment that's really a success. Tell me, first, what is your expectations of the evening, or the day? And let me tell you what we can do or not do." And it might be that, "Oh, well, we're going to have 40 relatives come over, because they haven't seen you and the kids and so forth." And you can say, "Well, you know what? We can probably tolerate about 10 people."

So like I'll give you a perfect example, having nothing to do with special needs. Over this particular Chanukah holiday, I have several very

young grandchildren. And we started the party about an hour earlier, for the little ones. And we had about a half an hour overlap, where we have the adults come. And so they could have some kind of interaction, but they were basically getting ready to leave as the adults were coming. There was a few minutes of interaction but really the children had already had their special time, where they had their presents and they had their age appropriate support. Then the adults-- Their parents took them home and then we more of the adults' evening function. A couple of people said, "Oh, wouldn't it have been nice for the children to stay a little bit longer?" I said, "Well, yeah. It would have been nice. But you know what? They're little and we have to acknowledge that they have needs. It means they have to go to bed earlier. So I appreciate the fact that you have that feeling."

Chantal: You know, there's a question here that's not specific about the holidays. I'd be interested in hearing what kind of advice you could possibly give these people, if you don't mind?

Dr. Hess: Sure. No, go ahead.

Chantal: Christine, from Raleigh. "My 11-year-old son [so it's an 11-year-old son with Asperger's] time taking someone else's perspectives and yet he's extremely intelligent. So he uses logical arguments to persuade those around him to do what he wants. For example, I might need to spend the morning baking for a family get-together in the afternoon. I make it clear that he needs to finish chores before he has free time. Instead, he'll pester his brother; sneak TV time; read in his room, everything but get his chores done. By the time the family is ready to go, he hasn't finished his chores and he's ranting that he won't get his video time because we're leaving the house. It becomes a battle and everyone is agitated. However, his 9-year-old neuro-typical brother understands that if you make mom happy, by doing what you're told, you get video time and the household is peaceful. I can see why his teachers will call him, "Oppositional defiant," even though I don't approve of that terminology. What strategy do I use to convince this very smart, immature boy to work with me?"

Dr. Hess: Thank you. I think that's a fantastic question. And I want to emphasize the fact that this is such a smart boy. Okay? Because he's sort of strategically figuring out how to do things that he wants to do. He doesn't like to do chores. It doesn't feel good to his body. It's boring or hard or whatever it is and he'd rather do other things. But he doesn't obviously know how to organize his time appropriately to do what he

needs to do. Plus, then also get his videos done. And he's very good at creating kind of chaos for the family. One of the things that I would do, is I think-- I'm guessing that this mom is verbally giving him tasks that he needs to do, in terms of his chores. For a lot of our kids, who have auditory processing concerns, they don't necessarily get all the messages that we tell them verbally. It's almost like being on a bad cell phone conversation, where they get bits and pieces of the message, rather than the whole point.

So what I do, is you can certainly give him the verbal message, but you have to supplement that, again, as we've been talking about all evening long, with visual maps. "This is what we need to do and this is the timeframe you need to do it." And he has to do it and check it off. Then also you put down, and the consequences. For this particular type of tasks, you get this kind of video time. I guess the question was, he'd get upset because he doesn't get his video time. And this young man, at least at this point, cannot be left to his own devices. One of the things mom's contrasting is the fact that there's 9-year-old neuro-typical brother who really gets it. The problem is even though this young man is 11, it doesn't feel like he's 11. She actually even mentions the fact that he is immature. So again, I use that DIR framework. Even though he is chronologically 11, this young man feels younger. He feels more like 8 or 9 years old at best, even though he's very smart. So we, with an 8- or 9-year-old, I'm going to be much more involved, to sort of micro-manage a little bit, in terms of the tasks that I need my child to complete. So I may check on him much more frequently than I would an 11-year-old. So part of it is even though he's very intelligent, is coming to the terms of the fact that right now, I have to help with my relationship (my R) support his [whatever the underlying individual neurological issues are] because I'm really dealing with a child who's 8 or 9, so I have to give him a little bit more support, than I would even his 9-year-old brother.

Chantal: Very good. Interesting situations the families have. Isn't it?

Dr. Hess: It's real life. You know?

Chantal: I know. I guess, you're never bored with the work that you do.

Dr. Hess: I have to share with you-- You know, I joke around and I say I have the best job in the world because I get to play with kids

and toys all day long. But I love what I do, and I really do. Because my families teach me every single day, by their-- by example. By their humbleness, by their perseverance, by their advocacy, and I'm just honored to be in their company. I really am. But thank you for that compliment. Because it just-- No, I never get bored whatsoever, and I just enjoy it enormously. You know, to be honest with you, we have four children. I've shared with my kids, the one blessing that I give all of them, no matter what direction in life they take, is to just find something that you're passionate with and just love what you do every day. You know, I've been blessed to have found that within the work that I do.

Chantal: And I think that people are blessed that you're there as a resource.

Dr. Hess: Thank you very much. Thank you.

Chantal: Okay, here's one, probably going to be the-- Well, maybe not. We probably have time for two more. Here's a question. I don't know who it's from. "How do I get through this holiday season with family and friends who don't know, or haven't accepted my child's needs, and how should they be handled?" So how do you go about telling the family and friends without offending them? In a way, if they're already not accepting the child's needs. Do you have some suggestions?

Dr. Hess: In other words, one more time. So in other words, so this is a family or friends who are just not accepting a...?

Chantal: It says, "Who know, or haven't accepted my child's needs?"

Dr. Hess: Well, you know, to some degree, you can only do what you're going to do. You have to go ahead and-- As I said before, in a couple of other similar questions this evening, where I believe you can alert families, family members ahead of time, to the situation. Sometimes families or friends just don't get it, for multiple reasons. I run several support groups at our Center, and one of the support groups I run is for grandparents. And I've had grandparents who-- They range from the grandparents who totally get it and are always available to help their families, to grandparents who are just disbelieving. They just think that the parents, their children, their adult children are just poor managers of time or don't have any capacity to really know how to discipline their kids and so forth.

When I really get down to trying to help them understand that this is a real situation and the children aren't in, because they don't know how to manage time and so forth. What they'll share with me is basically their sense of helplessness, that they really don't know how to even wrap their heads around this idea that they have a grandchild with disabilities. They feel very sad and they don't like feeling helpless when it comes to knowing how to support their adult child and certainly their grandchild with disabilities. Sometimes I have to get to the root of really what the issue is that prevents them from hearing the message from their adult child. The other part, where I share with the adult child is, "You can try as best you can. If a friend or a family member is unable to take in the message and you've tried a variety of ways (emails, phone calls) and you still get a lot of resistance, you then have the right to protect yourself and your child. And you can say to them, 'If you are unable to support, I may not be able to be with you as much as I would like.' And you can protect yourself and your child by saying, 'We're going to have to limit our contact. Because this is our life and this is situation that's not going to go away. I would love your support, but I also understand that maybe it's going to take time for you to be comfortable with that idea.'" And some families never are. I still have families who say that, "My child is 9-years-old and is autistic and to this day, my mother doesn't acknowledge that."

Chantal: Yeah. It is tough. It's really tough, when you are in situations like that. I always tell parents that sometimes they just have to decide what the boundaries are going to be.

Dr. Hess: Ah-hum. Exactly. Exactly.

Chantal: Limit your children-- You and your children, your immediate family comes first.

Dr. Hess: Right.

Chantal: And you have to kind of limit the outside stressors, so people can be helpful and they can be helpful and stressors and then some are just downright stressors. So you just kind of have to not feel guilty about spending all the time with these people, because they're related to you, if they're creating more havoc in your life and it's something that you can't-- With information to them, with knowledge to them-- If they're really not open to it-- You can just offer it every once in a while, but you can't allow their stresses to become your stresses.

Dr. Hess: Exactly. Exactly right. Exactly right. And this is part of a parent kind of coming to terms with this acceptance that we were talking about, you know, in terms of-- You know, when you have a child with special needs, that sometimes it's not about being perfect and meeting other people's expectations. It's about taking care of yourself and your family.

Chantal: You're absolutely right. We're going to be ending this in a couple of minutes. I did want to let people know that on my website, you can have access to an article that I wrote on, *The Examiner*, about holiday tips, and you can get that by going to my website, which is -- I'm going to spell my very complicated name, *ChantalSicile-Kira.com*. And if you go to my Home Page and click on *The Examiner* button, you will go immediately to the article. Otherwise, you can go to *Examiner.com* and type in my name and you will find that article, if you want to sit down and read that. Otherwise, Dr. Hess, would you please like to remind everyone of your web address, where they can get more information about you?

Dr. Hess: Absolutely. And I also had one more piece. But let me give you my web address one more time. It's *www.CenterForTheDevelopingMind.com*. And I'm also a monthly columnist for *L.A. Family* magazine. In the December issue, we have a whole page of suggestions regarding how to get through the challenges associated with the holiday. Then, if you can stay tuned for January, we're going to talk about New Year's Resolutions, and particularly, how to deal with self-care issues of parents, which is to a large degree what we talked about today as well. That's *L.A.FamilyMagazine.com*.

Chantal: That's great. That's really important. The self-care, as you mentioned earlier, it's nice to know that you have a whole issue, or at least an article on that topic.

Dr. Hess: Yeah, absolutely.

Chantal: Okay. So I would like to remind our listeners that if they'd like to get feedback, they can call 877-211-0212 and press 1. Again, that's 877-211-0212 and press 1. And I would like to tell our listeners that our next webinar is on January 11, 2010. It's about *Succeeding in College with Autism or Asperger's Syndrome*. My guest is Ann Palmer, who has been working for 13 years with families with individuals with autism at Division Teach, and she has a son with

Asperger's and has written a book about preparing for college. Thank you so much, Dr. Hess, for being my guest this evening. Thank you for all your advice.

Dr. Hess: It's been absolutely my pleasure. Let me wish you and your listeners, tonight, a wonderful, wonderful holiday season, and the best of Happy New Years.

Chantal: Thank you very much, and yes, to all our listeners from me, and also from *MomsFightingAutism.com*. All the best during this holiday season and I wish you all the best for a happy, healthy and wealthy 2010.

Dr. Hess: Okay, please. Amen.

Chantal: Thank you, Dr. Hess, and goodnight to everyone. Until next year then, be the change that you want to see.