

ANNE: Shannon Rosa's writing and interviews are featured in *Huffington Post Parents*, *The New York Times*, *the Wall Street Journal*, *Parents Magazine*, and many other publications. She also writes at [Squidalicious.com](http://Squidalicious.com), and is a co-founder and editor at *Thinking Person's Guide to Autism*. She speaks at conference, and has edited several anthologies as well. She and her son Leo were featured in Apple's iPad Year One video. Shannon and her family live near San Francisco with her husband and three children.

I'm so glad to have Shannon on the show today. Shannon Rosa, welcome to the show!

SHANNON: Thank you for having me.

ANNE: A lot of people tuning in will know you as a founder and editor for the blog *Thinking Person's Guide to Autism*, as well as your amazing work as a writer and advocate for autistic rights. But not everyone knows how it all began. How did you start doing activism and advocacy work?

SHANNON: Well, I'm the parent of an autistic teenager. He's now 18 years old. When he was diagnosed, he was three. And he's continued to be a high-support autistic individual. So he goes to a school for autistic people who need one-to-one support. And, initially I fell for a lot of the autism pseudoscience and anti-vax nonsense, because in the mid-aughts there was very little information for parents, and very little information countering all of the carpetbagger-y nonsense that was available at the time.

Since then I've learned better, by following legitimate research, and also by listening to autistic people about what works for autistic children. And now I know better. It was a long hard road to follow, with a lot of really bad hiccups, and I think that my son could have been a lot happier if knew then what I know now. So I'm trying to help other people leapfrog past all of the fear and confusion and get right to supporting their autistic children—or themselves, if they're newly diagnosed—straight from the beginning.

ANNE: That's great. It's interesting, because you've written about those transitions for yourself, really eloquently and with understanding, about how parents can blame things like vaccines for autism, and I guess that's all informed by personal experience for you. Is that right?

SHANNON: Yeah. I have a lot of empathy for parents who don't know what to do and who are scared, because our culture—in the United States and in Canada—tends to be really fearful of autism in general. There's not a lot of positivity or even real honesty about what autistic lives can be like, if parents and autistic people have the right kinds of supports and accommodations to live good lives, and we want to really get the word out that if you can start by understanding what your child needs, in terms of their sensory needs, their processing needs, and then their disability accommodation needs too.

Our lives can be really great. I'm not saying that we can fix everything, because there are always things that are going to be things about being autistic in a world that's not set up for autistic people that are going to be hard. But we can make things so much easier if we know what to do!

ANNE: I guess that's one of the great things I see in these partnerships and conversations that are happening between actually autistic people and neurotypical parents online, and in the community, right?

SHANNON: Yes. I think it's really important to have a lot of humility if you find yourself being immersed in the autistic community because of having an autistic child, and then you don't have an autism diagnosis yourself, and you don't know anything about autism. There's a lot of people out there who are going to try and tell you what your kid needs, but really, autistic people are the ones who *\*do\** know. [both laugh]

And of course autistic experiences are so varied, and individual. When it comes to my son's personality, for instance, he's much more like his father than he is like me. And that has nothing to do with autism, and has everything to do with his personality, right? But know that, that he's a good-natured wonderful person, and then knowing also that he has accommodation needs, the combination of that knowledge helps us really create a home environment that works for everybody.

ANNE: Why do you think there's some antipathy towards listening to autistic voices? I'm thinking of groups like, I can't remember what it's called, I think the Council on Severe Autism, or some other groups that are led by parents that really take an abrasive approach towards autistic self-advocates?

SHANNON: Again, I have empathy for those parents, because I think what has happened is that a lot of them have listened to... well, a lot of them tend to be very wealthy, a lot of them tend to be in good school districts. So they say, "We have the best services. We have the best experts. And they *\*failed\** us. Because our kids are still 'severely autistic'" (though I don't use that term, but that's what they use; I use *high support*). "So obviously everything has failed, and we need to fix things and put our kids in these boutique homes, these group homes, so they don't get stuck in with the rabble like other parents autistic children do, who don't have money."

There's a lot of fear, there's a lot of anger, and I think when autistic people come in and say, "Actually, if your kid is breaking things, maybe figure out what's going on: is there anxiety? Is he sick? Is it a sensory thing that you can maybe substitute something else for?," then the parents say, "No no no, we had ABA and it didn't work and our kid still does these things. Why would I listen to you? I had the best experts. I paid for the best experts. It didn't work. He's a high support person who is going to need support the rest of his life and I need a place to stick him."

So I think that these are people who were failed by what they were told were the best available experts, and because I think they don't know how to think out of that box, and I think they don't have the ability to recognize that their children are part of communities that they don't belong to, and that those communities—specifically the Autistic and Disability communities—are looking out for their kids, whether the parents do or not. And they know what the kids need, in terms of to have the best quality of life day-to-day. I think [those parents] feel failed, and I think they feel like they have to be the ones to take care of things because everybody failed them, and so they don't want to hear it.

ANNE: That's really interesting. Some of the distrust, it's been hard for me to understand. Maybe it comes from being betrayed by other institutions such as the institution of ABA or programs like that.

SHANNON: I think that's it...and I think that also a less empathetic take would be that these are all people who feel that, who come from wealth and privilege, and they feel that autism is the one thing that's not going right in their life and so they believe that if they could just make their kids not autistic, then everything would be great.

Some of these organization, some of them are parents who were involved with the anti-vaccine movement and pseudoscience, and some of them are not, but they've kind of moved on from that. And now they're all, "We need to \*treat\* our kids. We need to cure our kids." They think that if they put enough effort into making their kids not autistic, then their lives would be fine—as opposed to recognizing that their kids are autistic, and that autistic people have always been here, and that what we need to do is make sure that the world works for everybody, including autistic people.

ANNE: Right. It's interesting that it comes from a place of privilege, I've noticed that too. Economic privilege is often the hallmark of these organizations, even in Ontario with the battles that go on here.

I'm just wondering, if coming from that privilege might make it harder for a parent to be resilient, or flexible, around their kid being neurodiverse?

SHANNON: Well, I think so. A lot of these parents are extremely high achieving people who have done everything right. They've been set up with wealth and privilege, or they have worked their way into wealth and privilege—and so they've always been able to make everything happen the way that they wanted to. And this is something that they can't control. And it doesn't matter how much money they throw at it, or how hard they work at it, their kid is going to be autistic.

And so I think that having humility, and listening to other people who they see as not having the same kind of hard-working privilege and expertise as they do, or who are not accredited professionals—that's not how their minds work. That's not how their culture works.

ANNE: Right. There does appear to be in some circles a lack of imagination as well. And that's very limiting when you're looking at neurodiversity, and coming up with accommodations for disability. You really need to have creativity, and apply that.

SHANNON: Sure. Absolutely. If you think, "I've tried ABA and it didn't work and my kid's still autistic," or "I don't know how to communicate with my child, they're non-speaking," but you haven't actually put real effort into providing a communication system when we \*know\* that trying just one AAC system isn't [usually] sufficient; you really have to work, and you really have to bring the communication into your child's realm, and make sure that they're approaching it from a number of angles: Are they visual? Do they need repeated exposure? Do they have really long processing delays?

A lot of the things about AAC and communication that we don't communicate enough, ironically, is that it takes a really long time and a lot of work to get to a point where [communication/AAC] starts taking, and a lot of these parents, that's not how they work, because the parent actually has to do the work. This is not something you can pay a professional to do for you. I mean, I suppose you could. But the communication has to be part of your home environment, it has to be part of your interactions with your child. So if you don't understand your child, and you're used to paying professionals to take care of your child, and “treat” your child—and then you're asked to you, yourself have a mindshift, you yourself take on the responsibility for understanding what your child needs, that's a little difficult.

ANNE: I think it is. I think you could even extend that to schools, and inclusion policies. Because they seem to think that, just pile more aides into the classroom rather than making fundamental changes to the classroom that would involve not just the teachers and staff but also the students, and everyone had taken an inclusion approach—and the resistance to that. It's almost like, “What system can we buy, what product can we buy? What thing can we do?”

And maybe that's also why pseudoscience appeals to people, because pseudoscience purveyors tell you, “All you have to do is **buy this**, and it will fix your problem.”

SHANNON: Yes, and also, there are no easy answers when it comes to figuring out what an autistic person needs. Again, because they're individuals, right? My son goes to a school with 60 other high-support autistic individuals. They are [laughs] sooooo different, so different.

So you have that variety, and then when it comes to things like inclusion, parents or professionals will say, “Well, we can't just stick our kids in a class and have them all figure it out together.” But that's not what we mean by inclusion. Inclusion is hard work! Inclusion means figuring out where a student can be included, and when they can't; and when it's reasonable and when things can be adapted. It doesn't mean sticking them in every class, all day long, with kids, without support.

It can be a little frustrating to talk about these things with people who, again, don't understand that you can't just have a professional come in and turn on a switch and everything will be fixed.

Although in some cases that does work! It does work in cases like, “Well, you have a child who's having real difficulty in the classroom, so maybe switch out the fluorescent bulbs for incandescent bulbs?” And then suddenly the child is not having a meltdown all day long anymore, because the bulbs aren't flickering. Or, let them wear headphones in the class. Sometimes there are easy fixes. But they're not the kinds of things that people who come at these problems and inclusion issues from a mainstream perspective are going to consider, because they're not listening to autistic people, and the people who listen to autistic people.

Things are a little bit better in the UK, there is, I think, more listening to autistic voices, and more autistics as professionals that are included in the mainstream establishment, but still not everyone, not everywhere.

ANNE: They do seem to be tuning in over there, in an interesting way. I really model some of

what I do and what we do (in A4A) on what people are doing over there [when] it seems to be effective.

You advocate for more research into communication support technologies, for AAC, as well as for research that focuses on quality of life and supports, rather than, as you described it: “on the causes of autism, infant studies, and mouse models.” The International Society for Autism Research, INSAR (formerly IMFAR) seemed to be evolving on this. What do you think the future holds for the direction of autism research?

SHANNON: Well, there's what the future probably holds, and then there's what I'd like to see the future hold. [laughs] When it comes to autism research, the main issue is that even if autistic people are saying things—a lot of the things I've been talking about, we know about from talking to autistic people. Things like flickering lights, and auditory sensitivities in classrooms.

But if we don't have research to back it up, then professionals don't listen. And then once you get research to back it up, people say, “Oh! How would we possibly know this if there wasn't research!” As if it's a revelation, and then all these professionals are like, “Let's do this wonderful thing!” And all the autistic people are shaking their heads and saying, “Yeah, we told you that.” So research is really important, to back this up. Because we need evidence about how these things work, otherwise professionals don't listen.

That's the direction I'd like to see research going in, more quality of life, like you mentioned. And more communication, because when it comes to AAC, Augmentative and Alternative Communication options like talker devices or typing to talk or even using icons to communicate, we just don't have enough research into how different autistic people communicate, and how we can help them communicate. Because we know that there are so many people who have either issues with apraxia, with being able to form speech, or who have other motor issues that make it difficult for them to actually control their movements, or they have impulsivity issues where even if their brain is telling their body to do something, their body won't do it. And these can be really difficult situations to tease out, and to figure out what kind of system will work best for each individual.

And right now, even if you get insurance, or if you get the school district in the United States for instance, to cover AAC, they'll usually only cover one option. And even if it's a wonderful option for some people, and some people are having success with it—like there's a great app called Proloquo2Go that's available on the iPad, that is a symbol-to-speech app, it's a wonderful, wonderful app—but it doesn't work for everybody, some people need different approaches. But we just don't have the research, and then because we don't have the research, we don't have the infrastructure and expertise in a wide enough availability to actually help all the autistic students and adults who need this kind of communication support. So, that's what I'd like to see.

I have seen, over the past—wow, it'll be my ninth time going to INSAR this year, in Montreal—I have seen a big shift away from the pseudoscience. Though every year there'll still be a lot of [goofy voice] “We've found this one thing that causes autism!” And the problem with that—and the people who run INSAR should know better—is that they have press conferences that go, “Woo! We have this study!” And the news outlets will take this supposed discovery and run with

it—but we're not usually talking about long-term studies that actually prove this, we're talking about this one study that showed this one thing that maybe happened this one time: they're exploratory studies, for the most part. It's not the kind of proof that the news outlets think it is. It's just so funny.

Although, again, things have really improved over time, like last year there was a great study at the press conference by this woman who was showing that, “You know this screen time thing? Not as bad as you think it is, and actually autistic people? They kind of really do love their screens?” [laughs]

I've seen things shift. There's been a lot more autistic inclusion at INSAR, though there still aren't as many *out* autistic researchers, even though we know that there are a lot of autistic researchers, but some people don't necessarily feel comfortable coming out. There's been a lot more participatory research, there's been a lot more autistic-directed research, a lot more focus on things like helping families in low income and racially diverse communities in the United States access better services, because we know that those communities have a disparity in being able to access diagnoses and services, and why that happens.

One thing that happened a few years ago was that we were finally getting some life course studies, actually finding out what autistic quality of life is like over the life span, as opposed to just studying kids. And the suicidality research that's been going on, by Sarah Cassidy at the University of Nottingham—for the past four years, she's been doing special interest groups, and coming up with phenomenal results that help us understand so much more about why autistic suicide rates are higher, and in which categories of autistic people they are higher, and why that is—really solid participatory research that I think is going to help a lot of people.

So I've been heartened by the direction of research—but most of it is still on causation, most of it is still on “treatment,” and that's depressing, but things have been shifting, slowly.

ANNE: Did it all start with—and I'm going back to this idea we were talking about before—privileged parents? It seems to me that the way autism was introduced into the mainstream culture was by those parents, it was introduced by the people who founded Autism Speaks...

SHANNON: Well, Autism Speaks is fairly new.

ANNE: I'm not saying the diagnosis itself. But when people think about autism today, people outside of our community, or people who don't have a personal relationship with it—Autism Speaks is a really recognizable brand. And the idea of autism being an epidemic, trying to stop the epidemic—the kind of language that's used by Autism Speaks—doesn't necessarily raise eyebrows. Even in this day.

SHANNON: No, because the history of autism in our culture has always been a horrible one, it's always been one of fear and misunderstanding. And Autism Speaks is just the latest parent and grandparent-run organization to run with that.

Although the history is that autism used be view through the “refrigerator mother” theory of

Bruno Bettelheim, where he was actually blaming parents. And so parents, all their kids were basically institutionalized if they had an autism diagnosis, and the parents wouldn't even know each other. Their kids weren't in school, there was no IDEA, there was no inclusion at all, there was no real special education. Finally, in the 1970s, parents starting getting together and actually forming groups, and saying that “we can be stronger together,” and these groups were initially about support, and the kinds of things that wouldn't be unfamiliar to you and I today, although they weren't autistic-informed because most of them had never met an autistic person besides their own kid.

Then things shifted, like with Wakefield and all that scare-mongering. And the daughter of the Autism Speaks founders, who is the mother of the child for which Autism Speaks was founded. I just don't understand her at all. She is a complete off-the-wall anti-vaxxer, mercury-causes-autism truther, Generation Rescue board member [correction: SafeMinds]. I got into a thing with her on Twitter, even though I've told myself so many times, “Do not interact with her.” There was a lawsuit brought against Generation Rescue, which is Jenny McCarthy's mercury-causes-autism organization. And they sell these hyperbaric oxygen chambers, and a child asphyxiated in one of them...

ANNE: [Gasps]

SHANNON: ...and the parents brought a lawsuit against them. And I was saying [on Twitter] that “if you fall for these kinds of mindsets, then you're set up to abuse and possible even cause your child to die, and that's a horrible thing, that's just as horrible as the scandal as what's going on with the Catholic Church, with the child abuse there.” And her whole thing was, “I can't believe you're comparing this wonderful organization to the rape of children,” and my response was, “Uh, okay, I was talking about a kid who \*died\*.” He died! But she couldn't even conceptualize why anybody would say that the organization was bad. [laughs mirthlessly]

ANNE: My god.

SHANNON: There's this real cult mindset that parents can fall into if they get this bad information. And like you said, when Autism Speaks came into the forefront, yes, they were all about “the epidemic.” There are still plenty of autism organizations that purport to be “science-minded” that will still manipulate statistics to make it look like there's an epidemic, when even if you go to the most mainstream science sources, like the Centers for Disease Control in the United States, they'll say, “Yeah, there's no epidemic. We're getting really better at diagnosing people, and finding people, and actually the diagnostic criteria have broadened to include more people and that's actually a good thing, because more people are getting supports.” But these parents don't want to hear it, because they're so used to thinking of themselves as victims and thinking of autism as a catastrophe, because that's the mainstream cultural approach—and if you don't know any better, and if you haven't received good information from the beginning, then why would you think any differently.

ANNE: Well, being a parent is hard, and you don't get a lot of props for it, right? Being the parent of any kid is hard. And I think that what some of the organizations do in their fundraising is they pat parents on the back, and help them to feel good, and that is a great way to raise

money.

In my own work I often get feedback from people that is usually off-camera or off to the side, and someone will say to me—because I do a lot of work against autism pseudoscience—that “You know, parents are \*desperate\*. I mean you can't blame parents, right?” And it's said in this way that I'm supposed to then say ... well, I don't know what I'm supposed to say. I still don't know what they expect me to say, but it's kind of like a nudge and a wink, or a “you're in our club,” and “We all know how bad this is for parents.”

SHANNON: [Laughs]

ANNE: I like being a parent but I guess I'm weird. And sort of implicit in the question is this idea that just bringing up the topic of phony cures for autism, or human rights for autistic kids, that somehow it's hurting *parents*. And I think that really stifles a lot of important conversations. It's a real conversation shut-down, because we're expected to place parents, still, at the centre of autism stories, and not place the children [at the centre].

SHANNON: It's extremely distressing. My response to those kinds of queries tends to be that I have a lot of empathy for parents who don't have the right information, and I can understand how parents can find themselves in that situation. But once you've been told, you can't not know. You know what I mean? And actually it doesn't have to be that way. There are plenty of parents who don't have access to good information, so \*that's\* the tragedy: that the parents don't have the supports they need to bring their autistic kids up the way those kids deserve.

And it doesn't mean I'm going to identify with a parent who is saying awful things about their child. In that case, I'm going to say that that parent is unfortunately ignorant, and I can empathize with their struggle, but I can't empathize with the way they're treating their child, because there is a better option. And I can help them find that option! But they don't want to hear it, because... I don't know. Many different reasons.

ANNE: Sometimes they do, and sometimes they don't. We're in the position of being parents, and the thing about being the parent of an autistic child is that we're in a privileged position in some ways, within mainstream society, because we're parents! And sometimes media talk to us *just because we're moms*. What do you think about being in that position?

SHANNON: It's interesting. I've talked to a lot of people over the last fifteen years, I've talked to a lot of outlets. And I used to, because I was so hopped up on getting out the right message because I don't want people's kids to go through what my kid went through; I don't want other parents to go through what I went through. So I would talk to anybody. But over the course of my own education—which is again ongoing and will probably always be ongoing—I've realized that there are some things I can talk about with expertise, as a parent, because if you don't have a kid you wouldn't know how to talk about things from that perspective.

But when it comes to my kid's autistic experience, I really need to defer to people who have that experience. So if there's a situation where we're talking about the autistic experience, then I try to find an autistic person for them to talk to. Because otherwise they're dealing with hearsay, and

that's not great for journalism. You want to speak to the source.

ANNE: I see that in the Thinking Person's Guide to Autism; most of the work that comes out of there is by actually autistic writers.

SHANNON: It is now, but it wasn't at the beginning. That's part of the evolution I'm talking about. Initially we were very much a science-oriented site, pushing back against the pseudoscience and anti-vaccine stuff, but still with a lot of...I wouldn't say parent victims, but more isolated parents trying to connect with other people who understood their experiences, but not understanding how that didn't necessarily shine a good light on what their kids needed, if that makes sense.

We have since kind of shifted over to mostly having either autistic individuals who don't have kids talking about their own experiences, or autistic parents talking about autistic parenting. We still have some non-autistic parents, and non-autistic professionals—but you are absolutely correct: we strive to have most of our writing done by autistic writers.

ANNE: That's great. I think your experience as a parent also speaks to people in a really powerful way, because you went through a whole process. Can you talk about what that process was like, for you, from the time of diagnosis until where you're at now?

SHANNON: Sure. [laughs] How much longer do you have? Also you could read NeuroTribes! [Both laugh] I know you know that. But Steve Silberman, the author, was kind enough to feature our family's story from complete ignorance, and embracing pseudoscience and anti-vax information to where we are now—which is as far away from that as you could possibly be. So, when my son was first diagnosed, I didn't know anything about autism, except for to be scared, and I didn't have good information. So I went looking for information, and the information [books] that I found was all about dietary cures and ABA. That's pretty much all that was available, in terms of like we talked about before: needing to DO something. Those books gave me something to do.

We pursued both of those avenues, and much more quickly for the pseudoscience we realized that was really not in my son's best interests. Although [laughs] I say in this case it was the ABA data keeping that helped us identify that, because the dietary cure and supplements approach said that my son had all these food allergies, and that was causing his autism. And my son is very quick, he's sly, he's very smart about getting the foods that he wants [laughs] so he would steal something that was supposed to cause all these "autistic symptoms," and we had the data to track and say, "Actually, no. The only thing that affects how my son behaves is whether or not he's \*sick\*. If he has a cold, then things change. But it has nothing to do with diet.

So there was that. And then the next few years—it took a lot longer—I came to realize that the behavioral approach was not about helping my son; it was about controlling his behavior. And so we have backed away from that as well.

One of the things that distresses me the most, I now remember, is my son being distressed because his head was hurting, so he was having behavior that reflected that his head hurt. And

the ABA therapists said, “OK, we'll set him at a counter, and we'll let him have one treat for every 10 seconds that he doesn't hit his head.” And I was like, "He has a \*headache\*. We need to figure out why he has a headache!" And it turns out that he has sinus problems, so now if he has a headache I give him a Sudafed.

ANNE: Right, right.

SHANNON: But if we followed the ABA approach we would just be trying to teach him to ignore his pain because it didn't matter. And thinking about that is really distressing. So I really want to try and help other parents understand why these pseudoscience approaches—diets and supplements and anti-vaccines that just leave your children vulnerable to diseases—and then these normalization approaches that don't try to understand your autistic kid's experience or communication at all, are just going to make everybody in the family miserable, most of all your kid.

ANNE: That's interesting, and I've read about your approach in communicating this to other people, and it's always stuck with me: You said, “Be visible, not judgmental.”

SHANNON: I \*try\*. I'm human. Sometimes I'm a bitch. But I really try. I've got a hair-trigger temper; I try.

[Both laugh]

ANNE: What would you advise someone who has, maybe, a friend or a relative or a colleague, who has someone in their family looking at doing pseudoscience with their autistic kid? I'm wondering how we can intervene if this is happening with someone we know.

SHANNON: Sure. Well, it depends on how the person reacts in general to being confronted about their beliefs. So if you know someone who's general willing to have discussions, so then I would say that at the Thinking Person's Guide to Autism, the very first link that you can click on, on our site, is our Mission Statement [<http://www.thinkingautismguide.com/p/mission-statement.html>], which gives you guidelines for identifying good and bad autism “treatments.” We also have a link at the top about good and bad autism organizations, and how to identify ones that will help you and ones that won't. So if there's somebody that's open to discussion, you could say, “Hey, I found this stuff, do you want to talk about it? Because it seems to me like you're trying these things that maybe, you know, are not necessarily what your child actually needs...”

And if they are not amenable, then I can say that what works for me—because I have a strong personality, and when I believe something, I \*really\* believe it—is as much exposure to good information from a variety of sources. I just kept seeing, over and over again, “Vaccines don't cause autism, and here is the evidence. Here is all the research that shows that mercury poisoning looks nothing like autism; here are the symptoms of mercury toxicity and here are the symptoms of autism—and look at that, there's actually very little overlap!” Things like that; those are the kinds of things that actually got through to me.

It also really depends on what kind of community you're in. If you're involved in one of these secret groups for parents, like Generation Rescue, those parents are going to the mat for an organization that allegedly caused the death of a child. And so we need to get to the parents before that happens. So I would say try and get as much good information as you can.

We're desperately trying to get out the second edition of our book, hopefully that will be out by the end of the year [*ed: scheduled for some time in 2020*]. The first edition of our book was very much more of the evidence-based but not as much of the autistic perspectives that I think truly help families support their kids. So the new edition of the book will be, I think, much more helpful. And at that point I can say, "Read the book!" But right now I can say, "You can go to our website, and there is a short checklist of our most important articles for understanding autistic experiences, and what parents need to do, on the right-hand side. So please do that."

ANNE: I can't wait to read the new book. And the fact that it's updating, and how much it's updating, is really interesting to me, because I think so much has changed in the past decade, even five years, in terms of how we're looking at all of the things we've just been talking about. And I guess I wonder what to do with parents who have regret. I'm certainly hearing from parents now that have regret for various things that they did or engaged in, in the past—and are trying to move forward but sometimes get caught in sunk costs, because they invested so much into it that they want to keep believing in it, yet they don't. And I see that, as this unfolds in Ontario, that it's actually very painful for a lot of families.

SHANNON: I can tell you that it's embarrassing for me, to talk about what I've been through, but I also know that in sharing my story I am helping other people avoid having the same mistakes. So I guess I think of it from a position of paying it forward, so that other people can benefit, and also having a little bit of empathy for people who make mistakes because there's so much bad information out there, and if we don't know where to look, it's really easy to fall for bad information. And if parents do that initially, if they didn't know who to trust and these people tricked them into trusting them, that's not entirely on the parents and they can't really blame themselves for that—and if they know better now, they should feel good about that.

ANNE: What about the book? Can you talk a little bit about when it comes out, more about that?

SHANNON: I'm hoping to have it out by the end of the year.

ANNE: Wow, that's great. Shannon Rosa, thank you so much for coming on the show. It's given me and our listeners so much to think about. I really appreciate it.

SHANNON: Well, I appreciate the opportunity to share my experience, and I appreciate that you're willing to listen to it. So, thank you.

ANNE: We were speaking with Shannon Rosa. She spoke to us from San Francisco. You've been listening to Noncompliant. I'm your host, Anne Borden King. Noncompliant was recorded at DB Audio and MCS Recording Studios. Episodes were engineered by Dave Boire, Nathan Grevat, and T.J. Liebgott. Thanks to our engineers, and thanks for listening.