Autism 101 The Basics

Chantal Sicile-Kira.

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SUMMARY

CHANTAL Sicile-Kira is a writer and expert on autism. She is also a mother of a child with autism. This call highlights questions asked by listeners who are mostly parents with children who are diagnosed with autism or aspergers some of the areas covered:

- Autism diagnosis
- Autism behavior control
- Interaction between autism children with neuro-typical children
- Autism children’s education
- Functional behavioral assessment
- applied behavioral analysis
- diet
- autism life skills book
- scripting
- occupational therapy
- resources on teaching organizational skills
- home therapy services

TRANSCRIPT

ERNEST:First off, I want to introduce myself, my name is **ERNEST** Priestly, I'm the founder of xx, and we're very, very fortunate today to have **CHANTAL** Sicile-Kira, is that the correct pronunciation? She is a wonderful speaker and we're going to ?? so much of her today, I'm going to give a background of her. She's been involved in the autism disorder for over 20 years and she has a very special perspective because her son is also one of them. She happened to ??[00:38] and she has lived in 3 countries: France, UK, United states where she raised her son. She currently hosts a radio show in English and also in French on autism on radio. And **CHANTAL** also writes for various publications including Ask **CHANTAL**, which is a column on the autism file and she blogs occasionally on the ?? Post. Her family has been highlighted in the Newsweek cover story, Growing up with Autism and she is featured on the NTV documentary a two-light series: I have autism which is the recipient of the 2008 ? Award. She is also author of 3 books. The first book on autism disorder: a complete guide to understanding autism disorder, asperger syndrome, a recipient of 2005 Autism Society of America outstanding literary work of the year award and she is also nominated for the 2005 Michael ? for non-fiction. Her 2nd book entitled "??? Autism Spectrum" a parent's guide for social, pivotal transition for teenagers with autism was awarded 2006 family book of the year for Best in Health fitness. And her 3rd book is coming up very shortly, she's going to tell us a little bit about that, about communications and self esteem and interesting book she's going to talk about. She also has a very special announcement to make later on in the call so you want to stick around and hear that. I think I've covered everything. **CHANTAL**?

CHANTAL: I think you did it, first you got my name wrong but that's ok. The name is ?? [2:31]Sicile-Kira.

ERNEST: OK. The hyphen, I forgot about that.

CHANTAL: very important when people are looking me over, they're used to my name and they go, "who is she? I've never heard of her" but if you say the whole thing, people go, "oh, I might've heard of her".

ERNEST: understand. I'm really excited to have everyone here today. We have people from all around the united states and around the world listening to the call right now and I wanna tell us a little bit about what you're working on and what you're up to. A better idea: what sort of relationship, what sort of struggles you had with your son, where you're coming from.

CHANTAL: first of all, I want to say thank you for inviting me to be here and I'm really happy to be here. I hope you don't mind me teasing you about saying my name wrong. Actually you've said all those things about me, is he really talking about me? If I had thought 5 years ago I would be in this place now, I won't believe it because I've worked in the field of autism a long time ago and I had my son when I was living in Europe and there were no resources at that time and in those countries and what kind of led me to write my first book was I didn't want people to go through what I had gone through when my son was little. And I just kept writing to provide more information to parents because that's what I really enjoyed doing. So the kind of things I'm involved with right now are basically the same thing. getting information out to people, which is why I continue to write, which is why I do the radio show for Autism on the internet, it's free to everyone so I really like to talk about that. And also why I write this ad on ?? [4:20] for this magazine called the Autism file. about 2 or 3 years ago, I was thinking wouldn't it be neat to have a Dear Abby column for people who have kids with autism because how many times you have this question that you don't know who to direct to, and you really want an answer and Dear Abby sounds like a perfect person. I'm always thinking at the back of my mind, maybe one day I could do that and ?? [4:45]called the Autism file contacted me and asked if I could write. In the end they called it the Agony Aunt, Dear Abby is an Agony Aunt, I guess you write to tell them your agonies. So I agreed to write this column and this magazine is coming to the States so that's something we could talk about later. So that's why I write ?? [5:07]column. I continue to do all of that but the most important in my life right now is helping my son because he's in the last 2 years of where he'll be eligible for Special education services. He's turning 20 in January and up to the age of 22, he'll have access to help for his education, so that's what I'm really focusing on.

ERNEST: that's a great background here. I think people are given an idea of where you're coming from. You've experienced these things first hand and you've had the opportunity to write about which is really good. Gives one an idea what you're up to here and I really like the way you've explained it all. Do you want to get involved in questions right now. Quite a few are coming in..let's see here. I'm going to find a question. Here we go.my son, her name is Elisa Parkington from Columbia, South Carolina, and her question is: my son has been diagnosed with high functioning autism. I've been trying to get a diagnosis since he was 3 when I realized something was wrong. When do multi functioning kids get a diagnosis?

CHANTAL: that's a really good question and usually they do tend to get diagnosed at around 8 or 9 years old. Technically it has to be aspergers. And I'll explain differences between aspergers and high functioning autism in a second. But the reason why they do that is because I don't know how many who are familiar with children, who have worked with children. In school, they tend to do the same things everyday and you tend to have a same pattern and then they give you homework when you're in 2nd grade that you return the next day. When you start to get around the age of 8, that's when in the classroom they start organizing things differently, so that they give you a homework, pack it maybe on Monday, some of the things you do the next day, but there's a project that's due at the end of the week, for example. And this is where they start noticing that kids with aspergers have difficulties in different areas and that's when they totally fall apart because of their organizational skills. This is why at that time, and also the time when little peer groups start happening, they get together ?? [7:47]in school, people are starting to have a little cliques and that's why you notice it. And the technical difference between high functioning autism and aspergers has to do with whether or not the child develops language normally or not. In other words, if they speak before the age of 2, technically they're supposed to have aspergers's diagnosis and if they do not develop speech before the age of 2, that's when you have the high functioning autism diagnosis. In the end, it looks the same, there's variance degrees but Tony ?? who's expert in aspergers syndrome, he likes to say that the only difference between high functioning autism and aspergers syndrome is the way it's developed.

ERNEST: that's a great explanation. I just have one more question, thanks a lot for the answer. One more question here is Keenan from Upstate, New York. My 10 year old son constantly hits himself in the face, why is this and how can we stop this behavior?

CHANTAL: ok, he constantly hits himself in the face. Have they looked to see if there are any antecedents, like it only happens at certain times. The first thing that I would say is try to see if there's a reason why. For example, observe when he hits his face, what was he doing before? And try to see if there's any pattern evolve over a week or so. The other thing I would say is; my son tends to do that every once in a while, but my son has many sensory challenges and to him, it's linked to that. Because he'll hit his face every once in a while, he'll hit his chest every once in a while, and it's to relieve pressure. A calming influence, sensory-wise. That doesn't mean it's true for everyone. For somebody else, they may be slapping their face because they're mad about something. Maybe there's something that's irritating, a sharp noise at their side of the room, right near their ear or something happened right before and that's the only way they have of communicating. They haven't turn out the words to express themselves and so it's good to see if there's a pattern before analyzing what to do about it.

ERNEST: understood. That's a great answer. Let me get another one. Her name is Heather ??[10:33]. her question is : I have a 21 year old son who has asperger. He seems to be more ?? and sensitive than ever. Is that an isolated case or did some of the negative behavior from age?

CHANTAL: there's really no research on that but I can say this from my travel and from what I read is that a lot of times, people with asperger's as they get older sometimes they get more frustrated because they realize, this is one thing that has been shown in research, there's a higher incidence of depression linked to asperger's as they get older, and we think it's probably because they realize as they get older they're different from their peers, and so that frustrates them or makes them sad. And it maybe essentially he's unhappy, there could be signs of depression, and that is his way of getting it out. I don't know what his ?? situation is, but it could be he's having difficulties with real life, he is different from other people.

ERNEST: we got another here that just came in. her name is Stacy and she's from ?? [11:54] Wisconsin. How do I get the school to work with me and not fight with me about how to work with my son? I'm sure you can talk about that for a long time.

CHANTAL: that's a great question. My son..I'm not sure how many people are familiar, have read my book or have seen ?? on NTV but my son is very much on the very impacted end of the spectrum. And so my fight has always been to try and have people believe he is smart enough to learn something and if they can't teach him, then they just haven't found a way to teach him. All they're saying is they have no idea if my son really understood or not, but I want him to reach his potential whatever that may be. So my way of dealing has always been more of a mediator, that's kind of my background, having been raised in a French environment in America, then having to be a social worker where you're trying to get what people need but you have to do it in a way that's politically correct and then moving to France, where I work with French and Americans and they never understood each other and so I always try to get everybody working together. I find myself doing the same thing and I also realized from my life experience work-wise that you get more sugar with vinegar. You know that expression, to catch more flies with honey than vinegar and so I would always..what I would do is figure out what are the things that would really make a difference to my son's education and arm myself with facts and figures and I always discuss things with a non-emotional manner. ??[13:56] meetings are basically business meetings

& you have to convince them and you're not going to convince them just because your kid deserves it. It's really about why you think something will work for your child & how it has helped other people. Maybe you've tried it at home and it worked. And also in the classroom, I have found that sometimes you get teachers that are very old fashioned and just waiting to leave, most people I've had to deal with are those who – hey they came into social education because they love kids, not because they're going to make a million dollars. The point is ?? [14:33] support them and seeing the light when it comes to your child. One way I was able to do that was give them one or 2 little things that they could try with my son that would work or show them what I did at home because they were amazed at how much my son did at home than he did at school. If I could get a home visit out of it or a tape recorder, I mean a video tape, document. The other thing is I would also find out what it is the teacher needed in the classroom because I did found out that when you're in a ?? meeting, my first experience when I first moved back into the States with Jeremy, the school district administrator would say, oh yes, we could do that, can we, Mrs Johnson? And he asked the teacher Mrs Johnson, could she do this and of course she would have to say yes as the school district administrator is her boss. But she did not have what is needed to follow through with my son. I found out it was like a trap so what I would do was make friends with the teacher and find out what it is she would need in your classroom that's going to make you able to provide the education my son needs. And when I find out what that was, then I would go to ?? meetings and ask for these, leaving the teacher out of it, they all thought it was for me. The thing you realize is the parent has all the power. The teacher have no power. But you do have to be in a situation where people are going to listen & I have been in situations where school administrators no matter what you say, they're not going to listen. I always start with trying to support the teacher and aides. Because they're the ones in the front line.

ERNEST: because that's the way to ??[16:23]there for sure, to talk to the teacher, to get them to help you out. That's a good approach there. As matter of fact on Wednesday, we have a tele-seminar on IP from an attorney specialize specifically on ??

CHANTAL: I have used attorneys in the past and attorneys are great. The only thing you want to remember is when it's all said and done, even if you win, the attorneys leave. And you are left to pick up the pieces and get those relationships going again. You want to make sure the attorney's helping your case but is not ruining your relationship.

ERNEST: Right, good point.

CHANTAL: You might want to bring that up in the meeting & attorneys will have good suggestions on how to good relationships in this kind of situation. I do want to say, sometimes people say, oh, she's written 3 books and she's an expert, she doesn't have any problems with her school district, that is not at all the case. Just like Temple Granden ?? [17:33] has written some forewords for my books, he's written and ?? some pictures, she's probably the world's most famous person on autism or woman with autism and she always told me you're never an expert in your own backyard. She designs handling facilities for animals, before they go out to slaughterhouses. Before they go out to be killed to be – hamburgers for McDonalds ?[18:08]? And it's the same thing with my IT and my son's IT here in my school district. It doesn't matter if I've written a book or if I've written 500 books, I don't know anything.

People may pay me money across the country to go give them advice on what to do in school districts but my school district doesn't want to hear from me.

ERNEST: I'm glad you said that because I know a lot of parents out there are struggling on the very same thing and it's like the whole world's against them & they feel alone and you sort of put it out there ?? all the time. You just got to get in there & do what you can for your child. I like that.

CHANTAL: I always try to do it in a very positive manner and before I get into the ??[19:04] and attorney which I had to at one point, because it came to abusive situation in the classroom. That clearly is a line I do not cross and so at that point, before ever hiring an advocate or an attorney, I suggest that people get a hold of their state's Protection and Advocacy, you can google it and you can get simplified versions of what your rights are in Special Educations. In California, I would carry around, I would download it and print it, I would carry that to my meetings so people would know oh, she knows something. There's a gentleman who's more knowledgeable than I am in that arena –

ERNEST: I don't mind because I think you can look at it from a perspective of someone who's worked with IEPs using an attorney or without an attorney ??[20:09]

CHANTAL: I like to go to meetings with solutions. Like, I have a problem, here's a solution. That's what I try to do, too. I get that it really depends on who's sitting on that table.

ERNEST: tell me a little bit about that. Usually it's the teacher, someone from the regional centre or whoever you have with you..

CHANTAL: I always tell people, I used to do an IEP 101 Workshop for people in my area. This is what new parents need to know, how to have an effective IEP and it is very hard when you go into an IEP at the beginning because if you and then if the teacher, the school administrator, usually there's going to be a speech therapist. You feel like there's a lot of people and you're all by yourself so I always say, never go by yourself. And if both parents in a single parent situation or only one parent can go because you know we have jobs, right? And so, always go with a friend even if they're just going to take notes for you. And also this is what I always do. I told you I'm a mediator, right? So I always want the meet to feel good. This is not about feeling good and I have to remember what are the 3 or 4 things that I did not want to negotiate on and I need to make sure they are taken care of. What's going to happen, when it's going to take place & who's responsible. So just have a person with me, whether it's my husband, a girlfriend, I give her a lift before I go in there and she's supposed to kick me under the table to remind me you didn't get an answer on this. Or get back to this. And she also takes notes for me as I'm going to be listening to everybody that you might forget some crucial information.

ERNEST: This is a great take away for people out there that, you know, bring someone with you.

CHANTAL: You want to go there, looking professional. Clean clothes and papers in order. The thing is, don't be nervous. Because they all look like they've been in it for a long time. But remember this. They have 500 million kids they're trying to remember things about, you just have your child. So you go in there, and you know more information about your child than they do. You're the expert on your child.

And I always try to turn everything that’s negative into a positive. For example: once this assessment came back about my seminar. Look at this! This isn’t even the right assessment. It was supposed to be a functional analysis assessment & they had wanted to do and I thought, oh my god. What is this? This gives no information, this doesn’t answer the question and I'm thinking, how could this be? I started reading from the beginning and I realized they did a whole different assessment. And if I looked at it from the point of a whole different assessment all the sudden I realized, hey this guy actually spent a lot of time and this person actually worked really hard at writing this so I went into the meeting not angry, I just said, I had a feeling this is not the assessment that we need that’s going to help the teacher understand my son better, I think we need an XYZ assessment because I thought it was going to be a functional behavioral assessment, it isn’t so. So the district person said, oh yeah, you’re right. This isn’t really about the behavior, is it? And then the next thing you know, I had also done my homework and found out who were the 3 people in the area that wrote really nice assessments, who knew what they were doing. That they were happy about the assessments of their children, when it came to a functional behavior assessment and I hoped that they would pick one of those 3 people. The district person came back and said, what if we had Johnson to do this assessment? And so, I could have gone in there angry, but I decided to look at the positive. The positive is somebody spent a lot of time writing that report and doing observation and it was a well-written report. Unfortunately, it did not answer the question. How are you going to make something positive out of a negative?

ERNEST: could you describe for us what a functional behavioral assessment is?

CHANTAL: what a functional behavioral assessment is? Functional behavioral assessment is when someone who’s qualified with an ABA background or a psychologist, will commune and observe the child to see what behavior’s the child’s exhibiting and why he’s showing those behavior. So for example earlier when we’re talking about the mother who had a question about why her child is hitting himself in the face, if someone was doing a functional behavioral assessment, they would look at what function does that behavior have? Why is he hitting himself in the face? What happened before, what happens during, what happens after? What is the antecedent, which is what happened before? What’s the behavior and what’s the consequence? And then it’s important to look at the consequence, what happens afterwards, because sometimes it’s what happens afterwards, rewarding the child for exhibiting certain behavior. Once you do a functional behavioral analysis, you have an idea on what the behaviors are that are happening and why someone thinks they’re taking place, because of what’s happened before or during or after. Then the most important part is creating a plan to deal with it. For example, you might look at toileting in the same way. You know when you’re having toileting, you might do a functional behavioral assessment of the whole toileting issue. So you can solve any problems that they are.

ERNEST: that was a long answer for a very short question about the school. That means that you have a lot of experience in that area here about schools.

CHANTAL: I hope you’re not trying to tell me I talk too much.

ERNEST: no, I'm glad you talk because we've got a couple of questions that have come up while you were talking.

CHANTAL: I'd love to hear them.

ERNEST:Here we go. This question is from Stacy Lewis. How can I make the transition from summer daycare to school so that he starts being more aggressive. The last 2 weeks of summer the daycare thinks he's doing bad behavior-wise, it's not easy to handle, all the future student ?? [27:56]. I guess the gist of it is how can I make the transition from day care to school?

CHANTAL: does it sound like it's not going well?

ERNEST: this is a question that she just posted.

CHANTAL: I can answer about how you can make transition easier. It is true that some kids do act out to transition. Transition is the number one problem with people of the spectrum. I'm going to answer directly to that question. I just want to say that this is really brought into me strongly when I interviewed people on that spectrum in my 3rd book which is coming out in October which is ?? skills. I interviewed people of that spectrum to find out what was it in growing up that was important to them? What made their life easier? What made them learn the essential skills they have today? What made them be able to live as adults and be happy about it? And one of the things they talked about why transitions were so difficult is that a lot of the transition stuff have to do with sensory not being able to predict what's in the environment. And that's going to affect them. I could not believe how much sensory processing affected everyone including everyone on the more able end of the spectrum and I'm making a point with this because we always talk about sensory processing; kids like my son who are more impacted by autism but every single adult with asperger's that I've introduced in my book talked enormously about the impact of sensory processing environment when they were growing up. And so the number one thing that everyone says that helped them was letting them know what's going to happen. We talk a lot about that when we talk about schedules but it's not just about schedules. 10 years ago, we talk about schedules, ok, it has to be icons, it has to be on the wall but anything that explains what's going to happen next. For example, how old this you say this child is? Anyway, it would be the same. You would just do what would be more age-level development mentally, developmental level appropriate. The first thing I would do if you're changing environment is to show; have a book that you take pictures of where they're going, you videotape where they're going, even if you can't get inside the building, outside the building. You also take them on walks, take them to where they'll be going. For example, you can do this when they're little or when they're teenagers. Even when they're very able teenagers, such a stress, one of the things the adults said was, even in high schools they got so stressed trying to get to their classes in time, they couldn't focus on the academic subjects they were listening to. They were just worried about how to get to their next class. They can walk through the school or around the school or at least the outside of it when it's empty, when there's no classes going on. When it comes to new staff are you able to get pictures of the new staff or meet them before hand? And then everyday or every evening talk about what's going to happen before it happens, like you're going to start school. Even if you don't think your child is going to understand, I was told you're going to put him in an institution, he doesn’t understand anything. It turns out my son understand everything we’re saying to him, he just couldn’t communicate it. And so all these years, he’s been listening and you don’t know if your children are listening or understanding. You always assume they understand you. And you use words, you also use visuals because you don’t know their visual processing is working or their auditory processing is working. So you want to prepare them by telling them what’s going to happen, who they’re going to see and if you tell them everyday beforehand and you have a calendar, you visually show today’s Friday and on Monday you’re going to a new school, you talk of a positive experience in a positive manner of these new experiences, that’s best on how to prepare your child. And you want to make sure that your child has familiar items with him. For example, certain things that your child likes to eat or have, make sure they have that with them. You can tell them too, when they go to school, I'm going to make sure you have this thing. you’re going to eat the same thing you like to eat, you’re going to have the same lunch box. Something they have that’s the same.

ERNEST: that is really good because the parents are taking the kids from home to school. That information is really powerful. Take photographs of the staff and essentially walking them through what they’re going to experience. That’s fantastic.

CHANTAL: even if they understanding, do it because some things, you don’t know. My son’s behavior is immediately. My son is never aggressive but we used to have behaviors where one parent has experienced this when they tried to take their child to the dentist or the hair cutter, places that is hard for people who have a lot of sensitivity, I can get my son into the car, but I can't get him out of the car, this is why I knew he understood everything I said because I knew something was processing because this is in middle school and we wouldn’t know what he understood. I would have a schedule, I would always have an icon with a haircut and I would put those out a week ahead and say, Friday, you’re going to the dentist. Friday, you’re getting a hair cut, whichever one it was. Reminded him everyday, the day he had to go, I would remind him in the morning, we’d get on the bus and ok, we’re going now. He wasn’t happy about going but he tolerated it. It’s sort of like, he’s prepped himself but if I forgot to put the icon out, if I just got him on the bus and you know what, I forgot to tell you we had a dentist appointment there was no way he was getting out of the car when we got to that place. It was like he wasn’t able to get himself ready. It does get better over time because my son now is 19 and I can actually say, you know, your hair is getting long, you feel like a hair cut? And he’ll say yes or no, depending, but he’ll do it. And other days when There’s a dentist appointment, it’s like he’s self regulated himself. This is an important life skill and I talk about life skills in my book because this is what the adults told me but if you’re going to be living out in the community, no matter where you are in the spectrum, you have to be able to self regulate.

ERNEST: that’s great information there. Matter of fact a little later on in the call, I’d like you to tell us a little bit about your book. I'm sure people would want to take a look at that book when it comes out. We have another question here from Heather McGee from ??, not sure where that is but : my son is in the process of being diagnosed with ASP. He is 2 ½ years old right now. How important it is to start a structured school environment before age 3? Our school district does not have classes available before that age.

CHANTAL: it really depends on the child and how they're exhibiting ASP because every child is different but it is important to have some type of structure. And so it is really important and early intervention is very important . but there are various ways of providing that structure, I don't know this parent's situation. For example in California, we're lucky enough. If we don't have a structure school situation that's available, there is early intervention that's provided in the home. There's other options for therapy so we do have some kind of structure even though it's not a structured school situation but it is important to have some kind of structure and to be working on teaching the child. Like I said if they have a hard time making sense of their environment, we need to be creating that sense to the environment for them.

ERNEST: OK. I have another question here from Elaine from Boston. Her question is can you give advice to parents with newly diagnosed children as the best approach to helping their child to the diagnosis of autism. How should you prioritize your approach?

CHANTAL: that's a really tough one too. When you met one person with autism, you've met one person with autism. I think it's very healthy that this parent is asking this question because the problem is when you throw everything at once, you don't know what's working for the child, that's the first thing. secondly, you can't do everything. You may think you're a super parent, and we are all super parents. It's sort of like you have to be a marathon runner and not a sprinter, you can't just go fast, you have to have ?? approach. So the first thing that I would suggest is to see if there's any medical issues. I would never have said this 20 years ago but I do say it now. Because the types of autism that we see now is different from the type of autism that you would see 20 years ago. For example 20 years ago, and these are figures from the autism research institute in San Diego. 20 years if you had 5 children with autism in a room, 4 of them would be born autistic, meaning they never developed properly or normally, I should say and then one who develops normally who regress around the age of 18 months and 2 years of age. But now we're seeing the opposite. If you see 5 cases of autism somewhere, usually 4 of them would have developed normally, and then around 18 months and 2 years, have lost the skills they acquired and you only see one who has never developed normally. In other words, appeared autistic from the beginning. What we are finding or what people are finding, for some of these kids, there are medical issues. And I'm not saying all ? causes autism, but I think that what we consider autism now is autism but for different reasons. Not everyone's autistic for the same reasons. For example, my son was born with autism and I know where his autism comes from. It comes from genetic, chromosomal defect. For somebody else, it's the environmental impact on a chromosomal issue or genetic predisposition. And so that's why you see this regression. And this is the theory now. It's not always the ?? it could be something else. Irregardless of why they're regressing, a lot of these kids tend to have medical issues. In other words, chronic diarrhea or they have a gut problem, or they're constantly crying. Maybe they're crying because they're in pain or they're trying to communicate but they just can't get the words out. Or some reasons why they're not comfortable. So I would really suggest to people to look for doctors who have a ?? medical background who have background on diet. For example, some kids have allergies and it's the allergies that's making them sick, making them worse. I'm not saying it's causing their autism, it's making their autistic symptoms show up more. Look at the medical aspect to make sure your child is healthy, I would say, do some type of structured 1 on 1. ABA is the proven method that works. I would suggest some floor time because floor time takes care of the developmental levels and the emotional connection. And also have fun! We forget to have fun sometimes with our kids. Fun may not look the same to what we consider fun with our typical kids. You have to figure out what it is that they like, how can I get into that with them?

ERNEST: can you describe what ABA is?

CHANTAL: ABA is applied behavioral analysis. Whatever we do in life it's because we're motivated. If you act a certain way or you do something it's because the consequence is important to you. You want that reward. In other words, you work because you're going to earn money. Or you work because you enjoy the type of work you're doing. We do ?? volunteer for people because we want to help people and it makes ?? [42:28]good to do that. A child is going to learn if he puts his hand out to touch fire and he gets burn by the fire, he's going to learn not to touch fire, that fire hurts him. You break down all the steps to learn something into separate discrete steps and then you teach each step a little at a time and you reward with something positive when they have learned something, if they're going in the right direction. And we keep adding on skills that way. The rewards are tangible, they can be candy or cookies or some video they like to watch. As they get older, they should internalize those rewards, they do them because they want to do them.

ERNEST: we have a question which I'm sure people have experienced with their children. Her name is Hannah and she's from ?? , our son's screeching a lot, he cannot say what he wants or needs when he's bored. He's 3 years old and he's diagnosed with PDD? He has?? How should we redirect him ??[43:45]

CHANTAL: he's screeching because that's his way of trying to communicate. Communication is very important. So all behavior is actually communication and that's his way of communicating because he's having a difficult time, speaking is not coming out quickly for him. I always suggest and research proved that just because you're using some alternate type of communication that does not mean you're going to hinder speech. People should teach an alternative way of communicating which will help ?? for example either writing or putting icons that are pictures together that are words. This will both ?? speech because it will get him not to focus so much on the actual muscles and anything like that that needs to say something, he'll be focusing on the other part that he's doing. The speaking part will come more naturally because he'll have the other support. Or using augmentive communication devices that can speak for him. This all will help him develop speech. A lot of times parents don't want to use augmentative devices or use an alternative form of communication because they keep saying oh, he's going to speak soon or they're going to keep him but research does not prove that. Research proves that using an alternative form of communication will help bring out the positive communication. The verbal communication. What I would try to do is when he is screeching, replace his screeching with words that he's trying to say. For example, he's frustrated because he's trying to open the door but he can't open the door. Oh, I want the door open! put words to what he's doing. Sometimes that will help him too.

ERNEST: I have another question here. I'm not sure you can answer this one but I kind of feel for her. Her name is Brandy, and she's from Utah. I have an 8 year old daughter who has for the past few years constantly claws at her skins until she bleeds. She is now covered in scars. The doctors say it's self mutilation. Any suggestion on how I handle this?

CHANTAL: I feel very ?? for the mom but I don't know what kind of doctors she's seeing. He's not very familiar with ?? to me, if somebody's clawing away on their skin, yes it is self mutilation but it's because somethings bothering them. To me, it's a cry of pain, I don't know it's sensory thing with the skin or is there something going on inside. Maybe they have gut issues and I really think if I were that person, I would see someone – at the Autism Research Institute they do have doctors who are experienced in biomedical ways of helping children with autism. And I would look for a doctor like that who understands those things. In saying that, be very careful. I'm not trying to push people spending hundreds of thousands of dollars. You have to find a doctor who knows about this type of things, be sensible too. If I have a child who's scratching away, I would say this kid must be hurting inside. There's something bothering him. I would try to find what kind of test that I can do and see if there are different allergies that this child may have. That's what I would suggest.

ERNEST: we have Cliff from California. My son is 2 years and 9 months old, just diagnosed with autism. He's obsessed with touching ?? he also loves vegetables. Any connections? Any ideas as to why this is happening?

CHANTAL: no except I would say that most people would love to have her son. I would say, first of all to be very careful. For example, my son doesn't really eats plants but he will sometimes take something, take a leave and put it in his mouth because he loves salad so much. ?? make sure when we move into the house, that all the plants on the outside were not poisonous. I live in California too. You have to be careful about the fact that you don't want poisonous plants around and again I don't have any experience as to why this is happening. You might want to ask the diet counselor who's coming onto your show in a few weeks but I know from my son he does love fruits and vegetables so maybe the leaf looked to him like lettuce. I should ask my son. Those are one of the things my son is able to communicate to us now, I don't know why I haven't thought about asking him, but I will ask him.

ERNEST: we have Janice from Boston. One of my son is diagnosed with PDD [49:38]?. He just came from a residence treatment center. He doesn't get along with his younger brother who has Aspergers. and the school suggests a weighted vest. What are your thoughts on weighted vests?

CHANTAL: the weighted vest is supposed to be like a calming thing, perhaps he realizes he needs sensory input. I know this seems like the shortest question, maybe he needs some deep pressure. He needs ?? for that. But that doesn't reply why he doesn't get along well with his brother. I don't know these 2 children but I do know there are autism issues and there are sibling issues. When I look closely in my family, because I have a daughter who's 16 who's ?? and there's a lot of stuff to do with autism, but you know what a lot of that stuff is sibling stuff too. You just need to differentiate between what is because of the autism and what is because of sibling. That's easy for me to do because I grew up with 5 brothers and sisters. And there were a lot of different personalities. So I know what sibling crap is. I'm not trying to belittle the question but trying to say that some of the issues we see are serious but some are less serious than we think they are. Try to figure out, do we have a sibling or autism issue?

ERNEST: here’s a question from Debbie from Spring hill. My son was diagnosed with ASP from February 2008 but previously being diagnosed with ADHD, ADD and Laurette's Syndrome. Is it possible for a child to be successful after years of mixed therapy and intervention and ?? children of the spectrum? How can you make up for this messed therapy and early intervention for a child that’s diagnosed with ASP at 10 years old?

CHANTAL: usually kids with Aspergers Syndrome are diagnosed later and this happens a lot – diagnosed with ADD or Tourette’s or something else. Especially with adults because adults didn’t have Aspergers Syndrome diagnosis available to them. It’s only been around for a little over 10 years. But ADHD or OCD are seen as a kind of extension of the autism spectrum and I'm not talking about ?? in the field people. Experts will talk about it and it seems like it’s sort of an extension and so a lot of things that work with someone with ADHD it could also work with someone who has Aspergers. so I don’t feel that because she had a different diagnosis, she necessarily missed out on a lot because when it comes to Aspergers, there isn’t much that they do when they’re younger. It’s never too late to start. In fact, it’s one of those things in interviewing adults in Autism life skills, as I said there wasn’t a diagnosis of Aspergers before, so many of these adults didn’t have a clue. They were misdiagnosed with other things and no clue they had Aspergers until they were a lot older. Now they’re learning what they needed to learn and they realized oh, this is why I had a problem in this particular area and how can I help myself? It’s really good she can have the diagnosis and now she can actually work towards getting the social skills that’s really important and also the organizational skills. That’s another thing the adults said was so important to them. Some of our kids on the spectrum - the ones who like to line up their cars, the ones who like to do everything exactly the same order. But most kids don’t translate that into organizational skills and so those need to be taught. When I talk about organizational skills you can use color coding. You can use different ways of organizing their work like a planner, so they can see when they have things to do. How they organize their ??[54:23] to and from school. There needs to be communication between the teacher and the parent but there’s definitely lots to be done.

ERNEST: I have another question here from Lisa ?? from Columbia, South Carolina. Interesting question here, probably tied to what you’ve just been talking about. My son has just been diagnosed with high functioning autism. He’s 8 years old and I’ve been trying to get a diagnosis since he was 3 when I realized something was wrong. At what age do most high functioning kids get diagnosed? What more can I do to speed along the process so I can help advice other parents?

CHANTAL: the first thing I want to say to all these parents out there who are asking these kinds of questions is I totally support and understand where they’re coming from because I knew there was something wrong with my child and it took me years to convince people. You’re the mom, you know when there’s something wrong with your child! You have to believe in yourself and just know you’re right. You may not know what is wrong, you may not know what to do about it, that’s the whole ?? when you know what’s wrong, then you can do something about it. I want parents to really pat themselves on the back that they are the ?? don’t let anybody tell you you’re not an expert on your child. Because you are an expert on your child. The 2nd thing I want to say is don’t beat yourself up and say what could I have done that could’ve speed up the process? Because you know what, we all do what we think is best at the time, ?? it’s just too easy. You look at your husband, and you say why did I marry him? If you knew what you knew 20 years ago, would you have taken the job now that you hate, if you knew what you knew back then. If you knew back then what you know now. The same thing with your children even if it’s much more serious because you’re responsible for your children you do everything you know as best. You can't beat yourself up about what you should have done. Part of my question in writing the 3rd book when I interviewed people in the spectrum was because having Jeremy who was 19, I know he was aging out the system and Rebecca who’s neurotypical who’s 16, you start asking yourself questions as parent even with Rebecca who’s neuro-typical. Did I do the right thing in raising them? Am I being too strict to Rebecca? Am I being too lenient? Am I asking her to do enough chores at home? With Jeremy, what kind of decisions did I make about him? Should I ask him ?? all the time? Should I have done a different type of therapy than I did? And I realized in interviewing all these adults, yes it’s important that you do, but the most important thing that every adult had in their life – I interviewed people who were very high functioning, very able, to people who were more impacted, who would type on their computer like Amanda Beck on CNN, people who are non verbal like my son and all of them said the number one thing that was important to their wellbeing was they had parents that were there for them, a mom or a dad that was there for them by their side the whole time. At the end of the day, therapy was important , I'm not belittling that if you think you’re making a decision you think it’s right all along, your child feels that. That’s going to guide you. You’ve got to think about and analyze what you have done and why you should have done it differently and do it now. All this talk about windows of opportunity if you don’t do these therapies by the age of 2, it’s all over. That’s not true. Early intervention is important but what’s really important is their whole life span. They always continue to grow. The brain is plastic. Look at people who are in accidents, in strokes, who have to go through rehabilitation and have to work on physical therapy and getting their bodies back working. That’s all the brain cells working. People do recuperate and those are the brain cells that are going to keep growing with your children. It’s never too late.

ERNEST: I'm glad you said that, that it’s never too late. Just the fact that kids need a parent. ?? you’ve touched on your book a little bit, could you talk a little bit about your book, let people know what they’re going to expect when they finally get their hands on it, sounds there’s some really interesting stuff there about life skills and looking at autism from the people who’ve lived it and now are being asked what their life spans are all about and how ?? looking for help ??.

CHANTAL: my first 2 books were really based on what research would say. I did look at what the people on the spectrum would say, I thought of them throughout the book and it is very practical. Both my book: the autism spectrum disorder and also the adolescence on the autism spectrum are very practical and this stuff is so practical from a different perspective. I was going through this whole thing, oh my gosh, there’s only 2 years left , what happens after high school? There’s nothing out there and that’s another ?? if you want to talk about that after this. What is it that’s important to these people growing up? What made them who they are today? When I talk about people being happier, being successful, I'm not saying, they’re driving that car, they’re earning a lot of money, but people with autism who feel that they’re successful. For example, Sue Reuben, she’s very autistic-like and she ?? a movie that’s called autism in the world. And she communicates by spelling out. She’s very smart. Then you have to go the other end of the spectrum who are very intelligent and can speak very well and have all kinds of interesting jobs. But they saw other difficulties in their lives and I wonder what is it that got them where they are. For sue, she is successful because of her way of communicating she never had before. And her whole life now is open to her because of that. All these individuals talk to me what was it that was important to them for growing up to be the people they are now. Who was important in their lives and what they wish they had known sooner. These 10 different areas/chapters, which is actually the subtitle of this book – autism life skills, from communication, ?? self esteem and more. 10 essential abilities every child needs to learn. The 3 areas that people spoke most about was sensory processing. The 2nd one communication, you could be someone who's non verbal, you could be someone who's really intelligent but you don't get the 2nd meaning so you're always misunderstood because you don't really understand what's going on in a conversation because you don't understand the lingo or the metaphors. Safety was such an issue with many people. Most people said they were either bullied or made to feel that they were disliked. Many were abused. Some did not even realize this is abuse because no one had taught them the difference. And so this has made me realize how many things we can do now to prevent some of this things happening in terms of safety issues. But also in discussing with them I realized how much the things we don't think about like self esteem and self advocacy. These are things they think about in high school years but are actually things people try teaching to their children when they're little. What I did in these chapters is when I interviewed these adults, I put it into little practical tips. So you can read through that as a professional or as a parent. Wow that kind of reminds me of my kid. What could help him in these areas. It's really mind boggling the things I learn. I noticed a lot of your questions are from people with really young children. The older parents out there will understand my grief but I would never talk about toileting issues when my son is 19. Forever people has always made it feel like toileting issue is somehow related to the less able end of the spectrum. One of the person who has aspergers in my book, I'm actually sitting in the lobby and I'm interviewing her, I'm not going to mention her by name, because a lot of people I ask the same question and they have the same issue. All of sudden, I hear this timer go off , she said just a minute, I'll be right back. I asked are you ok? Oh, that was just my timer to remind me to go to the bathroom. She said when I'm in crowded area such as this I can't feel my body. So I forget to use the bathroom. Sometimes I feel it at the very last second and then because there's a lot of people, I'll have to wait in line and then I get into the restroom area and the toilet paper's on the other side that I'm used to be, it's confusing. Everytime I go in public, I set my watch so it will remind me to go use the bathroom and I go regardless of whether I feel I have to go or not. Then I started asking many of the people I interview. I didn't ask everybody. Many in there said they did have problems with feeling their bodies, especially when they were in these overload situations and that's why many of them put themselves on a schedule. For someone with aspergers you can set your watch and no one knows the difference. But when you have a kid like mine, you can't answer the phone, I can set it for him, we're teaching him now to rely on that in events that one day he'll be able to. It made me realize how much ??[1:06:41] everybody. They just don't realize it ?? for those at the more able end of the spectrum. I had little tidbits like that when I was interviewing people.

ERNEST: we want to be on the lookout for that book. Could you repeat the title one more time?

CHANTAL: the main title's autism life skills and the subtitle is from Communication, Safety to self esteem and more. 20 essential abilities any child needs and deserves to learn. Actually it's going on sale October

7th. I have not even updated my website, I'm going to be doing that this week. If people ? my name they should be able to see the book on the internet somewhere. I should announce this autism file magazine that I'm writing for is actually the 1st autism magazine that's in so many stores in Canada and the USA. It's going to be in Barnes & Noble and Borders. 2000 stores in September. Isn't that amazing?

ERNEST: that is amazing, whats the ?? of it? Can you say?

CHANTAL: it's called the autism file. it's got 138 pages the premiere issue and it has articles on bio medical, some articles on educational, on the teen perspective on the spectrum. I wanted to bring it up too because for those interested in buying my book, Penguin put an ad in my magazine and if you buy the magazine you can actually get 15% off my book.

ERNEST: that's great. Did you hear that folks you get 15% off the book if you get the magazine. It's going to be in Barnes & Noble and Borders, correct?

CHANTAL: Yes. The premier issue which has 138 pages is 5.99.

ERNEST: fantastic. That's going to be a great value.

CHANTAL: you can write questions to me if you want. Questions, answers in the magazine: Ask **CHANTAL**. There's also a doctor's column. The doctor is in, you can ask questions from the doctor.

ERNEST: fantastic, that's some great information for everybody out there. You might want to come down here in mid September. We're going to move along with the questions here. Thanks for sharing that for those of you who have hung out in the call to find out, that's great. There was one woman here, her name is ?? [1:09:34] from Texas. Her question: how do I deal with my two boys? My 6 year old have ?? and my 5 year old does not have it. My 5 year old doesn't understand that his brother needs more attention. That's probably a common situation with a lot of parents.

CHANTAL: it is such a struggle when you have kids that are on the spectrum and not on the spectrum because there's always a need for attention. I had a terrible time with my daughter because she's 3 years younger than my son. It really depends on where they are in the pecking order. I know of people who's daughter is neuro typical who's the 1st born and they have a son with autism and the daughter naturally likes to be maternal to the brother. So those kinds of situations nearly work out because they understand. A lot of times when it's different order, or different personalities.like my daughter is never the Barbie-doll kind, kind of tom boy so she never has the wanting to take care of her brother instinct. This had a lot of sibling issues but what we have worked out is, I always explain to her, he needs more attention but I make sure that I always have some time with my daughter. It's hard because there's mother, father, and the kids. And everybody seems to need their own attention. We have times when we do family things together and I have times when I do things alone with my son and then time when I do things alone with my daughter. It's really important to keep those lines of communication open where you have to explain to your child especially when they're little that just because they get more of your time does not mean they get more of your love. That's the important thing you need to tell them. Yes, maybe he needs more of my time but it doesn't mean he gets more of my love. I know it's hard to find time. If it's only 10 minutes at breakfast or 10 minutes when they're going to sleep at night, that little mommy and me time or daddy and me time, that is so important . you just have to keep repeating it over and over. I know my daughter, she's 16 and you think by now she's over it but she goes how come I have to do so many chores and Jeremy doesn't? how many times you have to say because he's autistic! I always make sure that I taught him a few chores because he has a lot of motor issues, so it's hard, there's 3 things he can do. He has to be supervised. I now can say, oh Rebecca he did the laundry yesterday or he emptied the dishwasher.i argue for him because he can't. she's laughing now at this point because she gets it. I know she cares very much about him and over time it works itself out as long you make sure they realize that although the child takes more of your time, they do not get more of your love. And that's the important point.

ERNEST: that's a great point. We have a question here from John from Melbourne, New York. My son is 6 years old and DS with PDD and OS. PS: very high functioning , he ?? and ??[1:13:32]. What is a good redirection technique to start scripting? Can you describe to people what scripting is?

CHANTAL: scripting is when someone is always – for example there's tv shows or movies that they like, constantly talking about that or using that as a base for communication. That's kind of a tough one for me to answer. If somebody is doing that it's very good as it shows they have patience, they are capable of carrying on conversations but the redirecting is the hard part and I'm not very good with those questions. What I would look at is looking them up on the internet. I'm going to get back to you on that. Maybe using social stories about situations they have and using the transcripting to focus on their situation. I rather they look at somebody else. I'm looking it up on my computer while continuing to answer.

ERNEST: another question from Martha from Denver. My son with autism is a very picky eater and lately he's accepting a less variety of food: milk, cheese and spaghetti. Do you know any technique to help him accept new things?

CHANTAL: how old is he?

ERNEST: she didn't say. Can you repeat it? My son with autism is a very picky eater and lately he's accepting a less variety of food: milk, cheese and spaghetti. Do you know any technique to help him accept new things? I guess new food to eat?

CHANTAL: the first thing I would look at is the reason why he's only eating those things. It's important to find out if he's only eating those things because of the texture, or color or maybe there's other issues we're not aware of in terms of medical and diet and that would be a good question for the diet person you're going to have on. I would ask her that but I know there are ways of getting people to change some of their diet. If there's no medical problem then it's all about caring. For example if he has his favourite item, have him agree to have one spoonful. Then he can go back to the other items. See over time, if you can slip in one more bite of the unwanted food. The fact he used to like things that he doesn't that kind of concerns me. I want to see what's going on medically speaking.

ERNEST: so she should seek the help of some professional in that area.

CHANTAL: there's a book out there. My books are out in the hallway. Do you have the emails of these people?

ERNEST: yes I do.

CHANTAL: because I can write down ?? [1:17:26], I want to answer that one and also I can give them the name of the book and the author. There's a book out there about seeing the difference between an eating disorder due to a medical situation or when you can actually get them to eat more food and how you go about doing that. And also the scripting.

ERNEST: Another one here, Michelle from Minnesota, my 8 year old son does quite a bit of hand flapping and running back and forth down the hallway or around the table. Why does he do this? She want to know if it's beneficial or should she find a way to make him stop what he's doing and what suggestions you might have?

CHANTAL: you talk to people who are really into behavior therapy: applied behavioral analysis and they will say, oh no, you have to teach him to stop that. They need to do some appropriate behavior because it's not appropriate to do that. A lot of people on the spectrum that I spoke to when I was writing my book Autism Life skills, they would say they're doing that because they need to do that. My son he does other things sort of like the running around, arms flapping that really aren't appropriate that look kind of strange when you're out in public. I taught my son not to do those behaviors out in public and giving him other little things he can do. Of course there's exceptions to the rule. Sometimes he just can't help it. When he was little, I had to drag him around to a lot of different stores after awhile he couldn't help but do that if I couldn't give him some smaller behavior that was less noticeable. But now he's a lot older and he knows he can do those behavior at home. I talked about giving him an alternative form of behavior in public is – he likes to stand and rock and twiddle a piece of string. I have discovered that it's a visual thing for him, moving the string back and forth and I was able to replace that with a book. So when we go out in public, he would carry a book, an age-appropriate book. That's his little security thing. sometimes he still rocks but he's holding a book, it doesn't look quite as strange. If I'm going into stores and I absolutely have to take him with me and there's a lot of fluorescent lighting and a lot of noise, I always have in my pocket, a tiny piece of string. Otherwise if he sees all the tags on the clothes he will want to grab those. First I try the book. The rule about it at home, he can do it but not constantly do it. Right now he's finishing his high school diploma which is another interesting thing I want to encourage people about and talk about in a little bit, at home he has to listen to a ?? textbook to him. Because he can't visually process the information and he won't listen to books on tape unless they're my voice or his favorite tutors' voices so someone is reading the book to him. He will stand and be rocking in his room and we will ask him questions to make sure he's been listening and he has to write his summaries. Sometimes he will continue to want to stand, he takes that piece of string and starts flapping it around. If he can still put out the information and he's focusing then I allow him to do it. If it's interfering with the work, then I don't allow him to do it. In school, he's not allowed to stand in the classroom. It's kind of funny.in NTV through life they showed him standing at school and I almost died because he wasn't supposed to be doing that in school but I guess Jeremy was nervous with the crew and was afraid he was going to look bad. The thing about those behaviors, I would find out why he's doing it. Jeremy is because he’s anxious and that kind of helps him with that. There are kids with medical issues where they have pain in their gut so you have to look are they sick? Why they are doing the behavior, that’s the number one question.

ERNEST: great answer. That comes up to a pretty important question I have here from Keenan from Upstate, New York. I'm sure parents have experienced it before. Our 10 year old son is just beginning to potty train. He is able to request the potty train but only after he’s had an accident. How can we get him to ask prior?

CHANTAL: I know for her, it must be very upsetting. You have to look at it as a positive because he’s actually made the connection between the potty and having an accident. In other words, he’s made the connection that’s what the potty’s for. I don’t know the background here toilet training, he had to sit on the toilet until he went and then got rewarded for that? Because that’s how he would associate with getting rewarded with the toilet by going on the potty. That’s one thing. maybe they’ve already done all that. I think that maybe in this case, the child not feeling he has to go until it’s too late? Remember when we talked about that issue not being able to feel whether you had to use the restroom or not? We had some issues like that with my son. As he gets older, he’d look down and be really surprised he’s starting to pee and he’ll run to the bathroom to finish. Sometimes he finishes and we have a reminder so I think she should look at the schedule of how often he’s having these accidents. Chart that over a 2 week period of time, at home and at school. You can get the staff at school to do it too. And note how much time has happened between accidents. Prompt him to use the toilet before the accidents and have him sit on the toilet and reward him for going. Eventually he will go on his potty on his own.

ERNEST: great answer. I know that’s a common question people ask. A most difficult thing I guess parent have to try and train a child with autism to deal with the issue of potty training. That’s a lot of work.

CHANTAL: all the self care issues are hard.

ERNEST: lets split up here for the last half hour. I can't believe it’s been an hour and a half. Let me pick a few more questions here. Here’s one I'm sure a lot of people are facing now. Her name is Amanda and she’s from ??[1:25:56] Massachusetts. I'm looking for advice when my son starts school and dealing with other kids. Either teasing or making fun of him because he’s different from the other kids. That’s a great question.

CHANTAL: my first advice to parents. A lot of parents they don’t want the other children, the teachers to know their child has a diagnosis. I don’t know about this particular case because I don’t know this is an issue or not. The first I would do is immediately have either the mom, I'm not quite sure how old this child, have the mom write a short note for the teacher to read to the class. Showing what autism in a positive way, or asperger’s in a positive way. For example my son may be different but he’s really good at this. Or some other reasons why he acts the way he does? Just be non chalant about it. Not in a negative fashion but if there’s anything positive they can say..sometimes it’s hard to know if there’s anything positive but some kids do have a talent that people know right away, others don’t. my son is one of those, we don’t know he has any talents. I think that what I have experienced, kids believe they are afraid of what they don’t know, what they don’t understand. If people knew why somebody is different or in what way he's different a lot of the bullying stops. Also need to make sure that the school is behind you. The teacher's not going to support the kids that are doing the bullying. There is a person on the spectrum who writes about bullying and he's name is Nick Duvan. He has a book out and he also writes on his website about bullying. That is the main thing that everyone on the spectrum. These are people who admit they have autism so they're happy to talk about it and Nick says it would've been so much easier when they were younger if people knew what they had and why they had it. If they felt supported by the school staff. You need to explain to your son sometimes people are not nice, sometimes people are just not nice. Period. There are people out there who are just – doesn't matter what country you're in, there's always people who's not nice. That's the reality of life. You're not going to be able to protect your child. He has to know that, that's not right.

ERNEST: very good. We've got a few more questions coming in. let's see. Here's one, my son's being having difficulty in public. Her name is Renee from North California. I took all 3 of my children to a store and my son became very upset at first. I couldn't figure out what it was that was making him upset. He seemed to be focusing on pattern on the floor. How can I help him feel more comfortable?

CHANTAL: I don't know her son but I had a lot of people talk to me about this, people on the spectrum as well. A lot time fluorescent lighting is a big problem and so you might not notice it at some stores, less intense fluorescent. I'm just guessing because she's saying that he was focusing on the patterns on the floor. There's really bright lighting and it's shining off the pattern, making a pattern look more intense. He's obviously focusing in on certain things in the environment. If it's bothering him, if he's focusing he needs to get away because she can't get on with her day. If he's able to wear some kind of tinted lenses like sunglasses, sometimes that helps. Or a baseball cap to keep the fluorescent lighting out of the eyes. Of course I'm just guessing it has to do with fluorescent lighting or being in a place very crowded. It has a lot to do with preparing someone before they go. Talking about where we're going and what store we're going to and it's helpful to wear a hat and sunglasses if they will tolerate those. Another thing to do is to remember to tell people how long they're going to be in certain situations. Sometimes we forget that, we're just going to pop into the store for a minute and it's not really a minute, we're going to be 10 minutes, then we're going to be half an hour. Some people can handle it for a certain amount of time, they can't for longer. They need to know. Even if they don't get it the first few times, eventually over time, they will understand it.

ERNEST: I've got this question from ?? from California.

CHANTAL: I can't give specific answers if you don't really know what the problem is, I'm just guessing here.

ERNEST: that's good enough. People want information here and I've got great question here. ?? from California. How do I get my school district to give my child individual one on one in occupational therapy and one on one speech? They tend to push for group occupational therapy and group speech which will not work for my son.

CHANTAL: what this person needs to do is to get into assessment by speech and language pathologist specializing in autism and also an occupational therapist who knows and is trained in sensory integration

?? [1:32:47]assessment in the school district will have to take her request more seriously. It would be a professional that needs to say that this is necessary. The first thing she can do too if she doesn't have any resources is to ask the school to do an assessment. And if the assessment doesn't come out in the way that she's in agreement with, she has the right to get her own assessment done. She will have to pay for that. Sometimes the school assessment is going to be enough. It all depends on the situation and the school district and which professionals they use. Because sometimes they go to the same person who does the same kind of report and not going to argue against it. You can ask ?? assessment that you want, you can ask them to do an assessment but if you're not happy with their assessment then you can go and get your own assessment as well. You're not going to be able to argue without an assessment.

ERNEST: that's going to be a really great thing for her to do. Go ahead and get those assessments so that she can push to get individual one on one. That's fantastic.

CHANTAL: my son always has OT for a certain amount of time. Here's a one school district ?? that's great. And 6th grade was another school district. Because they split up after the grammar school. After 6th grade my son must have been cured because occupational therapy because they said oh no we don't do OT anymore. What do you mean you don't do OT anymore? My son still has the same problem. Oh we don't operate at this age. Because it's only good when they're young. What kind of reasoning is that? Someone's in a car accident when they're older, they give them occupational therapy and skills therapy because it helps. Occupational therapy would still be valid for my son and the school district has to provide it. It was interesting because that was based on an age thing.

ERNEST: I've got a question here that I'm sure it's right down your alley. It kind of relates to your new book. Patty from Chicago asks can you give some ?? materials or books on teaching organizational skills?

CHANTAL: I think it's a book in general, it's not just for organizational skills but it has great ideas regardless of whether your child has asperger's or not. There are 2 books, one for elementary school and one for adolescents. It's really about school success. I'm looking at the title now in my autism book as I speak. I have so many titles in my head, I can't remember them all. These books are for asperger's and how to be successful at school so there are a lot of organizational techniques and you can translate them into ?? [1:36:27] at home as well. It's kind of interesting my brain's not working at all because of this day's I had.

ERNEST: yes I know you did have a rough day.

CHANTAL: it's part of being a parent with a child in the spectrum. Go ahead and ask me another question and I'm going to answer this when I find the title of the book.

ERNEST: here's a great question from Alice from New York. What's the best way to request home therapy services for ABA from a school district for a child who has not had early intervention services at home and the child is 8 years old?

CHANTAL: what state is this?

ERNEST: New York.

CHANTAL:I can't really answer that because it really depends on the school system you're in. even though the laws are federal laws, the state is allowed to translate it and apply it their way and that's going to be a great question for the attorney. They will tell you where to get advise on that.

ERNEST: I have another question from a woman who's a grandmother and she asks what can she do to best help out her grandson who has autism. I get this a lot actually from people who have -

CHANTAL: I found the book I was looking for. For organizational strategies. It's called Asperger's syndrome in adolescents: Practical solutions for school success. And it's by Brendan Smith Myles. You may say oh, my kid doesn't have asperger's or I'm not really worried about school. There's tons of hints in there about organizational strategies and I've actually incorporated some of those for my son at home. I'm kind of organized in my own way but I have a hard time trying to figure out how to organize in a sense that would help him. This is really good for giving her a lot of ideas. Resources like that are listed in my Adolescents on the autism spectrum so I'm really sorry that I'm not remembering the title in my head. Many times they're written down somewhere I forget them. So grandparents on helping their grandchildren. This is such a good question because it really shows grandparents are trying to be supportive in the best way that they can. The first thing that I would say is if there is any possible way you can provide a ?? [1:39:36]for your children so that means you would need to learn some techniques for dealing with the grandchildren. I say that because some of them may have behavior issues or toileting. Any way that you can actually handle the child for a few hours to a week. I'm sure that's one area that would be really useful. If that's not possible because you live far away,another area is if you are able to visit your child who has autism grandchild is to find one thing you can do with the child to connect. If they're teaching the child using a certain kind of therapy, they might be teaching the child a skill like catching a ball or some kind of little skill like that. I say little skills but they're very hard to teach because it needs repetition. If you can just do that little thing with them that's the way you can connect with your grandchild and also will help your son or daughter. The other thing is just being there for them is so very hard to try not to offer advice because as parents, you were a parent so you have a lot of things to offer. It is so difficult having a child with autism that it kind of goes out the realm of neuro typical child rearing experience. Just the fact you're there is open to listening to your adult child and also if you could just spend time. Time is something they are very short of.

ERNEST: we've got another question here. Her name is Cheryl Lee from ? Ohio. Her question is there a good different plan to follow for children with PDD ??[1:41:50] my son is 5. Is there a good different plan to follow for children with PDD? To teach them to be a part of society. And her son is 5 years old.

CHANTAL: there isn't a plan written in stone, the things that are going to be important as part of society and here's the things I learned, my work that I said that's also really pointed out to me by the adults I interviewed in autism life skills. It's self regulation. What I mean by self regulation, you have to be able to control your responses to things. I mean responses in terms of emotional response and also in terms of sensory overload. For this to happen and this can start very young like at 5. When you see that a child becomes overwhelmed either emotionally or with a sensory overload, you need to be able to recognize when they're reaching a saturation point. And when they're in the ?? of that, you don't discuss that. But once they're out of it, that's the time you can discuss with them what it feels like when have that overwhelming moment, that emotional outburst, the time they couldn't control themselves anymore. Over time, this is all about self awareness, it's just an emotional overload problem, you have to teach them about recognizing emotions in themselves and others. A lot of times, kids will go scared, babies are crying and laugh when they think it's really funny. You have to explain what those tears are. You have to explain what happy looks like, what sad looks like, what anger is. You also give them numbers to their emotions, to their overwhelmed situations so that when their engine is too high or their engine is too low, it doesn't feel right. Eventually over time, you can teach them techniques to do when you're emotionally overloaded. And that's how they learn to self regulate. Unless they can self regulate, they're not going to be welcome in society, they're not going to have a fun time in society because people don't want to be around people who are afraid of people who can't control themselves. That's the number one life skill. The 2nd thing is self advocacy. Learning to speak up for yourself about what you need and want, but in a polite way. That also starts when you're young like ordering in a restaurant, being able to say what it is you like or don't like, to show your choice is respected, ??[1:44:58] as kids get older. When my son comes home from school now he's a teenager, I don't have a schedule all set up for him like when he has to do when. Here are the things you need to do today, what order you want to do them in? you figure out when you want it done. We have to help him and prompt him through it, teach him the order so he has more choice because now he's older. It's really about becoming self reliant in all these different ways and teaching him organization. There's no one master plan, it's really about teaching good life skills which is why I wrote that book. I don't want to sound like I'm ?? myself, but I realize that these are the life skills that we never think about. We're always talking about teaching them. Hey look at me! 1+1=2. But those things are the ones that count when they grow up. Things that count when you grow up are self advocacy, self esteem, self regulation. Those kind of skills.

ERNEST: fantastic. That says it all. I like the way you put that.

CHANTAL: can I say something encouraging about people? About my son Jeremy? He's 19 now , wasn't until 5 years ago that he could communicate by spelling out on a letter board and it's not facilitated, not holding a ?? [1:46:26]or anything but it is assisted, someone has to hold the letter board but he does that with 6 or 7 people he's learning to do this with. The point is up until 5 years we had no idea how much he understood what was going on around him. It turns out he's an auditory learner. He is now finishing up high school, he has 8 more classes to go. If anybody had told me 2 years ago, my son would be getting a high school diploma, earning a high school diploma and passing the test and everything, I would never have believed it. It wasn't a goal for me for my son to have a high school diploma but it's just amazing that is where my son is now. Yes, he's very autistic and yes he's a little slow, he's working on his life skills but he's smart. And he can communicate. And he is such a happy camper because he can communicate. The big thing you want to make sure that your kid don't have a problem is aggression. If you have a child who's aggressive, that's why you need to find out why they're aggressive. Is it because they're hurting, angry, sick or just lack of communication skills that make them so upset? Finding out the source of that and turning them around from being angry to being a little happier. I'm not saying that it's easy. My son didn't just one day type, this was over many years of sitting in classes, so he's listening ?? why are you doing that? I say he has to learn to sit in public, he has to learn to sit with big groups of people like the movie theatre, waiting room. I kind of based it on that, his educational needs because I didn’t have any proof of educational entertainment in terms of my son. Teaching him to spell out on the letterboard, that took many years too. It wasn’t an overnight process. He would never have been able to get there if I hadn’t given him the opportunity to hear and to be in a group of neuro typical kids. I always have ?? and half in especially because he needed both but I just wanted to tell parents, you can never give up. It’s the fact that he wants to learn and this is what he’s doing and now he’s going to have a high school diploma.

ERNEST: when will he be graduating?

CHANTAL:It will be in 3 years.

ERNEST: 3 years! That will be a great day. he has 8 more classes to go, he can handle 2 classes per semester so that’s going to be vocational stuff. The thing is I’ve fought long and hard. It wouldn’t have happened if the district people hadn’t changed and I managed to find the right professional. It works with people who have severe communication difficulties like my son. It was very validating to find out that everybody is behind my son. it’s more like I taught my son and my son convinced them. It wasn’t me, it was my son.

ERNEST: that’s a wonderful story. Brilliant. That’s going to give encouragement to a lot of people. I have here another question from Dan from ?? South Dakota. He says his son has 2 conditions. In general, it’s a question about insurance. I know there’s been a lot of debate about whether insurance will cover for some of the treatments for autism, could you elaborate on that?

CHANTAL: the latest I’ve been hearing it really depends on the insurance company. It depends on the state you’re living in too because there’s been many states who have been eradifying or putting acts into effect about how people can be refused for certain things after certain conditions have been discovered. I really can't answer that question because I have no idea about south Dakota. Even when you’re in a state where you know what the rules are very confusing because we all know that insurance, I hope I'm not insulting anybody out there who’s working in the insurance field but it’s very complicated. I find that often you get refused something and you have to keep plugging away and asking. One thing that I do know that there is an autism insurance Yahoo group out there, link up to that because there’s a lot of discussion information sharing.

ERNEST: I can google that and give a chance to link up to that and get some information from there.

CHANTAL: I'm really sorry that I can't answer but I’d rather –

ERNEST: it’s ok, we’re just kind of rolling along here. Her name is Rene, she’s from Newark, California. I think it’s the same one who called earlier. Did you change your son’s diet, I heard that gluten free diet helps children with autism. I know this is going to be a subject coming up here next Wednesday. Could you elaborate a bit. What your son’s diet issues are?

CHANTAL: he’s very much the typical canner autistic child who never develops properly and I have to say I have tried the diet with my son and I have tried other kinds of bio medical treatment and very little has worked with my son but my son is as healthy as a horse. My son doesn’t have any of the issues that a lot of kids with autism have these days. But I will say and I do know for a fact from many people that I see that the diet has helped. What I like about the diet is that something you can try. It’s a lot of work and you might spend some money. You don’t have to go see doctors , spend thousands of dollars and then wonder if you went to the wrong doctor. You can actually get a couple of good books. You just have to do it correctly, make sure that you remove everything and try it for a month and see if it makes a difference. In my mind, these is one of the first things to try just because it’s been helpful for so many people. Again we’re learning, the experts are believing that autism is really caused by many different things and that’s why you’re not going to find one thing that works for everyone. Autism is not diagnosed through a test, but through the observation of symptoms, behaviors. Oh, if you have these kinds of behaviors then you have autism. But why you’re acting that way, you can have many different reasons why your child is showing autistic symptoms. Somebody who is sick from mercury poisoning, from the vaccines or ?? immune systems that didn’t work. They may be showing the same behavior as someone like my son who is autistic for a different reason or has autistic symptoms for a different reason. The diet is going to work great for some people, it’s not going to work for others but I say, for anything that doesn’t cost you an arm and a leg or doesn’t make you mortgage your house and that makes sense for your child, I would go and try it if it’s not going to hurt. My son has sensitive hearing to noises , I tried auditory integration training because that made sense for my son’s problem. You have a child who has no issues with auditory, it makes no sense. It’s the same kind of thing with a lot of therapy. The diet is one I would tell everybody to give it a shot.

ERNEST: we’re coming up to just 2 minutes and 40 seconds left to the call. Final question. It seems really appropriate here. Trish from Albany New York. What do you think is the most important thing you learned from being a mother with a child on the spectrum?

CHANTAL:that’s a really loaded question. I'm not one of those people who says oh, if it weren’t for autism, I would never have met all these wonderful people. Having autism is like you’re getting on a plane that’s going to Italy but when you wake up and the plane didn’t land in Italy , you’re in Holland. Holland is nice too. I don’t really believe that way because I would have known a lot of nice people without having a child with autism but I do believe having a child with autism has really shown to me what’s important in life. There’s nothing like when your child does a little step in a positive direction and learning something and you see that life goes on over their heads or you realize that your child has moved one step up in a certain direction towards independence, understanding. Or you found something that really helps your child in terms of bio medical technique or strategies and it’s making such a difference in your child and you think wow. That’s what’s important in life. It doesn’t matter what car you drive, what clothes you have , what really matters is those little things. I'm taking things day by day is what I’ve learned from a child with autism. You have those days when you’re so upset because everything’s going wrong but then you have those days where you see that little glimmer of sunshine.

ERNEST: thank you so much for telling us that and we’re coming up here on the end of the call and I just want to say that everyone who’s ?? on the call, thank you so much for calling. I want to thank **CHANTAL** for coming in and taking their time off their busy day, coming to talk to us all. To all of you who are on the call, there’s a link at the bottom of the page that says ?? testimony, we love to hear what you think about the call and get your feedback or things we could do differently, we could do better. Once again chantel thank you so much for spending time with us today.

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