



Episode #99:

Barry Prizant Talks About His Book "Uniquely Human: A Different Way of Seeing Autism"

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Barry: So often what we have done has been done with all good intentions. It's totally understandable why a parent may want their child not to engage in behaviors that look different or that are attention getting in public or that may be stigmatizing for a child. But the bottom line is what are we communicating to a child if we're always saying stop that, don't do that, always correcting. And so there's a lot of attention now being paid to the impact of what we do on a child and eventually an adult, self esteem.

Debbie: Welcome to the TiLT Parenting Podcast, a podcast featuring interviews and conversations aimed at inspiring, informing and supporting parents raising differently wired kids. I'm your host, Debbie Reber, and today's episode features a powerful and thoughtful conversation with Dr. Barry Prizant, one of the world's leading authorities on autism. Barry is recognized as an innovator of respectful, person- and family-centered approaches for individuals with autism and neurodevelopmental disabilities. He has more than forty years of experience as a scholar, researcher, and international consultant, and he's an adjunct professor at Brown University, a certified speech-language pathologist and director of Childhood Communication Services, a private practice.

He is also the author of the must-read book *Uniquely Human: A Different Way of Seeing Autism*, which suggests a major shift in our understanding of autism. Instead of classifying "autistic" behaviors as signs of pathology, he sees them as part of a range of strategies to cope with a world that feels chaotic and overwhelming. As you listen to our conversation, you'll know exactly why I was so excited to bring Barry onto the show. He is at the forefront of the revolution in helping to change the way neurodiversity is perceived in the world and frankly I'm just so grateful there are people like him in the world doing this critical work.

And before I get to the episode, I want to make sure you know that I've just made available a first look at the first chapter of my upcoming book *Differently Wired: Raising An Exceptional Child in a Conventional World* on the TiLT Parenting website. Though the book doesn't come out until June, I wanted to offer a sneak peek for members of our community. The chapter is called "An Unmarked Path" and it shares some of my personal story and sets up the rest of the book, which I wrote to spark a revolution in the way differently wired kids, and us as their parents and caregivers, experience everyday life. So, if you want to get a first look at my book, just visit tiltparenting.com and sign up right below the main image on the home page, and I'll send you a PDF of the first chapter, as well as the Table of Contents right away.

And now, without further ado, here is my conversation with Barry. I hope you enjoy it!

Debbie: Hey Barry, welcome to the podcast.

Barry: Thank you so much, Debbie. It's a pleasure to be here.

Debbie: I'm really looking forward to this conversation and just getting a chance to talk with you about your work, your incredible body of work and you've been doing this work for so many years and I really want to learn more and introduce our listeners to your book, *Uniquely Human* in case that hasn't been on their radar yet. But before we get started into the meat of our conversation, could you tell us a little bit about, you know, just your story. I'm fascinated by, you know, how you came to do this work and how long you've been doing it.

Barry: Yeah, well, my story goes way back and I love to share kind of the early roots because sometimes younger professionals or even people who do not work in the field of supporting and understanding people with disabilities that sometimes very early experiences are so formative. So I actually started as a teenager working in summer camps in residential summer camps, mostly in the northeast and these were summer camps for children and adults, with various labeled disabilities ranging from autism to emotional behavioral disorders to learning disabilities to what we now refer to as intellectual disabilities. And those experiences were so important for me because I was a caregiver living with people and I was responsible for their welfare, for making sure they had a good time and that they were safe. So from very early on, I had the experience of what many families as they often say live 24/7.

And that was before I got into academia. So I was doing that for a number of years. And then I was academically in college, I was very interested in language and language development. Actually, I was a failed German major and then became a psycholinguistics major, which was a new field at that time. So just very quickly psycholinguistics has to do with understanding the relationships between a person's thought and how they organize their understanding of the world and how they can express that through language and other ways of communicating. So I had these two parallel tracks going on, my summer experiences, which I then supplemented with volunteer experiences while I was in college. And having that undergraduate degree in psycholinguistics and those experiences led me to the field of speech language pathology and communication disorders, which is what I did for my masters and doctoral degree.

Very early on I became interested in autism and we're talking about the early 1970s to the late 1970s. I did my doctoral dissertation in my master's thesis on autism. As a matter of fact this year, 2018 is the 40 anniversary of my completing my doctoral dissertation, which was looking at the language characteristics of autistic children. And very much I challenged the perception of that language was meaningful. That a particular form of language known as

echolalia or the tendency to repeat speech was just meaningless parroting and nonfunctional. And through video analysis, basically I was able to demonstrate that those perceptions were all wrong. And that then led to a number of publications over the, over the years on those topics. But I then pursued my journey in academia for a number of years working in hospitals and universities and fast forward for the last 20 years I've been in private practice, still affiliated with the university I've been affiliated with for 25 years, Brown University.

And so I get out a lot into classrooms. I spend a lot of time with families. Just yesterday I was in a preschool consulting to a number of kids and meeting with families, and I also have gotten involved on a different level with families. This year actually, in just a few weeks we will be having our 22nd annual parent retreat weekend where we raised money and we take 60 parents who happened to have family members with autism to a beautiful country setting and have them learn from each other. I get a great opportunity to learn from watching and listening to these parents. So another big piece of the work that I really value his work with families and supporting families. One other element I should add is that I'm a drummer and a performing percussionist. I play in a band and I've always been interested in the creative and performing arts and how that can be used for people with disabilities to enhance quality of life, but even more specifically to enhance language and communication skills and self esteem, so I'm involved in all of those areas right now. to varying degrees.

Debbie: It's fantastic. I mean, I can, first of all that you've been doing this work for so long. I can only imagine how much the landscape for the conversation around autism and what we know and are continuing to learn and think. You've witnessed all of that and been on the forefront of a lot of it as well and I can hear in your voice and it certainly comes through in your book *Uniquely Human*. Just how passionate you are about this. You know, I can hear the joy in your voice as you talk about your work. It's really cool.

Barry: You know, that's something I really try to get across and that now in my kinda more senior years in my career, I think it's important to get across to younger people who potentially could come into the field or who are already interested in coming into whatever it may be, speech, language pathology, special education, social work, any kind of helping fields that you're really creating a life for yourself. You're not just getting a job and getting a paycheck and the one thing that's been of such great value me is the work that I do as enhanced my personal life in so many ways. Being the most incredible people. You know, some of my close friends now are adults on the spectrum, including families who have family members on the spectrum and it spills over into my personal life. It's not that I'm doing it with my professional hat on. It's just I've met the most wonderful people who outside of if you will, consulting to their child or consulting to a school program, just have to become wonderful friends and I've learned so much through this experience, so it's really for me is broken down the boundaries between your so called vocation and what you do outside of your work.

Debbie: Yeah, I love that. I mean that's what I wish for. Really, everyone, right. If we can all have that blending of our personal interests and our passion and our work combined like that and I think that's when the best stuff happens, you know, and we can really be in a place of joy as were moving through our lives

Barry: And I think it's a younger people are much more capable of doing this now for. Let me just give you a quick example. I'm affiliated with the group at Brown University that's called artists and sciences as partners and there's a two semester undergraduate class and I do a little bit of teaching in that class and these students are amazing, you know, so what I asked them, well, what are your interests? What do you do? A student will say something like, well, I'm, I'm in cognitive neuroscience and I'm a ballerina. And then somebody else will say, well, I'm a concert pianist and I'm pre-med, and so right now universities are allowing for that kind of bringing together interests with vocational interests, with your personal talents and interests, and I think relating to supporting people with disabilities, some of the most exciting work that I see now, which is also more accepted now than ever before, is for example, the use of theater with students with autism and not just as a therapy, not just like theater or drama therapy or music therapy, but to enhance quality of life, which has therapeutic benefits for so many people.

Debbie: Right, right. Well, let's dive into your book *Uniquely Human* because there's so many, I have a lot of things I want to get through and we'll just do the best we can, but for listeners who haven't read the book and aren't familiar with it, can you tell us the big idea behind the book?

Barry: Yeah. First of all, it's important for me to make it clear that it's a mainstream book. It is not a technical book or an academically oriented book. I've published book books of that nature, but the big idea behind *Uniquely Human* is that we've really misunderstood the experience of autism for many, many years, even though people on the autism spectrum have been telling us what their lives were like. We come out of decades of what I refer as pathologizing autism, looking through the lens of deficit, looking through the lens of what is wrong here. And so the big idea of *Uniquely Human* and it's right in the title, *Uniquely Human: A Different Way of Seeing Autism*, is understanding people who happened to have a label of autism as evolving human beings who have their strengths, have their passions in the book after following a term coined actually by, a woman Clara Claiborne Park. She used the term enthusiasms that my child did not have obsessions, my childhood had enthusiasms. So really looking and it's not just kind of PollyAnna-ish looking at the cup half full. It's meaningful to have a different window and a different perspective into understanding the experience of autism. So a couple of more specific things that I really try to get to in the book is, number one, autism is not a tragedy for some reason people, you know, a parent will say, I have an autistic child, oh my God, it must be such a terrible experience. You must be such a patient parents. And yet so many parents talk equally as much about the joys and how much they've learned and how they live life more deep. And the notion that when we see a person with autism, they have all these autistic behaviors jumping, flapping, rocking,

echolalia, repeating speech and all of that needs to be stripped away because our goal is to normalize the child.

And so that also is... I have a whole chapter on talking about language characteristics and how we have to put those misconceptions to rest. That there's no such thing as autistic behavior. We have to understand the reason or the purpose and when we understand the reason why the purpose, it's not so different from the way we behave and what we do as so-called typical people. I also try to go right to the notion of high-functioning versus low-functioning autism because sometimes we cast in concrete our perceptions of a person which really limits possibilities for them and that there is no such thing. No human being can be taught to be spoken about as high-functioning or low-functioning. All of us are very good at some things and not so good at other things. And a couple of other quick points as part of the big message is that the best way to understand autism is to listen to autistic people. Listen to, what they have to say, learn from what they have to say.

And that's a huge difference. Of course between now and 20 years ago, 20 years ago, the only voice was Temple Grandin and now we have hundreds if not thousands of autistic people who are giving lectures, writing books, and they're telling us what we've gotten wrong as professionals all these years.

And then finally I really try to get across the point that autism isn't something that's in a person. Autism is a shared human experience. When I am with a person with autism, I need to change the way I talk, the way I react, if I want to have a successful time with that person in many cases, and it's also shared human experience in that I've become a better person by knowing people with autism. As long as we view autism as a condition within a person. And if you don't like what you see, then that gives us license to people to try to change and fix the person without taking the personal responsibility as a professional or as a parent, how do I need to change to best develop a trusting relationship and therefore be able to support this person?

Debbie: Yes, it is a packed book and you know, everything that you're saying and listeners, if you've been listening to podcasts, then you know, this is in complete alignment with the way that I see neuro-diversity that it is. It's not a deficit and it's, I do see it as part of an evolution and that we need to change the way we see it. And it's so beautifully laid out in this book and I'm curious to know, I mean, I would think some of these concepts when the book came out were really breakthrough, you know, what was the reception like when it first came out?

Barry: Yeah, well, so I would say some of the concepts were breakthrough, but some of the concepts are also kind of consistent with and building on what I refer to as the autism revolution, this kind of tsunami, this wave of change as clearly indicated. And Steve Silverman's incredible book *NeuroTribes* in so many different ways now. So I see, I see the book is part of a movement and certainly what autistic people are telling us, it's a very, very big part of that as well. So yeah, the initial reaction to the book and if anybody wants to see detail reactions directly for people that can go to the Amazon page, you know, for *Uniquely*

Human, what's been so gratifying is the breadth of interest and positive response to parents of newly diagnosed kids. Parents of adult individuals on the autism spectrum have said, oh my God, this is so consistent. Thank you for validating the way of what we see my child. Or you sent me on a new path. I think I've changed the way I interact with and respond to my child now.

Researchers, some of the top researchers in the field of autism. Dr Geraldine Dawson, who's the director, Duke University Department of Brain Science and Autism Studies is just one example and she's, she's also the Director of the International Association for Autism Research. So many people in academia have loved the book and then what's so important to me in addition to parents connecting with the book is autistic people. So many autistic people have either commented or actually written formal reviews and have said, Barry, thank you. What you described is something that I've experienced in my life as an autistic person, and thank you for saying that. As a matter of fact, one review from a wonderful woman named Judy Endow who was a blog, and that's e n d o w, she wrote a review of my book was Steve's book together what was called Uniquely Human Neurotribes. That was the name and she said about both of us. Thank you for writing these books. Would I have preferred that an autistic person authored these books? Yes, but you guys have really stood up for what our experience really is and take the message forward and join with us and that's, that's very valuable. So validating.

Debbie: Yeah, I imagine that's going to be incredibly gratifying and, you know, there are many things that I love about the book, but it is such a respectful approach to seeing difference and I love, you know, there's so many stories of your work over the years with such a range of families and kids and you know, respect is kind of this common theme throughout and I think that's so important for everyone to keep in mind to talk about this kind of fixing behaviors and that kind of thing. And that's not an even playing field, you know, but the way that you are meeting people halfway and trying to encourage people to look at this as communication, it is just such a positive, respectful approach.

Barry: One point I really tried to get across is that, you know, whether it be a parent or a teacher or a therapist. So often what we have done has been done with all good intentions. It's totally understandable why a parent may want their child not to engage in behaviors that look different or that are attention getting in public or that may be stigmatizing for a child. But the bottom line is what are we communicating to a child if we're always saying stop that, don't do that, always correcting. And so there's a lot of attention now being paid to the impact of what we do on a child and eventually an adult, self esteem. How do they feel about themselves? And how could you feel good about yourself if people are always trying to change you for who you are?

Debbie: Absolutely. I'd love to talk about behavior a little bit. I mean, when people first, you know, a lot of our listeners, the majority of our listeners have kids, who are in the early elementary school years and we have kids with differences of all kinds, but a number who are who are on the autism spectrum and they're just getting that information or they might just be starting to get feedback or

suggestions about different types of therapy and what are the priorities. And, and also, as you know, with, with younger kids and those early school years, it is often the behavior that's the first thing that we want to work on because it can be so disruptive in a traditional school setting. So can you talk a little bit about how behavior has been for so many years been like the target of our efforts and what your perspective is on it?

Barry: Yeah. Especially in autism, but this has occurred with other kids with different disability, especially in the United States approaches a number of years going back to the sixties and seventies were about, well, let's make lists of desirable behaviors the child demonstrates and let's build upon those. And let's look at the undesirable behaviors and get rid of those. OK. And of course, as you said, what is often attention getting his behavior that may be harmful to others or harmful to the child and they'd be disruptive in the environment, they'd be distracting to other people. Maybe unconventional looking very different so that child doesn't look like a typical child, but what we failed to do in the past is really looked deeply and what I refer to as the deep why, from the child's perspective, why is that child getting out of his seat in the classroom and bolting out of the classroom when we expect him to sit for 45 minutes and pay attention to the teacher?

Is it that he's being, and this is a term that's very popular now, oppositional or noncompliant, or is it that due to his neurology, he's incapable of sitting quietly for that period of time. So maybe that child for example, needs more breaks. Or maybe that child needs a different way of being taught rather than through lecture. Maybe that child needs more hands on experiential learning. So a lot of the changes that have happened is we try and it's not always easy, but we try to understand from the child's perspective and where they are developmentally, why they engage in certain patterns of behavior that we as parents and professionals may see as challenging or undesirable. As opposed to just saying, well, let's set up programs to increase behaviors and reduce behaviors, which what I'm describing now is kind of more of a notion of traditional ABA, applied behavior analysis where the focus has been traditionally going back many years on building behaviors and extinguishing or getting rid of behaviors without asking the deep why and without asking what we're doing. How does this impact that child's self esteem and that child's growing sense of who they are as a human being.

Debbie: Yeah. That idea of, you know, there's every, every answer. There's so many directions I could go with it and I have a lot more follow-up questions, but just to speak to that idea of looking normal. Like that's something that came up with my son who is now 13 and has a diagnosis of ADHD and Asperger's and I don't remember who it was, but a therapist at one point made a comment about the way that when he was drawing or trying to write that he, you know, the facial expressions he made and that that was something we'd also want to work on. And I was like, I'm sorry, say what? What are you talking about? That is the least of my concerns is I don't care what he's doing with his face, but there was such a priority placed on fitting in and looking quote unquote normal. And that was

really disturbing to me. But I, it sounds like that's been the way it has been for many years.

Barry: Absolutely. And it just raised another very important point and that is that part of not just the autism revolution but the whole revolution of supporting families and children and other family members who maybe adults is, let's understand the family's priorities. Let's understand what their perceptions are. Now, of course in education in the United States, you know, we have the IEP and parents supposedly you don't have to sign off on approving the goals and objectives and the procedures that are used, but too often that's just lip service and professionals go about doing what they're going to do anyway. But boy, you know, unless we really view, I'm speaking as a professional now, unless I see my relationship as collaborative and as a partnership with parents, then why do I have the right to expect parents to kind of follow-up on suggestions that I make if they don't value that or even more if they don't value that. If there's, as you just said, if they say, why would you want to work on facial expressions? How does that really, you know, stack up on the priorities I have for my son. It doesn't make any sense.

Debbie: Yeah. And one of the other things that came up as, as I was reading your book was you talked about just now desirable versus undesirable behaviors. And when Asher was in, I don't remember kindergarten or first grade, but he was at a point in time where he was really, his behavior was intense and big and undesirable, you know, in a classroom it was disruptive and there was other kids in the class who would the same kind of anxiety or frustration, it would trigger, you know, maybe falling apart into a puddle of tears and, and you know, same trigger, different response, but one was perceived as acceptable by society and one wasn't. And that was where the problem lied. That was really frustrating for me.

Barry: And I think one of the difficulties in that kind of situation, here's how I refer to that if as too often kids engage in behavior that people perceive as challenging to them that sometimes becomes part of that child's quote unquote reputation. So I've seen kids moving through the grades and you read the report and you hear terms like aggressive, noncompliant, and in some cases, and you hope this is the case, the new teacher maybe in the new school year says, well, I don't see that that's not happening here. And then you discover it's the lens through which the child is looked at, which leads to different ways to support the child. So if the approach initially is, let's just correct the behavior, you actually may get more pushback from the child, whereas if the approach is we have to develop this trusting relationship about line, then that makes a lot of sense.

Debbie: Yeah, absolutely. And I know that there is research backing that idea up that teachers treat kids differently depending on what they're told the child's gifts or talents or challenges are. So one of the things that you say in the book, you said that our attitudes and perspectives on people with autism can make a critical difference in their lives. Tell me why, why that is, what difference does have you seen it make in the lives of autistic people?

Barry: Well, to be specific, sometimes I still run into therapists and teachers whose attitude is for example, if a child is not cooperating, I hear phrases like, well he's just trying to get out of this, you know, or this is just being non-compliant. And so again, as I just indicated, if you always look through that lens, then what's your goal to break the non-compliance? To be compliant? As opposed to saying, and this is something I like to say often, well, there could be anywhere between eight or 10 different reasons why a person is not compliant. Any person, if they're asked to do something, they don't do it. It could be they don't understand what you're saying. It could be they've had negative experiences doing that before. And it's stressful for them. It could be they're just not interested in doing that.

There could be many different reasons. So our attitude shapes the way we try to come up with an explanation as to why a student may be challenging, which leads to very, very different approaches. And it's interesting a dear friend of mine who's in one of the leaders in the Asperger's movement, Michael John Carley, and he's written a few books and he's founded an international organization called Grasp. I quote Michael in the book a number of times. And one of my favorite quotes from Michael is, "if you want an autistic person to change, the best way to facilitate that positive change is to change what you are doing is to change your attitudes and change your beliefs." But I think too often we look at autistic people and describe any problems we see as kind of willful non-cooperation or laziness or whatever, as opposed to saying, what are we doing wrong? Can we teach this differently? Can we even use language differently? Simplify our language. Maybe if a child is very hypersensitive to the word no, because they associate that with a stressful circumstance, we can guide a child and even correct the child without using the word no if that's a trigger for that trial. Certainly everything from our facial expression to our tone of voice to do we use visual supports to help a child who has limited understanding of language. What underlies all of this is our attitude. What are the types and levels of support that a person needs to succeed as opposed to how can I get this child to do this, what I want them to do?

Debbie: Right. And that's a big reframe. Teachers and parents and you know, we all have to face at some point if we're educating our parenting or interacting with autistic kids is shifting. Because I feel like the message, if we don't do the work right, if we're not reading, we're not exploring this deeper. The messages that were that are kind of prevailing in society or that it's a behavioral problem, you know, there's this way to approach it. And so it does take some diving a little deeper and some coming to this new lens to see these kids.

Barry: it really is a new lens in a very concrete way. So for example, I mean autism used to be defined, some people still describe it as a behavior disorder. It is not a behavior disorder. It's a neurologically based developmental learning difference. Learning disability depends upon where you are politically in using those terms. But in my consulting I'll often be in a situation where somebody will say, oh, he's just being so oppositional or just being so resistant or he does that to push my buttons. And I always go back to. And I try to do it in a very,

very non confrontational way, but I may say to that teacher or a therapist who says that, OK, let's start from this fact. The fact is this child has a neurologically based brain difference in how he processes and understands the world that we know. OK, what are you saying? He's being manipulative or you're just trying to get out of this task. Those are your assumptions. You can't go into his mind and understand what his motive is. But what we do know is he has neurological differences that results in the way differences in the way he responds as opposed to a so-called typically developing child.

Debbie: As your sharing that, there is a story that I share in my book *Differently Wired* where I, you know, I think Asher was maybe seven or eight and he was being to use the word oppositional or overly non-compliant and a lot of areas. And I was talking with this therapist after a session, Dr John. I said, I'm really just having a hard time knowing, you know, what is the choice here? What's the behavior? what is it? Because of this wiring? And he just looked at me, he's like, Debbie, he's always autistic. Like that's always the lens that you're going to see this through, but he's not turning it on and off. There was always a reason why. And I just had to, you know, head smack, you know, like, uh, yeah, OK, got it. Moving on.

Barry: People. Parents, very often asked me, for example, around the three year old child, OK, is this three year old behavior or the autism? I'm seeing now, but then I hear that about teenagers moving through puberty OK, is this just early teenage behavior? Is this the autism? And I'm a developmentalist, meaning that all of my training is in social language, cognitive and emotional development in children. So what I, the way I like to say it is I will always look at a child through the lens of development and where they are developmentally, but then with a deep understanding of how their autism or how their neurological difference may color or shape or in some cases offer challenges to their developmental experiences as an evolving human being. So yeah, I mean lots of neuro-typical kids are extremely difficult moving into the puberty years, but as we know it can be a very difficult time for many kids who have a label on the autism spectrum, which kind of exacerbates or colors that experience even more.

But I think some of the problems that I see and, and programs for individuals with disabilities in general is developmentally inappropriate programming. So a child who may speak, a very young child doesn't have to be a young child, but may speaking one or two words, what we call utterances or phrases. And everybody's always saying, say the whole sentence. Say I want a big chocolate cookie, please. Add the child says cookie cookie want cookie in our approach, we value that the child is initiating and being spontaneous and clearly indicating their needs. And we're not so concerned that that developmental point about, is he saying a grammatical sentence? But that, that plays out in a lot of different ways. A child is only able to sit for 15 to 20 minutes at a time in a classroom and have a quiet body. We have no right to ask that child to sit for 30 to 45 minutes if their neurology does not that allow them to do that.

Debbie: Amen. Yes, absolutely. So. Oh goodness. OK. There's some many things that I want to ask you, but I'm gonna I'm gonna try to wrap this up, but before I want

to hear about what else is coming up for you, but before I do that, I have one more question. I just wanted to talk about this idea of emotion regulation and trust and anxiety. I really liked the way you talked about trust being such an important part for these kids in that you described that as the opposite of anxiety and it reminded me a bit of the work of Danny Raede from Asperger Experts when I first discovered his work and just like helped me look at Asher through that lens of, you know, getting out of defense mode and not being in fight or flight. So this all kind of connected for me, but the word trust hadn't ever been part of the way that I thought about what was really going on. So can you talk about the role of trust and emotional regulation?

Barry: Let me give credit where credit's due. The whole notion of trust actually came out of some of the work of Michael John Carley, who I just mentioned and he and I actually published a two part article which is a free download on my website about the primacy of trust, the importance of trust in getting to know and developing a relationship with a person on the spectrum. Now, let's just very quickly talk historically. For many decades people didn't even think you could even develop a relationship because these were kids who were incapable of developing relationships. That's another myth that we've pretty much thrown away. But the whole, the whole notion of of trust comes out of what's referred to as relationship based approaches. And our search model is a relationship based approach. And basically what we're saying is if a child or an adult does not see us as a parent or professional, as dependable as somebody they could rely on as somebody who could read their communicative signals. As somebody who knows how to help them regulate emotionally and physiologically when their experience, what we refer to as dysregulation, whether they're anxious, whether they're fearful, whether they're just so revved up in a high arousal state that they can't even control themselves. So the whole notion of trust and you know, I always like to bring this back to all of our experiences with people in our lives. There are certain people who we know we can go to if we're feeling very stressed and very challenged in our lives. And then those people are reliable, dependable. They're good listeners. They know what to do or say to help us. There are people we know we want to avoid in those circumstances. So why is it that we don't think those same kind of rules, if you will, are not applicable to people with autism or disability.

And that trust piece has been ignored for so many years. And if that trust is developed, if, if a child I'm working with sees me as reliable, dependable, I know when they need a break so I'll give him a break rather than forcing them to sit for another 15 minutes. I know if they need a little extra support, I'll do that, but trust goes the other way. I know when they're doing really well and they're really motivated, I'm going to raise the bar for them a little bit so they can succeed and feel good about meeting new challenges and so why would a child want to risk if you will, taking a lot of difficult task unless they're with a person who they know is dependable and will help them. So that trust piece is huge. It's the basis of a relationship and we seek out people were motivated by people and we'll take more risks with people where there's a trusting relationship and we won't do those things. If a person is undependable, inconsistent, unreliable, and doesn't see us in a positive light.

Debbie: Yeah. I mean I talk a lot about finding your people, how important it is for parents with definitely wired kids to find their people and to kind of ditch the people who just get it or you know, let that go because not everyone's going to get it and I really loved that you talk about people with the "it" factor in your book and you lay out these really great qualities of people who who get it and that those are the people I talk about it from a parenting perspective. Those are the people we need in our lives, but those are the people our kids need in their lives.

Barry: Absolutely, and again, let's give credit where credit's due. The "it" factor is a construct that I learned from my mother who was attending one of my workshops in Vancouver, Canada a number of years ago and she brought it up in the audience. Just saying here's how my family thinks about it and that's what the book uniquely human is really about, is what I've learned from families and autistic children are autistic people. So some of the things you've really connected with are actually things that I learned from Michael John Carley or this mom from Canada and there's just so much wonderful knowledge, so many gems out there that we could all learn from and I think those are the things that I find parents hold on to and that professionals need to hold onto rather than coming in with our own preconceptions and our own judgments.

Debbie: Absolutely. Well, yeah, I mean, again, there are so many great stories in the book. I really connected with them and it also shows just the work that you've done throughout the world. You travel all over the world doing this work and it was very inspiring to me and optimistic and hopeful. But before we go, I would love to know what is coming up for you> And then I'd also love if you could share, share with the listeners where the best place for them to connect with you is?

Barry: Sure, there so many irons in the fire right now. Just very quickly, some of the things we're very excited about is, we are replicating a theater expressive arts program out of California, developed by a mom Elaine Hall. It's called the Miracle Project. And we're doing that at Brown University and the Rhode Island Philharmonic Orchestra School. We actually had a camp last year and we're having ongoing programs in the coming year. We hope that it'll all work out well. We're continue to do our parent retreat, as I mentioned, and a possibility of a new book that's a follow-up to I'm Uniquely Human that's going to focus on what's important to put into the lives of people with autism that they can do or that we can do to really make sure quality of life is experienced, a positive quality of life is experienced.

I think a lot of people in the field of disability have shifted away from simply saying, let's train that person to get a job. I think now we're really looking at the whole concept of quality of life. What is a good life if you have autism? And even despite the challenges that autism may bring, what is a good life for this person? How could we put those building blocks together from very early on and not work on things that are meaningless to a person's life. So those are some of the

big issues. Many other irons in the fire right now, but we don't have time to get into them right now.

Debbie: Well, when you have more news, you can come back on their show and fill us in. But everything sounds great. It sounds like you're a very busy person and I'm really grateful not just for you stopping by the podcast and talking with us today, but just for the work that you're doing in the world. You are, you know, people like you are so important to parents like me and just knowing that you're out there fighting this fight and having such an impact is really fantastic. So thank you so much for joining me today.

Barry: Yeah, thank you. And let me just turn that around and say people like you are important to all of us. In terms of sharing information and your perspective both about your child and also everything you've learned as a parent professional. So thank you so much. Thank you.

Debbie: You've been listening to the TiLT Parenting Podcast. For the show notes for this episode, including links to Barry's website, his book *Uniquely Human*, and the other resources we discussed, visit tiltparenting.com/session99.

If you liked what you heard on today's episode, I would be grateful if you could take a minute to head over to iTunes and leave a rating or review. We are still in the top 20 in the Kids and Family category, and honestly it's just so exciting to see this audience grow and the podcast get more attention. It also makes it easier for me to land bigger guests, so it's a win win. Thank you so much for being a part of making this happen.

Lastly, if you aren't already part of the online community at TiLT, I invite you to sign up at TiltParenting.com. Every Thursday I sent out a short email with a quick note from me, a link to that week's podcast episode, and links to 5 stories from the news that week that are relevant to parents like us. Again, you can sign up at tiltparenting.com.

Thanks again for listening. For more information on TiLT Parenting visit www.tiltparenting.com.

RESOURCES MENTIONED:

- [Barry Prizant's website](#)
- [Uniquely Human: A Different Way of Seeing Autism](#) by Dr. Barry Prizant
- [The S.C.E.R.T.S. Model](#)
- [Carol Dweck and Mindset](#)
- [The Yes Brain: How to Cultivate Courage, Curiosity, and Resilience in Your Child](#) by Dr. Dan Siegel and Tina Payne Bryson PhD
- [Brainstorm: The Power and Purpose of the Teenage Brain](#) by Dr. Dan Siegel
- [The Whole-Brain Child: 12 Revolutionary Strategies to Nurture Your Child's Developing Mind](#) by Dr. Dan Siegel and Tina Payne Bryson PhD
- [No-Drama Discipline: The Whole-Brain Way to Calm the Chaos and Nurture Your Child's Developing Mind](#) by Dr. Dan Siegel and Tina Payne Bryson PhD
- [Parenting from the Inside Out: How a Deeper Self-Understanding Can Help You Raise Children Who Thrive](#) by Dr. Dan Siegel with Mary Hartzell, M.Ed
- [Mindsight: The New Science of Personal Transformation](#) by Dr. Dan Siegel
- [The Duke Center for Autism and Brain Science / Geraldine Dawson](#)
- [International Society for Autism Research](#)
- [NeuroTribes: The Legacy of Autism and the Future of Neurodiversity](#) by Steve Silberman
- [Uniquely Human Neurotribe](#) (blog post by Judy Endow / Ollibeau)
- [Differently Wired: Raising An Exceptional Child in a Conventional World](#) by Debbie Reber
- [Asperger Experts](#)

- [Michael John Carley](#), Founder, GRASP; Author of *Asperger's From the Inside-Out*
- [Primacy of Trust Article](#) (co-written by Dr. Barry Prizant and Michael John Carley)