

* **Content Warning:** Detailed description of abuse

Noncompliant Podcast Transcript

[“Co-Regulation is Key”](#): A Conversation with Occupational Therapist Greg Santucci

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Transcribed by Julie-Ann Lee

(Theme song – soft piano music)

Anne: Welcome to the Noncompliant podcast. I’m your host Anne Borden King. Today I’m talking with Greg Santucci. Greg Santucci is a Pediatric Occupational Therapist and the Founding Director of Power Play Pediatric Therapy. He’s been an OT for over 20 years, and currently is a Supervisor of Occupational Therapy at Children’s Specialized Hospital in New Jersey. Greg is the creator of the Model of Child Engagement, and has been lecturing nationally for over a decade on topics related to sensory processing, child development, behaviour and best practices in the public schools. He has dedicated his career to promoting neurodevelopmentally-informed relationship-based interventions to help parents and teachers support children of all abilities and learning styles.

Greg, welcome to the show!

Greg: Thank you so much for having me. It’s great to be here.

Anne: Great. I wanted to start off with the “wool hat story” which happened earlier in your career. When you told that story, I think that’s where a lot of autistic advocates first tuned in to your work. Your story tells a lot about the environment of coercive control that some people have been forced into in Special Ed, in autism therapy and in institutions. So, tell me what happened that day?

Greg: Anne, it...it’s hard to talk about it, and I will say that it was my worst day as a professional. I was working in a school for autistic children. It was a summer program and I was picking up a kid for his weekly OT session, and I was late. In the session beforehand, the child had some problems with transitioning, especially away from OT, so that’s par for the course for what I do, so I was a few minutes late to this session, and the class was already outside on the

playground. I proceeded to go pick up my kid on the playground and he was already on the playground equipment. As soon as the teacher saw me – it was a young teacher – she called his name and said ‘come inside it’s time for OT’. Now, obviously the child didn’t want to come, it was outside on the playground on a gorgeous day in the summer. so he resisted. And, I told the teacher OTs are really flexible and can adapt to just about any environment, so I was perfectly fine with working outside with him, and going in and getting some stuff--to play with him outside and work towards our goals there. But the teacher refused because she said ‘the demand was already placed’ for him to come inside, so she had to stay with that.

So at that point, confused, but you know not wanting to overly challenge a co-worker... ‘okay, if you’re going to get him inside,’ I stepped back and let her do what she thought was right. That insisting that he come in escalated to her and another para-professional trying to physically remove him from the playground equipment. And in resistance he dropped to the ground. That makes sense to me, he wanted to stay out there. Oh, I will say that this is a child who had very little verbal language, so he was communicating in other ways that he didn’t want to go.

He dropped to the ground, they tried to pick him up and then he started flailing and kicking them, and that’s...that was interpreted as aggressive behaviour, which is interesting to me because the aggressive behaviour actually started with *the adults* trying to pull him off the playground equipment, but that’s...

Anne: Mm-hmm.

Greg: ...something else, so. The aggressive behaviour triggered his Behaviour Plans. The Behaviour Plans said that if a child gets aggressive, a ‘visual screen’ is to be used. So the teacher asked her co-worker, “should I go get the hat?” Now, I had no idea what ‘the hat’ was. So, again, I had stepped back at this point just waiting for this child to come in to OT even though I was fine with him being outside. So, she went in and she got this grey, wool hat and her...you saw her morals kick in. So, she didn’t do the visual screen.

The ‘visual screen,’ as written in the Behaviour Plan is to cover his face with the wool hat until he calms down, and then follow through with the demand. So, they were blocking the vision of a child in crisis to get him to stop resisting- stop the aggressive behaviour, and then follow through with the demand they placed on him. But, her morals kicked in, and she just started taunting him: “Do you want the hat? Do you want the hat? Do you want the hat?” and it- I don’t know which is worse, actually doing it, or just taunting him with it. And, I can still hear him saying (panicked) “No hat! No hat! No hat!” and it was just awful... and the next thing she said was “Then go inside for OT.”

Well, he was broken.

They broke him, and I was broken. I couldn’t believe what I’d just witnessed. How powerless he felt, how dehumanizing that was, and you know... my OT time with him was ruined. We spent

the rest of the time just trying to co-regulate and feel some sense of normalcy and humanity again. And after I separated from him, I walked into the therapy gym and my co-worker looked at me and said, 'What happened to you? It looks like you just saw a ghost.'

Anne: Yeah.

Greg: And, ah, I ended up leaving for the day. And I went into my car, and I processed what I just saw for a second, and I called the State Institutional Abuse line...

Anne: Mm-hmm.

Greg: ...because I am a mandated reporter and that was clearly abuse, and was pulled in the next day to the principal's office. Got into an argument about how to treat children and them defending their practices, and I was fired the next day for insubordination.

That's my "wool hat story".

Anne: Wow. And how did the state respond? Did they take action against the school?

Greg: They came in. They investigated. I didn't learn that much because I was gone so fast. I can tell you from my friends in the program that the wool hats did go away. So, that being said, I am fine with being fired. Because it was part of the Behaviour Plan, there was no punishment against them, if you will. But I definitely woke them up and was proud to say, as painful as that was, that they used to walk around with wool hats in their back pocket I've learned, and they called it "the hat trick" and that practice has stopped.

And there are a lot of people who don't know that these things are happening every day in these schools, and they are! I stopped it in one school, but it's still going on.

Anne: Wow. I mean, yeah, it's really interesting because people that don't know anything about Special Ed, they often make a lot of assumptions about Special Ed that it's a happy, friendly, fun place, but when you start to look at some of what's really going on in many Special Ed programs, not much has really changed in decades, number one. There still is restraint allowed, seclusion--otherwise known as locking someone in a room--is still allowed and it often doesn't get flagged until there's an incredibly terrible incident when someone draws the media's attention to, and then sometimes there's action; or if someone like you reports it.

I mean, you're one of a few therapists who are talking really frankly about what they've seen and then how they were affected and how kids get affected by this kind of workplace or this kind of school setting.

So, I think what you've done, it's really brave first of all, but it's also really instructive to people going into these environments...I think about the kid who comes out of college, right, to do this work. Let's say they're going to be an aide in a Special Ed class, a CLC or whatever terms they use in the U.S. and they don't usually know what kind of an environment they're stepping into.

They really don't. I mean a lot of them are really full of ideas and they're very excited about it.

In the worst scenario, suddenly they're involved in a workplace that's harming kids and they're coming face-to-face with something like you came face-to-face with, only in many people's cases it's their full-time job, and they thought they'd signed up to help, and they're put into the role of instigators of sometimes really horrific practices, or at the very least they're bystanders to it. And then they have to make a moral choice, 'do I go against the flow? Do I report this? How do I respond to this?' And I'm wondering what your advice is to young practitioners whether they're coming into a school or they're working in the school when they witness something like this?

[9:30]

Greg: There's a couple of layers to that. In my situation as a mandated reporter, it's 2021 we can't be covering kids' faces with a wool hat. That needed to be squashed, and so I would encourage anyone to **report blatant abuse like that as abuse**. I can tell you that it was a huge financial hit for me. And, again, I'm fine with it, but I understand the angst that the therapists have who're there to do good. The teacher is a well-intentioned... is a good human being that thought she was doing right. That's what she was taught to do. So **abuse is abuse; report the abuse**.

On a smaller scale, and again, I tread carefully when I say 'smaller scale' because I really think there's a lack of humanity in the way we treat kids who are in special education. Something like sitting a certain way, or 'quiet hands'--those are things where you can actually make change. where you can show, and teach... teach the teachers; teach the paraprofessionals; teach people a different more positive, more healthy way of going about it.

And don't stop there. Talk to administrators. Have a professional dialogue but stay positive with it. If they feel like they're up against the system and we're talking about a problem within the system... It's a judgement call. I've learned over time that I can't work in places that I struggle to walk into every day. So I don't. But I understand the difficulties. You should report if you see something that really challenges what you believe in, but you should also be working very hard and very deliberately to **be the change that the system needs**, because our system for dealing with behaviours is just so antiquated, and there's so much new knowledge out there, so I would encourage them to as best they can – *be the change*, be willing to take the necessary steps to advocate for those kids.

Anne: Yeah. It's interesting that you mention that it's a really antiquated system. I've had other guests on the show say the same thing. I'm wondering first of all, what's really at the root of something like the wool hat aversive? Where does that come from?

Greg: There's two things. Well, at first I would say, straight up **ableism**. I mean, the belief that we can make autistic kids look just like neurotypical kids because that's what makes neurotypical people feel comfortable, when everybody looks and acts like everybody else. You know, just in terms of kids with autism and you look at the behavioural strategies and interventions that have been used... If you dive deep into the history you know that historically, autistic individuals have been treated less than human.

There's that famous article that Lovaas wrote back in 1974 that described autistics as 'severely disturbed' – those are his words. He talked about restraining kids for *six or seven years* – those are his words from this article, and then most famously about the need to construct a person that 'you have a person in a physical sense but not in the psychological sense that you have to build a person.' This is the foundation of where the behavioural strategies came from.

Anne: Mm-hmm.

Greg: So, they talk about 'new' strategies or 'new ABA' if you will, but the system still goes towards behavioural strategies. There's a conference occurring this year that talks about animal and human training. **Lovaas and Skinner are still part of the curriculum to become a behaviourist**, but not neuroscience – [neuroscience is] not part of the curriculum, which it needs to be. And, I mean it just... this is what's out there. This is what the literature was. There's even a book called "How to Think Like a Behaviour Analyst" and the author of that book also wrote a book called 'How Dogs Learn'. So, there's that and there's also the need to **control** and the power grabs just inherent in our system that are really frustrating.

Anne: Yeah. It seems like there's two factors. There's the influence of the Skinnerism... Skinner's had incredibly influential in ABA and it's not something that people always talk about... but there's also influence of this old, really antiquated way of thinking and this dehumanizing way of looking at things and then when you put it into a school setting which is also has authority and control problems, it gets amplified, right?

Greg: Right. Absolutely.

Anne: One of the things that I think is interesting about ABA is the jargon. People go into an ABA program and they learn all this jargon and they get tested on all this jargon and they feel like they're *experts* in the jargon and they feel like they're experts on autistic people...

Greg: (laughing)

Anne: ...And you did a great post about jargon in your field, but with the terms that are used like ah, someone's 'preferred item,' which is something they like to carry.

Greg: (laughing)

Anne: 'Edibles,' which would be like giving people food as a reward, like the dog training thing.

Greg: Right.

Anne: ‘Proprioception,’ which I think just means sensory stuff. Can you talk a little about this use of jargon within your...

Greg: ...I give them full credit, they are experts in their jargon. It is very difficult to have a conversation with somebody who uses that much jargon that they learn in a school program that we learn in. Yeah, so you mentioned some good ones. The edibles [one], I honestly think it’s because we’re embarrassed to say [reward with] food or even treats.

Anne: Right.

Greg: ...and the denial that the practice is similar to dog training. ‘Preferred items’ is another interesting one, because we all have preferred items. But we don’t necessarily need them all the time. When we’re in an environment when we feel safe we understand and we’re able to meet the expectations... like our jobs, we don’t need our preferred items, we can kind of follow along and meet the expectations. So our jargon gets a little bit ridiculous while we’re trying to sound fancy.

‘Proprioception,’ yes, that is in the sensory jargon...that one is a little bit different but it’s not, it’s the same thing but we have to be careful how we use it. It actually is a neurological term but in any evaluation that a professional is writing, especially an Occupational Therapist who is trained in sensory processing, if a parent is reading that, you need to not be using the fancy words, or explain them but then go into more layman’s terms...proprioception is body awareness, it’s what allows you to walk through a door without crashing into the doorframe. A parent would understand that.

Proprioception just is a fancy word that makes us sound important but it’s not about us sounding important; it’s about teaching a parent, or teacher or whoever is reading the evaluation so they can better understand their child. So I get it as a professional, I will talk professional-to-professional and use some of that jargon, but my favourite story is I was in an IEP meeting, and I was a student, an OT student at the time. So, this was decades ago... I’m that old.

Anne: (laughter)

Greg: And the OT was reading their reports (which you shouldn’t read a report when there’s live human beings in front of you, anyway,) but she had written “R.U.E.” in her report, meaning *Right Upper Extremity* ...and the very savvy parent stopped her mid-sentence and said ‘In our house, we call that an A.R.M.’

Anne: (hearty laughter)

Greg: (laughter) I almost died. When I looked around the table, like that was brilliant, and fabulous and like Oh my God... So yes, we have to be very careful with jargon and we have to speak in a language that the people who are also trying to help this child understands.

Anne: Yep, yep. That goes against the flow. And you know what, I want to talk about one other word that we hear a lot, because I think it's been misappropriated, much like proprioception.

Greg: Yes.

Anne: ...And that word is *resilience*. Some like to call it resiliency – whichever word you use. let's talk about what's been going on with the term *resilience*. How is it being used and misused?

[19:16]

Greg: Uh... geez, I'm diving into everything that's going on with the pandemic...and that term. I'm concerned about the kids coming back into whatever this new normal is going to be and the phrase that 'oh, you know, kids are resilient'. I think we have to be a little bit more sensitive to what our kids have gone through with this [and] what we've *all* gone through over this past almost... my goodness... two years. Of the kids having barely any social interactions; having to learn through a computer screen. If we start using the term *resilience* or *resiliency* I think we're in a dangerous place from a mental health standpoint. I've worked in the schools for 20 years. I still work in the schools – I was in a school today before we started recording this. The kids are.... There's a lot of challenges right now – emotionally, socially you see it.

So, I'm not using the term *resilient* right now. I am much more interested in using the term **co-regulation** and meeting the kids where they are, respecting this sustained trauma that we've been through. And supporting them wherever they're at versus just assuming that oh, 'we'll get through this, this bad thing happened, but we got this.' I think there's a different way of going at it.

Anne: Yeah, I like the way that you put a sort of *mutuality* to it because this is a big transition for everyone. I'm thinking so much.... We're putting a guide together for an organization that I work with about *un-sheltering*. I live in Ontario where we've had rolling lockdowns for a very long time. How do we *all* adjust to un-sheltering? We're all going through it, right?

And, the point is people looking at a child and saying 'oh he has trouble with transitions; he has trouble with his routines being disrupted.' You know, what we've realized from this pandemic, if we didn't know it before is that everyone has trouble with their routines being disrupted, but it's really the first time that some neurotypical people have had their routines disrupted to the degree at which a lot of kids get their routines disrupted on a very regular basis. So, in some ways it's been a lesson I think in how we define resilience and talk about resilience because we're *all* having to find that within ourselves right now, and maybe it can promote some compassion towards people who've been dealing with these kind of issues longer or in a harder way.

And this idea I think that you're talking about--about how we're going through this together and co-regulating throughout this, is really, really important because the lockdown and the pandemic has caused varying degrees of trauma for people, but it's also going to be really difficult in the period afterwards. There's going to be a *new set* of challenges, right?

Greg: Uh-huh. One of the things that I'm starting to hear now in the educational dialogue...and here in the U.S. we're all about our standards and our high stakes testing, I keep hearing the phrase 'catching up'. And that scares me. That, if we're going into this thinking that we should be catching up, so to your point, the first thing that I think we should do is lower our expectations a little bit, and see where the kids are at when they're coming through the door.

We try to build safe environments in the schools...our safety has been threatened for the past year or more with the not knowing what's happening, losing loved ones...There was so much stress, so if we go into this return to school thinking that we're going to 'catch up,' we're going to be creating more problems than we already have. I genuinely think we have to be very careful – lower our expectations, maybe put away the high stakes testings for a while here in the States? I don't know if the system is prepared to do that.

Anne: Imagine that! Wow!

Greg: Shocking!

Anne: Let's imagine that for a minute!

Greg: And I don't think they're prepared for what's to come. And I'm a little bit nervous for the kids, so you know just for whoever's listening and whoever is in education: **Co-regulation is key** – that kids need to walk into a school and they need to **feel safe**; and they need to **feel heard**; they need to **feel validated**; they need to **feel important**. So, let's **focus on safety first** instead of standards and start from there and see where it goes.

Anne: Right, and like *real* trauma-informed practices.

Greg: *Actual* trauma-informed practices.

Anne: Really important... see, that is another term that's really been misappropriated a lot lately. But, yeah.

Greg: Absolutely!

Anne: I think that it reveals really to me---because I've been reading a lot about ABA, I'm writing a book right now--the kind of ideology that drives ABA, and the way that they are constantly marking and evaluating. They have all these tools for evaluating and grading.

Greg: Yes.

Anne: And then I realize, well this is why – *maybe* why it has appeal to so many school environments, because in the school environment, especially with Common Core, or whatever you want to say that’s been happening in the U.S. that’s caused this to happen (it maybe goes back to the [space race](#), but) evaluating people against other people and having behaviour charts and having the standardized tests and being really *ruled* by that to the point where you can have something like a pandemic happen and people are still talking about what we’re going to do about these tests.

It hasn’t really *shifted* people or it’s very difficult for many to make the shift to say, ‘okay, well things are different right now, we need to respond differently and react differently’, and we need to let go of some of those tools and maybe throughout this process we could actually learn that, a lot of these tools should be either modified – I’m talking about schools right now, and grades and tests-- some of these tools could be modified and some could be *cast aside*. This would be a great learning opportunity I think for us to look at like the whole child and to look at ourselves as whole persons too, as parents and then for educators and providers, right?

Greg: Oh, you are spot on! So, we have become data obsessed in the schools. Another phrase that I hear a lot is ‘data-driven decision making,’ Data driven decision making...what does the data tell us and that’s how we make our decisions. There’s a couple of things. One, there’s no humanity in data, which is a big sticking point of mine. And in the behaviour world, they are excellent at taking data. However, their data doesn’t fall from the sky. Humans collect data based on whatever their training and competency is in. So I submit that we may be taking data on the wrong things.

I am a huge advocate for **relationship-based decision making** first, before we ever get to data-driven decision making, so we can make sure that we are partnering with our kids; that we are co-regulating with our students, and that they are able to be the best them. Then when we start actually taking data and measuring our outcome we’ll find that our outcomes are bigger and faster, and I don’t like putting a number to it, but 100 percent of the time that’s actually what happens. So yeah, we’re definitely data obsessed, and that is a huge problem in the schools.

Anne: How do we fix that problem? What’s the kind of disruption or intervention that needs to happen to get people to think outside that box?

Greg: The short answer is I don’t know. In the States we like initiatives. We like the big initiatives... ‘now we’re doing social-emotional learning; and now we’re doing PBIS.’ We like these big initiatives and we never get to a place of where we really need to be...supporting kids and actually teaching them versus just providing them information. So the first thing we need to do is a mindset shift. And I don’t know whether to do that on a large level or from a school or regional level.

So what can we do to change things? Well, first go to your point about restraints and seclusions: that should just be legislated. There should be no seclusion rooms in any school anywhere. And I don't know how adults think that that's okay. Here in the States, there are nineteen states that still allow corporal punishment. So, you can still paddle a kid in 19 states in the United States in 2021. That has to be legislated.

Ross Greene's work and his Collaborative and Proactive Solutions model. That is an evidence based model that can replace some of the archaic practices that we have in the schools. So, there are models out there. Then it's going to come down to money, and getting this education to the teachers so that teachers are actually doing what probably brought them to the profession in the first place, connecting with and teaching children. But for me making the change always starts in the trenches, with one teacher and one kid in one classroom, and having that success without the need for a clip chart or some Behaviour Plan. Having that success and then sharing that success...

[30:04]

Anne: Yeah.

Greg: ... with the decision makers, with the principal, with the superintendent, and starting from the ground up. I don't know what the answer is in terms of a starting point, so I'm kind of like okay, *wherever you're at*, let's go all hands on deck and let's start doing things differently.

Anne: Yeah, yeah. It's very organic. It comes from kind of the grassroots really.

Greg: Right, right.

Anne: It's just like the Neurodiversity movement. The changes that are happening, so many of them ...and I work for an autistic-led advocacy group and I do think the work that we're doing is important. But *equally* important and sometimes really above and beyond are these singular conversations that people are having – that parents are having with autistic people and learning about autism from autistic people. This is like something that's happening really outside of the system that within systems people don't always even know about ...and it ends up being the parents having the conversation, learning to understand their kids more and their kids' needs more by having these conversations – and a lot of it's happening online with autistic people, and then bringing that information to the teacher or the provider and saying 'I would like to try *this*. I heard about *this* approach. I don't want to use this *other* approach that you've told me I need to use.'

And these conversations...then that start to shift the therapy centre and then it starts to shift the school, and then the school puts pressure or the school board puts pressure to bring in someone like the SCERTs program or Ross Greene or someone like that. And then that starts to

push into the policymakers, and the policy and the funding. So, it's this very, very slow but almost I think domino effect that's happening...

Greg: Yes.

Anne: ...that's exciting to be a part of because it's so grassroots at the core, right?

Greg: *How lucky are we that we have an entire generation of autistic individuals who have been through these therapies and can now tell us what works, for lack of a better term, and what doesn't or what feels right or what may be abusive, or what promotes masking or what is ableist. We are so lucky to have that and then to have the neuroscience back up what they're telling us. It's a great time to be a professional out there trying to help these individuals be the best people they can be, when the science matches up with their experiences.*

But we have to put our professional vanity aside, and we have to start listening a little bit better than we are and not get so offended that what we we're doing, or what we *were* doing may have actually caused masking, or hurt somebody or at least made them uncomfortable. Nobody likes to hear that, but we *have to* hear it.

I know when I was first starting out in OT 20-plus years ago, I was convinced – here's a jargon word – *vestibular... vestibular*, I could *spin* the autism out of a kid and you know...

Anne: (laughing)

Greg: ...I've learned differently and we now, although the science of sensory integration has kind of withstood the test of time, we've learned more about active vs passive sensory input. We know a lot more about sensory overload from autistic individuals. And when you put it all together, the neuro holds up but we can improve our treatment. We are so fortunate to have those voices speaking out and we just have to do a better job listening.

Anne: Is that- what would you say to parents in the work that you do? And, maybe you could describe the work that you do, in the home environment for example. What can a parent do from that sensory perspective for their kid?

Greg: So, I love to use the term **sensory validation** to validate your child's sensory preferences, but by doing so you have to first understand how they're experiencing and sensing the world. For example, when working with a parent a common theme that they'll say for young children is the child loves being in the water, but they hate having their hair washed. That is perfect for an OT, and I have to be careful with my jargon, because that is the vestibular sense. But that [term] doesn't mean anything to a parent. What I can tell the parent is that when the child tilts their head back, that is scary for them. They feel like they're going to fall. Now, I could explain to them that it's a system in their inner ear called the vestibular sense, but that doesn't matter – they're scared. So, if you have them tilt their head forward or give them a little support – I don't want to say *postural support*, I can say give them support in their belly at their back, and tilt their head forward and maybe have them cover their head their face with a cloth, it might

not be as scary. Or even put goggles on them so that they can still keep their eyes open so they kind of know where they are in space and [parents] come back to me like 'that worked!'

Anne: Hmm.

Greg: And it's like, isn't that great?

Anne: (chuckles)

Greg: So, it is like that – those are the kinds of things that Occupational Therapists do, we learn about how a child experiences and senses the world. We respect that and that's the first... we're not going to *force them* to tilt their head back. I'm not going to give them a treat for tilting their head back because it made them uncomfortable. I'm going to respect their neurology. I'm going to work with it. We're experts at **activity analysis** and we're going to break it down and then as they get more comfortable, as they develop more, then they'll be able to take more chances, take more risks and then most likely take showers as an adult like we often take baths... or maybe not! And that's okay, but at least they can feel safe with their co-regulator – their parent -- and get clean.

Anne: Yeah.

Greg: (laughter)

Anne: Yeah, that's a great example. I like all the ideas that you just mentioned and also the idea of being relaxed about it. I think that it's very difficult for many parents to relax, especially in the period right after they get their child's diagnosis.

Greg: Yes.

Anne: It's really a big panic period there, and maybe there's an opportunity there for Occupational Therapists to step in and help them to slow down and regulate *themselves* around the stress that they're feeling about the diagnosis.

Greg: Yeah. They get a lot of things thrown at them. I've been in the room where families get the autism diagnosis for the first time and I know that overwhelm. I experience it *with* them and I have my own feelings.... I don't claim to feel what they're feeling but I know the overwhelm and I've talked to them about what they're worried about in the future. And you know they get all of these therapies and interventions recommended. It's just a full court press and 'is my child going to be living with me forever? And is he going to get a job?' and all of these things are rushing through their head.

From my standpoint and looking at it from a **strength based model** is if the child is autistic, they were autistic before they got the diagnosis and afterwards, so you've got the information but it's still the same child that needs you and loves you and so you move forward. I often tell parents as they go through all of these therapies and all of these recommendations from all of

these professionals who apparently ‘know everything’ that a parent’s gut should almost always override what the professionals are telling you. I always applaud parents who say ‘No’ to something that they either see and they don’t like. I feel that it’s not happening enough. I know there’s pressure to get as much therapy or as much intervention for your child as possible and your doctor who you trust is telling you you’re going to need 20 or 30 hours of ‘intervention’ and they’re going to come to your house in order for you to have a ‘normal’ life, whatever that is. And parents start to believe it.

[39:15]

Anne: (whispering) Mm-hmm.

Greg: And, well maybe your insurance company covers it, so then it must be okay and you’re getting this help. Then this nice professional comes into your house for so many hours a week and they convince you that *they* are the answer and when the child is getting aggravated or frustrated or complaining – ‘oh well that’s all part of it.’ No, it doesn’t have to be part of it! Again, go with your gut.

I understand the parents’ overwhelm but the number one thing to do is to look at that precious child in front of you and to learn about how they’re experiencing the world and start there. That you are their therapist, their banker, their clothes supplier – their everything. So, be their everything first. And the interventions should be targeted based on specific challenges that your child is having. Say with something like activities of daily living like dressing or hygiene issues or learning new motor plans so they can expand their play repertoire. Not just an insane amount of intervention because that’s what everybody’s telling you to do, which completely disrupts your life, and takes you away from your kid!

Anne: Right, right. Very stressful.

Greg: Yeah, very stressful.

Anne: Parents are sometimes supposed to mimic the behaviour of the therapist even after the therapist has left for the day.

Greg: yeah.

Anne: ...and do the reward and punishment

Greg: yeah.

Anne: ...and all that too. I think the piece that’s missing a lot of the time is friendship. I remember when my husband and I, we had our son and the hospital gave us this little booklet to take home about parenting, because they’re smart...

Greg: (laughter)

Anne: ... and they know that people need to read some stuff about being a parent! And I opened it up...we had gotten home from the hospital and I opened it up and the very first line in the book was, "You are your baby's first friend." And I was like, wow! that's kind of an ethic to keep throughout all of your parenting is that like, you're the friend too. Like, and you're modeling what friendship is and you're modeling relationships the whole time that the child is growing up and when I see parents turning around and saying you know 'I don't want to do 30 hours of ABA and I want to let my kid have their special object whenever they want it'...

Greg: Mm-hmm.

Anne: ...and things like that, and 'I want to relax about some of these things.' I really see that when they're advocating for their kid, they're modeling so many of the good qualities of friendship in doing that...and though their advocacy. And that's a piece that's often missing. You feel like- I think a lot of parents feel like they have to play a certain role in their child's life. But, kids- especially kids that are autistic- they really need an advocate and they need an ally. They need someone in their corner and that is usually going to be their parent.

Greg: Absolutely. So that- that being your child's first friend, I'm actually going to go home and tell that to my teenager tonight (laughing) because it gets interesting when it gets to the teenage years. I absolutely love that. Friend, absolutely and partner. You're solving problems together regardless of whatever their label or diagnosis is, or situation is. You're working together to solve problems that comes with a mutual understanding of each other and it's a great place to be and as a professional, I don't want to *take the place of that* or for you to rely on me. I want to be there to support- to maybe add some new tools to your toolbox, to help you understand a little bit of how the brain works or how they're experiencing the world, because that's what our training is in, but at the end of the day, the parents are their best friend and their best therapist.

Anne: Wow, and so what's going on with your work now? What are some of the things that you have going on in the future?

Greg: Well, I can't wait to get back on a plane again and start talking to everybody, and I hope I can get to Canada. Right now I'm doing a ton of writing. You had mentioned in the bio, the Model of Child Engagement and that kind of is a combination of all of the neuroscience that's out there with a very functional and practical twist to it, where a **child must feel safe in order for them to be regulated**, which is when your energy level matches the energy level of whatever task you have to do, and when you're regulated, then you can participate. If the child does not feel safe, they can't be regulated and therefore it's going to be harder to participate.

So I'm doing a lot of writing on the Model of Child Engagement. A lot of travelling – yay! – will be coming up. I'm doing some outcomes testing with the Model of Child Engagement, and that is so much fun and I have a team of therapists helping me with that. But, there's a lot of preaching going on because of what is going on in the schools and you know the more people

that we can get on board with this change of mindset, and that's really what it is....We're not necessarily talking about a program or an initiative, we're talking about co-regulation; we're talking about a mindset. And I will channel my Ross Greene here--my inner Ross Greene--and say that kids do well if they can.

And, that is huge and so important, that doing well is always preferred, so when a kid is not doing well, we do not need to move their clip, we don't need to take away their iPhone or ground them or put them in time out. We need to *help* them, because they're having a hard time and so, a lot of my writings and my speaking is focussed on celebrating kids. Celebrating the way they experience their worlds and process sensory input and supporting them and being a voice for the kids who don't necessarily have a voice of their own.

Anne: Thank you so much for coming on to the show Greg Santucci. It's been great speaking with you and we'll include some links to some of Greg's work on the podcast blog. Thanks again.

Greg: Thanks for having me!

Anne: I was speaking with Pediatric Occupational Therapist, Greg Santucci. He spoke to us from New Jersey.

(Theme song – soft piano music)

Anne: You've been listening to Noncompliant. I'm your host, Anne Borden King. Noncompliant is usually recorded at MCS Studios, and engineered by Nathan Greavette and TJ Liebgott. The Noncompliant podcast is transcribed by Julie-Ann Lee. Thanks to everyone involved, and thanks for listening.