

Nate Trainor

>> BERGREN: Hello, everyone, and welcome to "Disability, Inc.," INCLUDEnyc's podcast series. My name is MaryBeth Bergren, and I'm coming to you from Staten Island, New York. I'm a native Staten Islander, and an avid member of the special needs community. I have two autistic children, and know first-hand the struggles of navigating the world for children with diverse needs, and the fight for inclusion, both in school and in the community setting. INCLUDEnyc has been a lifeline for families like mine.

Today, I have the pleasure to be joined by Nate Trainor, a long-time advocate for the acceptance of people with disabilities, and author of "Nate's Triumph: Presuming Competence and the Fight for Inclusion." Although non-verbal, he is a powerful voice for inclusion. Here with Nate today is mom, Jean, and long-time friend and support person, Chris.

Before we begin, I want to inform you that Nate, who is non-speaking, and our very first non-speaking podcast guest, which is truly amazing, will be using an alternative communication method to converse today. There may at times be some short reflective pauses or silences as answers come in. These pauses allow you to experience what it's like to engage in spoken conversation with Nate, or anyone who may use alternative or adaptive communication technologies.

So just a little more about Nate before we begin. Nate is 38 years old, and up until the age of 21, he was unable to communicate using words. Nate was born with a rare genetic disorder called Joubert syndrome that causes abnormalities in brain function, physical movement, and fine-motor control. At just two years old, Nate was labeled severely and profoundly retarded by doctors and professionals, a label he unfortunately lived with for many years.

Nate is non-verbal. However, his disorder has not inhibited his intellectual development, and he advocates for people with disabilities, encouraging inclusion and the idea of presuming

competence. Nate learned first-hand the adversity of rejection, exclusion, and the presumption that he is incompetent to think, listen, read, feel, and love.

Nate, I am so excited to have you here today. I really dove into your book when it arrived, so there is so much to unpack here. Let's start from the beginning. Is that okay?

>> NATE: Good afternoon. Yes.

>> BERGREN: You mention in your book that at just two years old, you were labeled severely and profoundly retarded by doctors, and that no one knew what was going on in your head, or how you were processing the environment around you. What was it like before you were able to communicate with words?

>> NATE: Awful, because I am smart, but I couldn't communicate how smart I was.

>> BERGREN: You mention as you got older, by the age of six, you already were growing angry about how the outside world was behaving towards you. Can you tell us a little about what you saw and felt happening at that time? How did that affect your own behavior?

>> NATE: Hurt and confused. Everyone treated me like a baby, so I acted like a baby.

>> BERGREN: Let's chat a little about your first experience in school. You mentioned you attended a segregated preschool at the start of your educational journey. I'm going to quote you here, because I find this statement to be so profound: "Imagine being stuck in a place where the message, 'We don't expect much from you,' is reinforced every day."

Tell me a little about your experience, and Chris, I would love for you to jump in as well.

>> NATE: Eventually, you might come to believe it. People often start behaving the way everyone labels and treats them. Does it really make sense to separate special needs kids from potential non-disabled friends and mentors, who can help them get beyond what they thought possible?

If there are no role models, no positive reinforcement, and no one to demand better of you, there's practically no way for you to rise above your current ability. The game is rigged to keep you exactly where you are.

>> BERGREN: That's such a heavy statement. That was beautifully read, Chris. Thank you so much.

So let's move into your experience, Nate, with the Hansen Elementary School, an inclusive school alternative that your mom actually felt would be a better fit for you. Can you tell me a little about that transition, and maybe a little about your first teacher?

>> NATE: Hansen Elementary School and Jenny were awesome. I felt like I was getting out of jail.

>> BERGREN: Wow, that's amazing. What about friendships? You mention in your book that sometimes you don't need words to feel like someone's friend, which I thought was a beautiful reflection. And as a mom of children with diverse needs, very hopeful. Tell me about your friendship pathway, and your first experiences with a best friend.

And Chris, I would also love for you to speak, as you are one of Chris's closest friends.

>> NATE: Chris is my best friend. I always know he has my back.

>> BERGREN: That's really great. Chris, how does that make you feel?

>> CHRIS: Um, yeah, it brings back a lot of memories. I've known Nate a long time. We started out where I was working with Nate. I spent time taking him to his job, some things that he needed to -- there were things that he was responsible for in the community. But I think we hit it off right away.

When I met Nate, again, he didn't have the ability to type. But I share this story, and this is what really hit for me and that I go back to, is Nate's understanding. I had some things going on in my life that I was struggling through. And Nate and I were sitting and we were supposed

to be -- Nate was supposed to be shredding some papers. And I had kind of drifted off, and was thinking about some of these things in my life.

Nate picked up on that. And a few seconds later, he's just a few inches from my face, and he's got his hand holding my hand. That moment, I knew that we didn't need to speak any words. But I knew that I had a friend in Nate that really understood, and he saw maybe that I was hurting. And I knew he had my back. It's been 15-plus years ago, and I still share that story. And I can tell you where I was sitting and what we were doing.

Just since then, I've had an opportunity to do things with Nate and his mom and had some great experiences. Just two wonderful people, but it goes back to just, they're like family to me. I'd do anything for them. And I think of some of the other fun things that we've been able to get Nate to do. It's always -- being around Nate has really helped me find possibilities and ways to do things.

We've been on a jet ski a few different times. I go back to that. Just thinking about the support Nate needs to get down there. But once we're on that jet ski, I think Nate describes it as just being free. And having the wind blow through your hair. We just figured out those things, and have been able to enjoy those things together. So I appreciate him very much, both of them in my life.

>> BERGREN: Thank you for sharing that, Chris. That was really beautiful. And it gives someone like me, a parent of children with diverse needs that may not always know, a lot of hope and just a lot of excitement and maybe a little clarity around what to think when my children express to me in the way they can.

I want to jump ahead a bit to fifth grade, and the transition to middle school, when Nate, you say your fight for inclusion really ramped up. What year was this? What do you think was the biggest obstacle or worry to overcome for them -- the school staff, the district, the school community? And maybe what about for you as well?

>> NATE: I started fifth grade in 1995. I think the biggest obstacle for everyone was the fear of the unknown and I was afraid I would be sent back to the segregated school.

>> BERGREN: Wow, yeah. Fear, I feel like fear fuels a lot of the decisions that may be made when it comes to understanding the needs of diverse students, for sure. And I can't imagine what that was like for you to fear going backward instead of forward.

In your book, you say that it was not usually the kids that didn't know how to treat you. It was actually the adults. That the kids knew how to accept you into the community, even if they didn't understand what being a community meant. Tell me about the community method and how you used it to be successful.

>> NATE: The community method is inclusion where everyone is welcome.

>> BERGREN: I feel like it's such a simple answer, and it's so, so hard and complex. So when did you experience your first communication with words? What was it like to communicate your first word, and what method of communication did you use?

>> NATE: I first typed when we went to a workshop in Chicago when I was 21 years old. My name was the first word I typed and it was awesome. I use facilitated communication to type.

>> BERGREN: Wow. What changed for you after learning how to communicate with words? Is there any advice you could possibly give to parents or pre-verbal individuals looking for a way to communicate?

Chris, maybe you can share some words that Nate wrote in his book. Because I know there were some really profound things that were said regarding these questions.

>> CHRIS: "Everything suddenly looked different to me. I had come out of the dark, been released from prison, and suddenly had a way to interact with the world on my own terms. Literally, my own words, that I had never had before."

“To everyone that is still pre-verbal, and looking for a way to communicate, please believe in yourself. Don't waste your dreams. Treat them with respect. It's free, and you can find a method that might work for you that will change your whole life.”

>> BERGREN: Thank you, Chris. Let's dive a bit deeper into the communication battles you faced, Nate. How were augmented communication devices considered, tried, and chosen? Tell me about the struggles with the use of facilitated communication, and maybe some of the hurdles you faced with the disbelief that you could communicate at all?

>> NATE: Marilyn Chadwick and Darlene Hanson helped us get started with devices. I now use an iPad with an external keyboard. Those that know me know I am the one doing the typing. Those that don't, need to meet me.

>> BERGREN: That's beautifully said. When did you know you wanted to be an advocate for others that were struggling with similar challenges? And what is presuming competence, and how can it open the door to inclusion?

>> NATE: As soon as I got my voice, I wanted to help others get their voice. That's why I wrote this book. Presuming competence is believing that everyone has intelligence.

>> BERGREN: And I encourage everyone to go and get this beautiful book. What are you up to now, and what does your future look like for you and others that are non-speaking?

>> NATE: I want to write a children's book and help other non-speakers to find their voice.

>> BERGREN: That's beautiful. Thank you. Thank you so much, Nate, and thanks so much to everyone for listening. Tune in next time for another great conversation on "Disability, Inc." See you next time.