

# Education Through Autism

[00:00:00] **Stephen Calabria:** From the Mount Sinai Health System in New York City, this is Road to Resilience, a podcast about facing adversity. I'm Stephen Calabria. On today's episode, in celebration of April being Autism Awareness Month, we welcome Alex Kolevzon, M. D.

[00:00:17] Dr. Kolevzon is a professor of psychiatry and pediatrics and the clinical director of the Seaver Autism Center for Research and Treatment at the Icahn School of Medicine at Mount Sinai.

[00:00:28] In his role as clinical director, Dr. Kolevzon oversees groundbreaking clinical research and treatment for children, adolescents, and adults with autism. We'll also be joined by Marlee Marinelli, a mother and caregiver of a young son with autism. But first, we're honored to welcome Dr. Kolevzon to the show.

[00:00:48] Dr. Alex Kolevzon, welcome to Road to Resilience, sir.

[00:00:51] **Dr. Alex Kolevzon:** Thank you very much, it's good to be here.

[00:00:53] **Stephen Calabria:** Could you give us a overview of your background?

[00:00:55] **Dr. Alex Kolevzon:** Let's see, I was born in Mount Sinai Hospital. True story. I am a child and adolescent psychiatrist. I did my training here. I'm the Clinical Director of the Seaver Autism Center at Mount Sinai.

[00:01:08] My focus is on better understanding the biology that underlies autism and then using that understanding to develop better and more targeted treatments.

[00:01:17] **Stephen Calabria:** Could you tell us, what is autism?

[00:01:21] **Dr. Alex Kolevzon:** Autism is a collection of behavioral features that include social and communication problems and restricted and repetitive behaviors, childhood onset neurodevelopmental disorder.

[00:01:33] **Stephen Calabria:** What role does resilience play in the overall well being and quality of life of individuals with autism, and how would you say it influences your approach to their care?

[00:01:45] **Dr. Alex Kolevzon:** Ooh, I love that question. That's a question I've never been asked before. So let's see, resilience. So I think about resilience actually in terms of parents' resilience, right?

[00:01:54] I saw a parent yesterday, in fact, who was able to reflect on how grateful she felt for her child, who is profoundly disabled. And the reason that she felt so grateful is because it allowed her to look at the world with a different perspective.

[00:02:13] And I think some of the things that might bother you or me didn't necessarily penetrate her, her threshold for irritation. I think she's sort of naturally resilient.

[00:02:22] You know, I think a parent who brings that perspective to the experience of raising a child with special needs, was probably born with some degree of resilience. I see the kids who have varying degrees of impairment also have varying degrees of sort of temperamental characteristics.

[00:02:40] So some kids can be very agitated, very aggressive, very self injurious. And other kids can be very, very calm. And so whether that reflects resilience in the child or resilience in the parents, I'm not so sure.

[00:02:54] But I do find that the parents who are most able to kind of rise to the challenge that they face in raising these kids and can kind of come to them with a perspective of acceptance for sure.

[00:03:08] And, probably some degree of resilience, despite all the challenges. You know, those kids tend to have a better quality of life, as do their parents.

[00:03:17] **Stephen Calabria:** How many children and adults have autism? And how many new cases are discovered each year?

[00:03:24] **Dr. Alex Kolevzon:** Well, if you rely on the Centers or Disease Control in the United States, the answer to that question is somewhere around 1 out of 36 kids are diagnosed with autism. That is probably a significant overestimate but we like to think about, about 1 percent of the population has autism.

[00:03:44] **Stephen Calabria:** When was autism first really brought into the public consciousness? mean, if I watch movies from the 40s, don't see a lot of people with autism.

[00:03:51] **Dr. Alex Kolevzon:** Yeah, right. So autism was first described in the 1940s, 1943, and public consciousness, I think, you know, when you talk to people that are my age, for example, they never met a child with autism when they were growing up.

[00:04:05] Never. Does that mean that those kids weren't out there? Probably not. I think what's happened over time is, we're calling children autistic today, who we would not have called autistic 50 years ago. Public consciousness, I remember the first child I ever met with autism, it was 1990.

[00:04:24] So autism was there. I worked in a camp, there was a bunk for kids specifically with autism, so it was there, it was present. But then, soon after that, like the late 1990s, I think Autism Speaks put out a, they're a big foundation, they put out a campaign, 1 out of 150. Oh, wow, 150. And there was a round of funding, I think when Barack Obama was president.

[00:04:46] That kind of drew a lot of attention to the epidemic of autism, because then it had shifted to 1 out of 100. But yeah, the public consciousness, late 90s, early 2000s, and then it's just been increasing ever since.

[00:04:57] **Stephen Calabria:** What do we know about what causes autism?

[00:05:01] **Dr. Alex Kolevzon:** Yeah, this is a great question. The only kind of well established causal factors that are commonly accepted in the scientific community at the moment are genetic in origin.

[00:05:13] So we know that genes probably play the biggest role in causing autism. There are other risk factors for sure. But those risk factors have very small effects. And there's no specific risk factor that would be in and of itself sufficient to cause autism.

[00:05:29] Genetics, on the other hand, if you have a specific gene that, that gets mutated, you're gonna have some developmental disorder, often autism as well.

[00:05:38] **Stephen Calabria:** Now, I have a list of symptoms here. . Inappropriate social interactions, poor eye contact, compulsive or impulsive behavior, repetitive movements, intense interest in a limited number of things, problems paying attention, and the lack of awareness of other people's emotions.

[00:05:56] That describes, in some way, around 98 percent of the population, in one way or another. How do we determine what is autism versus what just are human behaviors?

[00:06:08] **Dr. Alex Kolevzon:** Yeah. So, that's true for many of the disorders that we have in our psychiatric, kind of, manual. Typically the answer to that question relates to meeting all the criteria, because you have to meet three out of three of those social communication deficit criteria.

[00:06:27] It relates to the severity of the symptoms, the persistence of the symptoms, the level of impairment of the symptoms. So it's not just enough to wake up, have a tough day, feel a little anxious, and be socially withdrawn. That doesn't mean you have autism, right?

[00:06:41] Autism is a pervasive condition, meaning that the deficits that you just listed exists across all settings, so it's not just in school under pressure, it's not just at home, it's everywhere and all the time for the most part.

[00:06:53] It also has to begin, you know, very early in childhood. I mean, you don't just develop autism at eight years old or ten years old or certainly not in adulthood. So it really has to be a developmental disorder.

[00:07:04] The other kind of key criteria that we often talk about is the idea that your social communication deficits have to be more severe than would otherwise be predicted based on your IQ.

[00:07:15] So if you have intellectual disability, you're going to have, by nature of that, social and communication deficits, but in autism it's more severe.

[00:07:22] **Stephen Calabria:** As our identification of the condition has improved, has the age of the average patient identified as autistic gotten younger and younger?

[00:07:31] **Dr. Alex Kolevzon:** Yes. And that's a good thing, because we know that the earlier you intervene, the better the outcomes. And there's been an enormous push by the American Academy of Pediatrics and by many other big governing bodies to make sure that when children show signs of autism early, actually to screen for those signs early, 18 months, they should be referred as quickly as possible for at least an evaluation to determine what services are necessary.

[00:07:59] I think it's clear that the prevalence of autism is increasing exponentially. I think the question is really why, and is it truly an epidemic?

[00:08:08] So I would probably argue, and most would argue, that it's not a true epidemic. It's really a function of, as you pointed out earlier, age of diagnosis, so you're including more people in your studies, changing diagnostic criteria, which has a huge impact on prevalence rates.

[00:08:23] And we're just doing a better job of diagnosing it. So kids that weren't previously diagnosed are now getting diagnosed, and rightfully so.

[00:08:30] I'll add that if you look at the studies that include people with autism according to the CDC, many of those kids don't actually have autism. Those diagnoses are sometimes based on record reviews or on an inadequate diagnosis.

[00:08:47] And so there's a lot of misdiagnosis that are going.

[00:08:49] **Stephen Calabria:** What makes treating children with autism different from treating adults?

[00:08:54] **Dr. Alex Kolevzon:** Treating children with autism versus treating adults with autism?

[00:08:56] **Stephen Calabria:** Correct.

[00:08:56] **Dr. Alex Kolevzon:** Oh. Well, so, you know, treating children in general is different than treating adults. I think the answer to that question in autism is very complicated because there's so many different levels of ability and language and intellectual ability and so on.

[00:09:09] But I think, you know, generally we take a very developmental approach to treatment and the needs of an adult are dramatically different than the needs of a child. I mean, in a very basic way for an adult, you're focused on independent living skills and vocational skills and things that are, you know, practical to day to day living and, and hopefully working towards independence.

[00:09:27] For young kids, you're focused on motor skills and language skills and just communicating needs in a very basic way, just making eye contact in a very basic way.

[00:09:35] **Stephen Calabria:** When an adolescent patient comes to see you, what are some of the first steps that you often take in that treatment?

[00:09:41] **Dr. Alex Kolevzon:** And we're talking about adolescent with autism?

[00:09:43] **Stephen Calabria:** Yes.

[00:09:43] **Dr. Alex Kolevzon:** Ah. Again, this depends entirely on the patient, the patient's needs, the patient's level of functioning.

[00:09:49] But oftentimes an adolescent who's coming to me, who's let's say verbally fluent and average, right? They are usually struggling with challenges around being different and trying to form their identity and yet, incorporate deficits that they're acutely aware of.

[00:10:09] And so one of the big challenges is often feeling quite depressed. When you're a teenager and you know, your goal is to kind of fit in with your peers and develop your identity, some people with autism come to that, you know, with a real desire, sincere desire to make connections and to fit in, but they fundamentally lack the skills.

[00:10:30] Other kids come to that and say, I'm not really interested. I'm perfectly content by myself, but yet the system and the school and the parents, everybody, are kind of pushing the kid to be social because that's the expectation of, you know, we're all social creatures.

[00:10:43] So in both those scenarios, which are pretty common, you get a real tension, a real conflict, where the kids experience it with anxiety and depression and just feeling generally irritable.

[00:10:53] **Stephen Calabria:** And so on the one hand, you have some kids who want so desperately to fit in, but don't feel like they can. And on the other hand, kids who don't care about fitting in, but are told that they have to, that it's healthy for them, that they don't have a choice because when they go out in the world, this is how they're going to have to navigate the world.

[00:11:11] How do you instill resilience in those kinds of patients? Is it the exact opposite approach, or

[00:11:17] **Dr. Alex Kolevzon:** You know, it really depends. I think there are the kids who are not interested, and you have to let them be okay with that. And

you have to let their parents be okay with that. Because you know, in the end of the day, if they're happy, content, eating well, sleeping well, you know, getting their job done, that may not include being social as a teenager.

[00:11:39] And maybe they'll come to it when they're, when they're older. Maybe they won't, but there's still ways to kind of extract meaning and pleasure from life, even if it's not social, for someone with autism.

[00:11:50] There's still activities that they can dedicate their time to that will help them derive a sense of real satisfaction. And then for the kids who want to be social, you help them, you help them navigate, you use social stories, you use scripts, you practice in the office.

[00:12:04] I mean, it's challenging for them to sometimes generalize what happens in your office. to the community, or generalize what happens in social skills groups to the community. But that's the effort. That's what you sort of work with them around.

[00:12:16] We are faced constantly with so many challenging cases. I mean, the challenge is really for the parents.

[00:12:21] They're the ones that are kind of shouldering the burden. I think when, when I see things that don't fit the themes or typical patterns, and the child is obviously in significant distress, and you don't know whether they're in distress because of some pain, because of some stomach related problem, because of some sort of infection, because they're having seizures, you know, you don't know what is causing the distress, that is very, very challenging, and so I think, doctors will often see what they want to see, see what they're expert in, and I think what it's taught me is you have to always be very humble and try to keep an open mind and really chase down every possibility before just assuming that it is what it is because that's what you've seen a thousand times.

[00:13:09] **Stephen Calabria:** You serve as the Clinical Director of the Seaver Center here at Mount Sinai. Could you tell us a little bit about it and what makes it unique?

[00:13:17] **Dr. Alex Kolevzon:** Well, the Seaver Center was founded in 1993. So what is that? That's 30 years ago, 31 years ago. It was founded by a large grant to Mount Sinai through the Seaver Foundation.

[00:13:28] And it was founded really to kind of discover the causes of autism, and then of course to develop new treatments. And that's what we continue to



try to do. It's built up over the years dramatically. So we have kind of many different groups, but there's a basic science side that's focused on genetic discovery.

[00:13:46] And then model systems where we sort of test the impact of changing and manipulating different genes in various models. We have a large epidemiology group that's looking for various risk factors in the environment and otherwise.

[00:13:59] And then we have the clinical side, which is what I'm most involved in, where we try to test new treatments, we try to develop better measures of assessing change over time, and we try to develop more objective ways of what we call biological markers.

[00:14:11] So, how do you assess change over time using something that's more quantitative? How do you try to predict who might respond to certain treatments?

[00:14:20] And, we see hundreds of kids every year and we're putting them all through these really kind of complicated studies that are extremely burdensome that the families participate in, you know, enthusiastically, hopefully.

[00:14:32] And they're all meant to, you know, either develop a new treatment or to learn something unique, about autism in general.

[00:14:39] **Stephen Calabria:** Could you talk a little bit about the interdisciplinary support that you receive at the Seaver Center and how many minds come together from different disciplines to treat a given patient?

[00:14:51] **Dr. Alex Klevzon:** Yeah, absolutely. I, you know, I think that's kind of the magic of the Seaver Center. We talk about the idea that we go from sort of the molecules or the genes to the patient.

[00:15:00] And that can only be done with a lot of expertise, so we have molecular geneticists, we have epidemiologists, we have computational biologists, we have statistical experts, we have clinical psychologists, we have pediatric neurologists, we have child analyst psychiatrists.

[00:15:16] There's many, many more people and we have an enormously robust administrative staff that supports this infrastructure and helps us get our grants through and follow our grants and do our budget. So there's a lot of people on the team that are sort of driving this forward.



[00:15:28] And I think the magic of it is that everybody on the team sort of understands what the, the goal is, what the mission is overall. Everyone has some understanding of what role they play and there's an enormous amount of collaboration and sharing. There's not a atmosphere of competition. There's an atmosphere of collaboration.

[00:15:45] **Stephen Calabria:** Is that normal in medicine?

[00:15:48] **Dr. Alex Kolevzon:** I think it's often the intention and it's the goal and it's the ideal, obviously. I think it's very hard to execute it often because by nature, you know, these things are competitive.

[00:15:57] People are often competing for the same grants, people are often chasing down the same ideas and there's real value to the individual to publish first. People are focused on advancing their careers and getting promoted.

[00:16:12] So there's a lot of competing interests, I would say. Much of it revolves around, you know, making sure that you're. You're able to kind of pursue the research that you want to pursue, but it's very competitive. I mean, grants are very hard to get.

[00:16:26] I think what the Seaver Foundation does is, it provides us with this infrastructure and it gives us a sense of security so that, for example, if you run out of grant funding, but you've up until now been quite successful, you know, you're not fired.

[00:16:42] You get some bridge funding until your next grant. And so that gives everybody a little bit of a, of a breath.

[00:16:48] And I think it, it allows us to feel a little bit less of that academic pressure to constantly be getting grants and writing papers, but not that we don't feel it, but it's, it's a little bit of a cushion, I would say.

[00:16:59] And that's in part what allows people to, to say, you know what, we're, we're better as a team than as an individual lab. And we want to collaborate.

[00:17:08] **Stephen Calabria:** From the perspective of a clinical psychiatrist, what are the most challenging and rewarding things about treating this particular patient population?

[00:17:18] **Dr. Alex Kolevzon:** The most challenging things is that, often these kids can't speak. They can't communicate their needs. You know, I think if you, if you sit down with a patient, you can often really understand them and their needs by speaking to them and by listening carefully.

[00:17:33] In autism, and in the people that we work with in particular, they're so disabled that you have to rely heavily on observation. And there's limitations to that.

[00:17:44] But then what's most rewarding is then you develop really meaningful and important relationships with the families and with the parents who are the experts in their kids. And you learn through the parents, through their observations, and you learn to listen to things that the parents say, and obviously take it very seriously.

[00:18:00] But much of your treatment decision making, depending on the child, is really based on seeing things through the parents' eyes, obviously relying a little bit on your own observations, but, but I think the most rewarding part is the relationships, you know, because it, it does require like, a lot of collaboration, you know, and a lot of respect for the parent's experience.

[00:18:20] **Stephen Calabria:** To prep us for the next interview, could you tell us about the role of caregivers, both in the lives of patients and how they impact your work?

[00:18:28] **Dr. Alex Kolevzon:** Mm hmm. Yeah. So, I mean, the, in child psychiatry and certainly in working with people with autism, you know, we have, We've got many different patients, you know, we've got the patient themselves, the child, we've got the caregivers who are the experts in the children, we've got the school, we've got the therapist, we've got, the various services that occur outside of school, there's so many people that are involved in these kids lives, and I think it's the parent, it's the caregiver that's like quarterback, you know, obviously you as the doctor can be something of a, of a medical quarterback, but, you know, if I see a kid for an hour a week, parent sees him for, you know, whatever it is, 90 hours a week, Assuming they sleep, which many of them don't.

[00:19:09] Yeah, the caregivers are amazing. I mean, the caregivers, we talk about parent warriors who are just pushing and pushing and pushing to get the best for their kids, to get the best treatments, to make sure that the providers are talking to each other, to get the best schooling, and they sacrifice everything.

[00:19:24] I mean, it's a full time job.

[00:19:27] **Stephen Calabria:** Dr. Kolovzhan, thank you so much for your time, sir.

[00:19:29] **Dr. Alex Kolevzon:** You're welcome. It was great to be here.

[00:19:33] **Stephen Calabria:** Thanks to Dr. Kolobzon for his time. And now, to get the perspective of both a parent and caregiver of a child with autism, we're joined by Marlee Marinelli, a New York-based copywriter. We're honored to have Marli on the show.

[00:19:48] Marli Marinelli, welcome to Road to Resilience.

[00:19:51] **Marli Marinelli:** Thank you. Thank you for having me.

[00:19:52] **Stephen Calabria:** Could you introduce yourself?

[00:19:54] **Marli Marinelli:** Sure. My name's Marli Marinelli. I have a 12 year old son named Alberto, who has severe autism, intellectual disability, and apraxia. I work in the field of communication, which is ironic since my son has two neurological communication disorders. We live up in Harlem, and we have a great life.

[00:20:14] **Stephen Calabria:** What's your journey been like in having a child diagnosed with autism?

[00:20:19] **Marli Marinelli:** I think I went through pregnancy like a typical mom, except for with an unusual craving for Thanksgiving Day sandwiches. Full term, nine-pound, smiling, bouncing baby boy. He had a very strong presence and he still does.

[00:20:34] And I think you just knew from seeing him right away that he was going to make a big impact to the world and everyone around him. And I would say as far as milestones go, you start to notice things like when you're with other play dates and their kids are rolling around or looking at each other or looking at their parents and your kid's not, but he's smiling and he's looking at the lights.

[00:20:58] And I think one of my biggest red flags was when his babysitter said, "Oh, he's looking at the angels." And I thought, that's, that's a sign but we went through the regular doctor visits. He missed the speech milestones.

[00:21:12] He was okay on like the physical milestones, sitting up, crawling, walking, but he wasn't doing, like the joint attention, which is children pointing and wanting their parents to see what they're looking at or even babies imitating other babies and children learn so much from observation and imitation, which I think is a huge, huge challenge with children of autism because they're not looking at the other kids around them, which is such a huge source of learning.

[00:21:40] So, his diagnosis, I think, around 12 months, I went on Autism Speaks. com and he literally had the entire checklist. I mean, he could have stayed up the night before and read it and exhibited all the signs, but spinning, flapping his fingers, side glancing, not looking up when his name was called.

[00:22:01] But he's just such a happy boy that, I knew there was, you know, something we needed to get checked out developmentally, and I wanted to get him diagnosed right away and then the pediatrician unfortunately convinced his father to wait until he was 18 months of age, which is too bad because I think anyone who has any doubts should have their children evaluated, and New York has an amazing early intervention program.

[00:22:27] **Stephen Calabria:** What was the reason for that, for waiting?

[00:22:29] **Marli Marinelli:** It was more old school pediatrician, you can't tell till a child's two, which is actually untrue. There's even like TED talks around being able to diagnose at four months of age purely based on eye contact.

[00:22:42] And not to say that you can do some major interventions at that early on but you know, you can start planning for things like services or I think given that from the ages zero to three, New York provides free services, at least New York City provides free services, like behavioral analysis, occupational therapy, speech therapy, physical therapy, because it's run by Department of Health because they understand the earlier you treat developmental disorders, the better the outcome of an individual's life.

[00:23:13] It's the best time to seek treatment. And also, your child has the most neuroplasticity at that age. So that's probably the best time for the most intense services. So it was actually excruciating waiting for that evaluation, and then he had a very thorough evaluation, diagnosed with autism, and we just started services through early intervention then.

[00:23:36] **Stephen Calabria:** And how old is he now?

[00:23:38] **Marli Marinelli:** He's 12 years old.

[00:23:39] **Stephen Calabria:** He's 12. And could you tell us what your day to day is like of being not just a parent of a child with autism, but also their caretaker?

[00:23:49] **Marli Marinelli:** So every day is different and unpredictable, which makes it all the more fun. But, I can typically count on my son exhibiting a range of emotions.

[00:24:00] He's a really happy boy. I get a lot of love and I feel very, very lucky. And anyone who doesn't view my son as a miracle, I think is neurologically impaired.

[00:24:10] But, the day can start with head hitting because his breakfast isn't ready fast enough, or it can start with a smile and a kiss, or it can start with crying for some inexplicable reason, or it can start with a perfectly-behaved child who is going through what we call tasks of daily living, because we've been working for a while on functional living skills.

[00:24:31] So getting dressed, eating, and then he gets on the school bus and he goes to school and then he has after-school services and in-home applied behavioral analysis. So he gets a very robust and well-deserved level of care, because of the severity of his autism.

[00:24:50] And there's also the intellectual disability to factor in because cognitive functioning does make a huge difference. And again, every child is individual, but throw in a few more diagnoses and you've got a really special formula.

[00:25:04] **Stephen Calabria:** Disciplining a child with autism must be difficult. It's like How do you reprimand someone who isn't responsible for the way they're behaving?

[00:25:14] **Marli Marinelli:** I believe you don't. I believe, and I learned this early on, through applied behavioral analysis.

[00:25:20] I guess the first lesson is to unlearn anything you ever thought you knew about parenting and to learn that a behavioral analysis who's under 30 and doesn't have children is probably going to give you some really brilliant advice on how to raise your children and that you're going to learn new things every day.

[00:25:35] And the more I learn about ABA, the more I realize I have to learn about ABA, but the whole principle of it is around antecedent, behavior and consequence, and the principle of positive reinforcements.

[00:25:47] So, you're looking at not just the behavior, like if there's a tantrum, but what was the precedent, what happened beforehand, did you make a demand on him, was he in the middle of a routine, was he seeking attention, so you, you have to sort of analyze what was happening at that moment, because that will determine the consequence, because the behavior is the behavior.

[00:26:08] The consequence, if say, the antecedent was he was seeking attention, the consequence is not giving him the attention. And you still block the behaviors, because my son exhibits self-injurious or, aggression.

[00:26:21] So obviously you block head-hitting or, or whatever, but, if there seems to be no antecedent, then it could be pain and medical-related. My son has, I think, headaches, tension headaches. So it's, I think that's one of the biggest challenges is ruling out when something's medical and when something's behavioral.

[00:26:41] It could be an upset stomach that's making him act out, and that's, I think, you know, if I could have, like, a permanent MRI in my apartment so I could figure out and separate it, because even the treatment team needs to know because they can't tackle a medical, I guess, condition with a behavioral management plan.

[00:27:02] Something as simple as if he broke his toe, but he was limping and we think it's a stim, that's a really bad example, but he was kicking off his shoes, for example, for a while, and then we thought it was a matter of, oh, he needs to learn how to tolerate keeping his shoes on. But actually, the insole was too sharp on one of the shoes, and it was as simple as that.

[00:27:20] So, I think, literally, you have to be in the shoes of the individual, but that goes back to the positive reinforcement versus when it comes to disciplining, saying no, I think is a absolutely useless. It's not a power word. And I think, my son loves social praise. He soaks it up like the sun.

[00:27:38] So if I praise him for following through and a good behavior, hypothetically, he will continue to exercise good behaviors and he'll learn that this leads to that, and they have things like token economies, for example, where, if you break down steps in a task, the child will earn a token per step.

[00:27:57] It's basically like a star chart, and then at the end of filling out the token economy, they get a reinforcer, which could be an edible, and when I say edible, I mean food,

[00:28:08] **Stephen Calabria:** Edible piece of food, yes.

[00:28:09] **Marli Marinelli:** Yes, or it could be an object or it could be social praise. My son actually loves tickles, so he'll work for a tickle. Every child is unique. I've seen kids work for orange peels. It's actually really super creative.

[00:28:21] Yeah. And that's actually one thing I really like about behavioral therapy is that it's very individualized to the child and not just how these sort of routine steps are, but what the child's needs are, what the child's motivations are, and what the long term functional skills and goals are.

[00:28:40] **Stephen Calabria:** Now, I'm not a parent, to my knowledge, um, but building resilience and grit in our kids, it's important that we teach kids how to power through challenges and setbacks.

[00:28:53] First of all, how do you do that instilling that there are going to be times that are difficult that you have to get through, but how do you balance teaching that with wanting to make life good for them, and easier for them?

[00:29:07] **Marli Marinelli:** So, I think my son is one of the strongest individuals I know, and I don't mean just physically, but I think he has so much character, and he has so much strength and dignity, and I think he works harder than anyone else I know.

[00:29:23] So I'm actually not worried about his power. In fact, I think he, he knows his power and it's actually frightening because his power is charisma and charm and his dazzling good looks, but I think, because he does have the cognitive delay, his typical communication style, if he's upset, is to hit his head, and you don't know what that could be.

[00:29:45] It could be from frustration, or it could be from a word that was mentioned to him or something that was said in front of him that wasn't delivered or maybe he's tired or he's hungry. So, I think, honestly, it comes down to communication, again, and speech and communication is our number one goal.

[00:30:01] So, he's learning how to use augmentative communication device. I think the formal name is dynamic speech generating device. It's basically an



iPad with a speech software and my son uses one called Proloquo2Go, but there's other ones called LAMP or TD Snap, Speak for Yourself, and they're all based around motor planning and they need to be tailored to a child's level of acquisition and using certain words.

[00:30:31] So my son's three core words are potty, eat, and water. Ideally, I mean, those are pretty critical.

[00:30:38] **Stephen Calabria:** You could get by as an adult with only those.

[00:30:40] **Marli Marinelli:** I'm finding that he's actually really fluent in food because he can get all the way to pretzel, banana, but with other things like play. He won't like specify a movie if he wants to go out to the park or swing or the concept of feelings, emotions.

[00:30:56] And that's an area I'd really like him to move into. Cause I think that would eliminate a lot of frustrations as well. But we accommodate his pace and we encourage him and we need to adjust to the level that he's ready for.

[00:31:11] **Stephen Calabria:** What have been some of the greatest milestones in his development that to an outside observer would have seemed trivial and not particularly relevant, but to you made a huge difference?

[00:31:23] **Marli Marinelli:** So we worked on handwashing for about six years and now when he goes up to a sink, he knows the basic steps. So, something as simple as, what a typical child would learn or observe takes my son years and years. I actually, one of the biggest successes is learning to enjoy playing iPad games.

[00:31:48] Because even Leisure Skills was a program for him. He had to learn how to play. . Because otherwise, again, he's not imitating other children. What is an iPad to him? What is this game?

[00:31:59] What is this thing moving around? So, during the pandemic, we explored a lot of different iPad games at home and I realized he really enjoyed this one genre that I managed to target, which was 3d driving games with just a very basic control of acceleration.

[00:32:16] And maybe a horn you could honk, but then you could manipulate the landscape. And he really liked, I think, being able to move the view around, watching the motion of the train.

[00:32:26] So we have a lot of train games on our iPad now, but I think that was sort of an entree into this world of iPads, and it's funny because you see most parents like looking up ways to get their kids off of their iPads and kids going into counseling because they're so addicted to their iPads.

[00:32:40] And here I am begging my child to even look at his iPad. But now he actually, um, I sent in an iPad to the school as a reinforcer, a non edible reinforcer. And he works for it.

[00:32:51] **Stephen Calabria:** He seems to be developing into a really stand up adult given how it seems relatively few adults actually wash their hands. Um, burnout must also be at the top of mind for a lot of parents with autistic children. Could you talk a little bit about that and how you keep frustration and exhaustion at bay?

[00:33:13] **Marli Marinelli:** I think you just have to roll with it. So, if my son wants to lay in bed and watch Kung Fu Panda, that's what we're gonna do.

[00:33:22] And, if it's a tub of Trader Joe's chocolate chip cookies, I love cookies too. I'll work for them and we enjoy those moments, when he's even in therapy and I think there's this misconception that if you're in therapy, you're sitting at a chair and someone's, especially with ABA, making you do discrete trials where you have to point to a field of three and identify a color or a number.

[00:33:43] And I think it's such a bad rep for applied behavioral analysis. It's the best ABA I've seen is invisible. And his therapist, if we go on community outings, actually facilitates really meaningful engagement. So like we went to, Architects of Air, it was like a balloon installation for children at near Lincoln Center.

[00:34:03] And it was just a sensory wonderland for him. And, the behavior analyst was there, and we were, it was just It was such a joy to watch him walk around this maze of wonder, get all of his like sensory input in there.

[00:34:17] He was better behaved, I'll say, than the neurotypical children who were doing all the things they were warned not to, which is climbing on the walls because it was a very delicate fabric. But Alberto just loved looking at the lights and being able to wander freely from room to room.

[00:34:30] And it was really interesting because he was dragging me in as therapist. Like, he felt it was a new space, but he felt reassured. He felt engaged,

and that, to me, was an amazing ABA session. That's, to me, what behavioral therapy is about.

[00:34:44] Helping a child get the most out of life and, ideally, teaching them how to practice those skills so that they can do as much as they can independently. And to me, a functional skill is enjoying life and recreation.

[00:34:59] **Stephen Calabria:** And I imagine that if you see them enjoying life, it makes it that much easier for you to enjoy life.

[00:35:04] **Marli Marinelli:** Yes, absolutely. So, another huge milestone is that he can now sit through a movie. And we went from 15 minutes in a theater to now he sat through entire movies. I think, Zootopia, Paw Patrol was one of the latest ones. Yeah. And I was stunned. And it didn't even take like three buckets of popcorn.

[00:35:24] He barely ate the popcorn. He was actually looking at the screen. And AMC actually does an autism-friendly Saturdays program, but he can also go outside of those times as well. They'll have the lights like slightly dimmed and they'll turn the music down, which I think is really, really nice.

[00:35:39] But, my son's actually walked into a movie theater and somehow he found the light switches and he turned the lights on for the whole auditorium.

[00:35:45] **Stephen Calabria:** It's a man who knows what he wants.

[00:35:46] **Marli Marinelli:** Yeah. He's able to shape his environment to suit his needs, and that's something I admire. That's something I admire. Like he can walk down a street and if he's getting tired, he'll just pull open a car handle. Extremely dangerous, but I like that he thinks all these cars are parked and lined up, ready to take him wherever he wants to go. And, it's a really refreshing view of the world.

[00:36:07] **Stephen Calabria:** The world is his open car.

[00:36:09] **Marli Marinelli:** Yes. Yes. There are people waiting on the side of the road to take him to whatever destination.

[00:36:14] **Stephen Calabria:** Right, right, right. Now, that speaks to his personality generally. And we've spoken about how great your son is and how he wouldn't be as great if he wasn't his whole complete self. Has his diagnosis,

would you say, endowed you with a greater sense of meaning and purpose in your life?

[00:36:34] **Marli Marinelli:** I think children endow parents with the greater sense of meaning and purpose. I see autism as a facet of his, I guess, characteristics or personality. It doesn't define him. To me, it's, he was born with brown hair. He was born with autism. It is what it is. And, we're going to make sure he has the best life he can with what he has.

[00:36:56] **Stephen Calabria:** What do you think is important that parents of children diagnosed with autism know about what it is they're facing?

[00:37:03] **Marli Marinelli:** That it's, can be really overwhelming if you look at it as a whole, but in some ways it's empowering because your child gives you the cues and there are so many supports in place to help. I think New York City is probably one of the best places to have autism.

[00:37:23] Just throwing that out there to all the fetuses that may be coming with autism. I think New York has a really great program. He, Alberto has a Medicaid care manager because he has a disability and he's under the age of 18.

[00:37:36] So, he automatically qualifies for Medicaid and his care manager is extraordinary. She checks in on him, his medical programs. Um, there's so many supports and groups out there that are dedicated to helping children with special needs and autism specifically, that it's the good and bad.

[00:37:57] I don't know any other parent who can literally ask a child specialist that exact same day about a behavior they just noticed was happening, but at the same time, you know, that parent also isn't facing new behaviors and new challenges every day.

[00:38:13] So there's the pros and cons but I think your child and your love for your child and your child's love for you is what gets you through every step. And I think any parent would say that about their child.

[00:38:24] **Stephen Calabria:** Listeners to this show know how seriously we take clinical trials and you've signed up your son for a series of clinical trials. Is that right?

[00:38:32] **Marli Marinelli:** Yes.

[00:38:32] **Stephen Calabria:** What's the process of that like?

[00:38:34] **Marli Marinelli:** Alberto had a psychiatrist at Seaver Autism Center who suggested he might be appropriate for a clinical trial and it was purely a series of diagnostic behavioral testing, which is great because that saved me like 7, 000 dollars for a neuropsych report, which I get every few years to both inform his programming and also to really get a sense of his cognitive functioning skills.

[00:38:58] So that was our clinical trial, which was incredible because he had the top psychiatrists and psychologists testing him through like the gold standard of autism tests. Since that, we've been on their list. So there was a human genome sequencing trial that came out and they asked if we would like to participate.

[00:39:18] And, it was something I was actually really excited to be part of because I really think Alberto can make a huge difference in helping make the world a better place. And, the whole idea of genetic studies.

[00:39:31] And we know, to me, so little about human genomes. And there's 70 percent of children diagnosed have idiopathic autism, which means there's no genetic cause.

[00:39:41] And that to me means there's 70 percent of children who may very likely have a gene we haven't yet discovered. So, Alberto's genetic information, I think 20, 000 human genomes that are sequenced are on file.

[00:39:54] And, as research progresses, they may actually identify a new genetic marker for autism and then you can start genetic therapy much earlier and that was great to be part of that study.

[00:40:06] And they also my, like samples of hair and his father's samples of hair just to look at neurological history to see if that also impacted Alberto's prognosis and his diagnosis and it didn't have an impact.

[00:40:21] So that was also really interesting to see which genes went out, which genes don't, what's been identified, what hasn't.

[00:40:28] **Stephen Calabria:** So if you're listening to this, enroll in a clinical trial. Last question to close us out. What is your favorite, most hilarious story about your son?

[00:40:40] **Marli Marinelli:** Every day? He actually has no, he loves sensory, anything sensory related. So he will roll on the floor, roll on the glass. This isn't

like my most favorite all time, but like this week he had, uh, an assistive technology evaluation with the Department of Education and he literally thought it was, I think, a party for him.

[00:41:02] Cause there were 10 people seated in a circle when he walked in and he literally started working in the room like a host. And then he started doing his like, stereotyping and stimming off the evaluators head cause he had a nice curly head of hair. I was just like, Alberto, you've got this. You've got this down.

[00:41:19] **Stephen Calabria:** Well, that was it for my questions. Was there anything else you wanted to say?

[00:41:22] **Marli Marinelli:** Nope. Nope.

[00:41:23] **Stephen Calabria:** Marli Marinelli, thank you for so much for coming on the show. Alberto, if you're listening, we love you. Please don't get into any random cars.

[00:41:31] **Marli Marinelli:** Thank you for your time.

[00:41:34] **Stephen Calabria:** Thanks again to Marli Marinelli and Dr. Alex Kolevzon for appearing on today's show.

[00:41:40] That's it for this episode of Road to Resilience. If you enjoyed it, please rate, review, and subscribe to our podcast on your favorite podcast platform. Road to Resilience is a production of the Mount Sinai Health System.

[00:41:51] It's produced by me, Stephen Calabria, and our executive producer, Lucia Lee. From all of us here at Mount Sinai, for listening. thanks for listening, and we'll catch you next time.