

Eileen Lamb 14:56:55

Welcome to "Adulthood on the Spectrum," in this podcast, we want to highlight the real voices of autistic adults, not just inspirational stories, but people like us talking about their day to day life. Basically, we want to give a voice to a variety of autistic people. I'm Eileen Lamb, an autistic author and photographer and I co-host this podcast with Andrew Komarow. Hi, Andrew!

Andrew M. Komarow 14:57:15

Hey Eileen! I'm Andrew Komarow. I'm the founder of "The Neurodiversity Index." Today, our guest is Scott Steindorff. Scott Steindorff is an international television and film producer and writer who specializes in adapting literary bestsellers and premium movies and television. His most recent project that he executive produced is "Station 11," a book to screen adaptation, which was released on HBO Max on December 16, with an outpouring of overwhelmingly positive reviews and accolades. Scott is also an ART board member, and neurodiversity advocate and regular speaks with high schools and colleges across the country, on the importance of emotions and feelings, as well as facing substance abuse. We like to start off every episode with asking about identity language. And we don't mean pronouns, although you feel free to share that too. We mean, do you have a preference? Person with autism? Autistic person? On the spectrum? Or no preference?

Scott Steindorff 14:58:26

I'm autistic. And proud of t.

Eileen Lamb 14:58:32

Speaking of when were you diagnosed with autism? And what was the process like and you know, what made you seek a diagnosis? You seem to be as successful in in life was it, was there an event, something that made you seek a diagnosis? Can you tell us about that?

Scott Steindorff 14:58:52

Well, I'm in my early 60s. And so I'm part of the last generation where there wasn't a lot of autism diagnosis for children. And I grew up in a small town in Minnesota. And at the age of 10, the teacher

took me out of class, and said, you can't make eye contact, you stare into space, you seem to have difficulty focusing, and we think you're taking drugs. So my first diagnosis was that I was probably sniffing glue. And then they took me to the principal, and my parents had to come in. And so that was my first unofficial diagnosis. In my early 20s, I was diagnosed with ADD and I was in denial of it, I did not want to accept that I had ADD and, and then in my, you know, I, I knew I had something associated with spectrum. But again, you know, I'm all there. So there wasn't a lot of information everywhere about it. And so I, my, my youngest daughter, who was diagnosed with ADHD, had been reading about autism and said, Dad, you're autistic, and you need to look at it. And so I got diagnosed, you know, many years ago, and got the official diagnosis and changed my life.

Andrew M. Komarow 15:00:35

Do you think it changed your life? What what did change getting a diagnosis so late in life and Eileen and myself, we were both diagnosed late in life as well, although I, neither of us are in our 60s quite yet.

Scott Steindorff 15:00:52

Well, I think the, you know, in my early 20s, I had a substance abuse problem. And, and so I got involved in recovery, and I've been sober my whole adult life and, and, and I think it was very much like that, in the sense that you get diagnosed, and then you start looking at your symptoms and your behaviors. And for me to look at a whole life raising three kids, having a business, all the difficulties I had. So it became a for the first time self awareness maybe, you know, being aware of why I did certain things. There was a lot of, you know, when I first got diagnosed, I was shocked. I was upset. But I knew I had it. And I knew I it had been a difficulty in my life. Since early childhood.

Eileen Lamb 15:01:55

That's exactly how I felt about my diagnosis, I struggled my entire childhood and adult life not fitting in. And I always felt something was wrong with me. Like it was my fault. And then when I was diagnosed, it was like a relief, in a way. It was like, oh, that's why I did that. That's why I can do these things that everybody is doing, and it seems so normal and easy for them. And so I totally relate to that. Really like the answer.

Scott Steindorff 15:02:26

Yeah. And so for me, it was, you know, I was socially awkward. In a social business, where I didn't want to socialize. I couldn't make eye contact. I couldn't, you know, I have a lot of stimming, I have a lot of special interests. And I didn't understand why people didn't love my special interests. And I love to read, you know, reading was my was my escape since I was a child. And it ended up becoming my career. And, and so, I look at the positive aspects also.

Eileen Lamb 15:03:10

So, you know, knowing that you're in the business, like, what do you think of Hollywood's representation of autism? Because I feel like we're starting to see it more and more like, do you think it's accurate?

Scott Steindorff 15:03:23

No, I don't, I don't like what's I think we're just at the beginning of understanding autism. And so I think there's so much misinformation. I don't like sensationalizing me and you and all of us on this call, is that, you know, we have to understand it, we have to understand what it is and what it isn't. And I don't think Hollywood ever got it, right.

Andrew M. Komarow 15:03:54

Do you have a, a favorite? Or maybe a, you know, a not the worst representation of autism in the media? Or a couple of them?

Scott Steindorff 15:04:11

I mean, I've I don't watch for somebody in the business. I don't watch a lot of it because it's uncomfortable for me. I think "Rain Man" was a little. I mean, I loved "Rain Man". You know, I saw it when I was young, and I loved the movie. I don't know if it's an accurate portrayal of autism. I don't like those reality shows that portray dating because I don't want to sensationalize because I know how difficult it is. So, you know, dating and relationships are difficult for us. So I don't think we should watch you know, that in a sensationalized way,

Andrew M. Komarow 15:05:02

Part of when we started this podcast, and part of the announcement was we said we didn't want to be inspiration porn. That that wasn't the point. We wanted real people, real stories. So what about representations of autism where I think the term would be worse were somebody's cannon were they don't say it. I'm seeing that a bit more. And like you know, I think one of my favorite over the past couple of years was "The Outsider." If you've seen where we're I can't remember her name, but you know the character I'm talking about.

Scott Steindorff 15:05:44

Yes.

Andrew M. Komarow 15:05:44

They never say that. She is right. But it's so clear that she is,

Scott Steindorff 15:05:50

Yeah

Andrew M. Komarow 15:05:50

And I really like when they do it that way like "The Bridge," you know, the FX version. They never say it the overseas version. What would be your least and by the way, Eileen has never even seen "Star Wars". I make fun of her. So she's never seen like anything so she doesn't know what we're talking about. (All laugh) But what about your least favorite?

Scott Steindorff 15:06:23

Um, I don't know if I have a least favorite or favorite. If you ask me. What's my favorite movie or my least favorite? I just don't look at things that way because I'm autistic. So it's not something that I

Andrew M. Komarow 15:06:39

Or some that you liked, or some that you didn't like, oh, you said you didn't like like the dating reality shows?

Scott Steindorff 15:06:44

Well, I love, I what I really liked was the little boy. I can't remember the name of the show if you tell me with his sister and family

Eileen Lamb 15:06:54

Atypical?

Scott Steindorff 15:06:57

Yes

Andrew M. Komarow 15:06:58

Yeah.

Scott Steindorff 15:06:59

I liked that show. Aspects of that show. I really do. And his relationship with his sister, and, and parents, I thought they did a good job there. And I know the writer has an autistic child. So she understands. You know,

Eileen Lamb 15:07:18

That's yeah, I love that show. And "Parenthood". I think that's one

Scott Steindorff 15:07:23

"Parenthood," is great. Yeah. So I think if you it's like, it's like everything, right? If if people involved are autistic or know about autism, they're going to have an honest portrayal. So it's like, everybody talks about, you know, race and religion and all these, but neurodiversity needs a seat at the table, and they haven't had one in Hollywood. And, and I really think it's important that we spread the word. So people that have are on the spectrum, can be heard, seen and felt.

Eileen Lamb 15:08:07

So here's my, my problem with Hollywood, I guess, you know. I have autism, I'm on the spectrum. I'm autistic. However, like, I don't mind about terminology. My, my eldest son is 10 years old, and he is level three, which, you know, high support needs nonverbal, you know, self harming behavior, it's like, it almost feels like a different diagnosis in a lot of ways. And I feel like most of the presentation in Hollywood movies and is more like people like us. And you know, it's such a broad spectrum, it's hard for everyone to feel represented, right. So I wrote a book that was published, called "All Across the Spectrum". And I talk about my experience being diagnosed at 25. And, you know, raising a child with nonverbal, higher support needs. And I, my dream is to get it on this on the screen, so I can tell both perspective in one in one place. And, you know, I took a try to some screenwriting classes and lessons and it was like, it's so difficult. Do you have any tips for someone who has a dream like mine?

Scott Steindorff 15:09:33

Yeah, keep going. Don't give up, persist. I mean, the one that, you know, as you guys are both autistic, and you are involved in the autism world, is, many of us have been bullied. Many of us were, I had a very difficult childhood. I stuttered, I couldn't make eye contact. I, I was bullied called names. And it was so difficult for me. I've also raised, you know, kids with autism, that had difficulty. So I think you guys are aware, I just did a documentary called Understanding Autism, which I traveled all over the world literally for five months. I interviewed 140 doctors, psychiatrists, families, people that have a lot of needs, and some that are higher functioning. So like your book, I tried to balance it, you know, that there are, you know, I have many non-speaking autistic people in the movie, and I'm very proud of the movie, and hopefully, it'll come out in the fall, I'm still editing. But what I discovered in this process is we're just at the beginning. And we're just learning so much about it. And we need more funding, and we need more help and support for your child and, and we need to, we need to have more empathy. We need to have more understanding of, of the parents. I, I always say the hardest part about autism is being a parent of autistic children.

Eileen Lamb 15:11:32

Yeah, I'm only if you're familiar with the online world of autism, but you know, outside of my work as an author and at Autism Speaks my day job I'm also you know, I blog I guess is what you would call it. I have a large platform and big issue I'm facing is that there's a lot like bullying, especially with parents and I, I get it's hard, I think because my platform is big. And I really wish, you know, it's not incompatible to support the autistic person and the parents, and I think it comes with the diagnosis, you know, it's hard to see the gray areas, and some people are really on me for the autistic person. But like, as someone who sees both sides of it, it's, we need it all, you know, it's the community as a whole, and it's hard.

Scott Steindorff 15:12:27

And the community needs to come together, and understand, we all have suffered and struggled. And we all want what's best for our children, and families. And the family is really, really important. And so, you know, I had, my children are on the spectrum, my siblings were autistic. So obviously, in, you know, my research and my point of view is that, obviously, it's genetic, just like heart disease, and many other things. And, and it doesn't really matter how we have it, we have it. So how can we create better support, better understanding of each other, and, and what we're going through, whether they're nonspeaking, or high function, you know, as my daughter was just visiting from Austin, and I was saying how lucky I am that I'm higher functioning, and I found a place in my life. And she looked at me and she said, Dad, you're not high functioning. You know, and, and the truth is, I do struggle with things. I struggle with motor skills, I couldn't change a tire, I have difficulty putting things together, I have lots of things and challenges. That got me to where I am to overcome those. And that's why I say to you, the gift that I got with my autism is, I don't look at outcomes, like other neurotypical people, I just do it. And it's allowed me to create a pathway of success for me to function.

Eileen Lamb 15:14:31

Can you tell us a bit about your neurodiversity advocacy work, I saw that you do a lot of that too?

Scott Steindorff 15:14:38

Well, when I'm not filming, I work with kids. And I, you know, one on one, because I look at it, you know, like somebody that has a substance abuse problem, you know, an alcoholic or a drug addict, is that they can help another drug addict, or somebody overcome drinking, right? I have autism. So I've worked with teenagers and, and, and kids. And, and they'll listen to me, because I'm not a parent of theirs, or a teacher of theirs or a psychiatrist. I haven't. So I feel them, I understand them. So I think that's important for all of us on the spectrum, to help others on the spectrum. Because we can relate to them, you know, little things that I've learned along the way to help them overcome. And I think the biggest, the biggest lesson I can give is, you know, if you find something, believe in that and keep going for it, don't give up. You know, I didn't give up the odds were so against me to make it in this business.

Andrew M. Komarow 15:16:01

Have you had others come to you and open up and maybe share their experience. I'm sure there's plenty that you can't share, but maybe I'm wrong and any names that you can.

Scott Steindorff 15:16:21

What do you mean?

Andrew M. Komarow 15:16:23

It's like have because of your one thing that I've experienced, for example, opening up in the financial community, I had a lot of people approached me saying, you know, they were autistic too or your family or friends. So I find so I'm curious if you had that same experience when you opened up publicly?

Scott Steindorff 15:16:48

Well, I would you know, several years ago, they wrote up an article about me in the Hollywood Reporter, which is our trade publication. And, and I talked about being autistic and my struggles and, you know, information about my own autism. And I've never, ever been written about where I had so many phone calls. And most of those phone calls were from people in the Hollywood community, talking about their children, their brother, can you help us, we don't know where to go. We don't, we're, we're having difficulties with school or, and, and it really opened up a lot of doors for me and them to communicate about autism. There was also a lot of shame and stigma. There was people that called me and said, Here you are, whoever I am as a producer and writer, and you're successful, why would you do that. And the reason why I'm doing it is like, very clear, I want to help other people. I want to help people not struggle and suffer with the same things, whether they're a child, a teenager, a young adult, or trying to create a career. And, and we need to guide and there's not enough support groups, there's not enough financial support for your child that is nonspeaking devices. And, you know, so many kids that can't get out of a bed or, or go outside you have to watch I mean, it's the hardest thing ever. And, and that's what needs to be portrayed in Hollywood, show the real struggle, because that's real. And, and that needs, those stories need to be told,

Eileen Lamb 15:19:00

Do you think with your documentary, you are going to be able to show that side too? I mean, just like you say, like, for instance, my son doesn't understand that putting things in his mouth. Like, he just puts everything in his mouth and you know, like litter, like rock, so if he sees a car, he's gonna run in front of

it. No sense of danger. You know, it's, it's really hard. And I feel like we don't see that at all at all in movies.

Scott Steindorff 15:19:26

I promise you, I, I showed that.

Eileen Lamb 15:19:29

That's, that's great.

Scott Steindorff 15:19:29

It's really important to me. You know, I have several nonspeaking people that can't, that need help that are in the documentary. And then I have the superstar Elizabeth Bonkers. I don't know if you're aware of her. That, you know, ended up going and being valedictorian at a university in Florida. And I mean, her story is remarkable.

Eileen Lamb 15:20:03

She did the speech with her AAC device?

Scott Steindorff 15:20:08

Yes.

Eileen Lamb 15:20:08

Yeah.

Scott Steindorff 15:20:09

It's the most, by the way. Talk about that video is the most watched video of any video in the history of the world. 4.5 billion views. And so, we need to tell those stories, and she's in my movie. Or a young boy that is autistic that started playing golf. And he's, I think he's 11 years old, he is Sports Illustrated Junior Champion, and found his way we can get, you know, and it takes parents, right. It's takes parents to believe that this is possible. It takes community to believe this is possible. We need to inform schools, we need to inform therapists, psychiatrists, doctors, so we're, we haven't scratched the surface with this.

Eileen Lamb 15:21:13

How about you know, people for whom it's not possible because all of you know, people on the on the spectrum who are higher needs are never going to be able to, you know, be successful, like that, they're gonna end up in like, homes and, you know, not everyone can be a successful and meaningful story like that. Some are gonna need help 24/7 for the rest of their life.

Scott Steindorff 15:21:36

But you know, what the people and I talk about it is the people that do need help their whole life that need the support their whole life. The parents need help and support the brothers siblings and sisters. They need help. And there's something very special in a lot of those cases that I filmed, and I call it autistic love. And there's something so beautiful. And I discovered that with so many families,

Eileen Lamb 15:22:12

It's it's true, you know, like, I see my two boys, you know, and one of them is, you know, more like us, and the way they interact with each other. I mean, it's different, obviously, because my eldest son, he just, he doesn't really understand much if I'm being honest, you know. And it's still beautiful to see them interact in their own ways. And, you know, the way his little brother just loves him, even though he can't play and, you know, it's, it hurts him that he can't play with his brother, like, you know, his friends at school and all of that, but he still finds ways to, you know, be with Charlie. I wanted to ask you about something you said in in an article, I think it was on Health? But I forget, but you said that, about ABA, if you know, you're a duck, you're a duck, you're not gonna turn me into a goose. And I think that's a misconception about ABA is that it's trying to make the autistic person into a non-autistic person. Because from my experience, I mean, Charlie, my son has been in ABA therapy for eight years now. And they've never tried to turn him into someone who is not, you know, like they taught him, you know, some self care, like brushing his teeth. They taught him how to use an AAC device. They don't prevent him from stimming, or they don't force contact. You know, I think ABA come a long way. And one thing I do I try to do is my platform is to really show that compassionate ABA, play based ABA is really out there. And it's just really trying to teach skills.

Scott Steindorff 15:23:54

And I think it's a beautiful thing. A lot of ABA therapists, because they really care, and they want to help and if they're doing it with compassion, empathy and love, all for it. All for it. And, but I also think that non-speaking autistic people should get devices and be allowed to communicate and be allowed to, you know, excel in their own way. So look, AA is 80 years old. It needs to be updated. ABA, I think also needs to be updated. teaching universities and, and doctors and psychiatrists and therapists needs to be updated. We're just, we're just at the ground floor. So if whatever works, great.

Eileen Lamb 15:25:01

That's, that's good. Yeah. So right.

Andrew M. Komarow 15:25:03

What I have one last question before Eileen takes it to the end. So you said, so, you have mentioned your struggle with, again, substances, and you just mentioned how AA needs to be updated? In what way would you update AA? And what advice would you give to other autistics who also struggle with substances?

Scott Steindorff 15:25:31

Well, it I also deal with that in my documentary, is that a lot of people with substance abuse problems, including myself, did it because we had underlying causes and conditions that needed to be dealt with. And I think what's really been the most important thing in me, trying to, you know, figure myself out, is understanding emotions and feelings, how to identify my feelings, how to understand my feelings, how to process my feelings, and how to express them. Because emotional regulation is a problem for all of us with autism, and I think it needs to be taught. I think it needs to be involved with the parents, with the children, with the schools, with the therapies and really stressing. Why is somebody having a meltdown? Why what is going on inside that little boy to cause him to have a meltdown? Is it sensory

overload? Is he feeling overwhelmed? Is he scared? aired. So it's understanding the feelings. And for about 10 years I've been studying this and it's really, by the way, I still have meltdowns. You know, I still struggle, but I understand why I have a meltdown. And I try to express my feelings, you know, differently. Or pause, you know, when I'm having anger and intensity, because I've had that since I was born. And nobody taught me anything. They taught me not to feel. Don't feel. Don't get mad. Don't get angry, don't get sad. There's still teaching. You can't do that with autistic people. And we need to do it with empathy and love.

Eileen Lamb 15:27:52

That's a beautiful answer. Thank you. And I'm going to ask you some some quickfire questions to end this just some quickfire questions. You just tell me the first thing that comes that comes to mind. Do you have a favorite quote? And if so, what is it?

Scott Steindorff 15:28:11

Never give up.

Eileen Lamb 15:28:14

Every movie? Autism or not?

Scott Steindorff 15:28:18

Butch Cassidy and the Sundance Kid.

Eileen Lamb 15:28:21

Favorite director?

Scott Steindorff 15:28:24

Oh boy, Martin Scorsese.

Eileen Lamb 15:28:32

What's your favorite food, comfort food?

Scott Steindorff 15:28:35

Sushi

Eileen Lamb 15:28:38

And is glow in the dark color?

Scott Steindorff 15:28:42

Green.

Eileen Lamb 15:28:44

So it is a color you think?

Scott Steindorff 15:28:46

Yes. For sure.

Eileen Lamb 15:28:51

I think it's a property. I can,

Scott Steindorff 15:28:54

Okay.

Eileen Lamb 15:28:55

Yeah. We ask everyone who just trying to figure it out.

Andrew M. Komarow 15:28:59

I think I am winning the argument, Eileen.

Eileen Lamb 15:29:03

Oh, well. Do you want to tell people where they can find you online and your work and all of that?

Scott Steindorff 15:29:11

Well, you can add me on Instagram, @ScottSteindorff. Dorf, or Facebook or, or LinkedIn. I'm everywhere. And pretty easy to find. And I I love autistic people. And this has been a really wonderful interview. I feel very moved by both of you. So you've inspired me.

Eileen Lamb 15:29:41

Well, thank you. I'm so glad you came.

Andrew M. Komarow 15:29:44

Yeah. Thank you. Glad you came.

Scott Steindorff 15:29:46

Thank you so much to both of you.

Eileen Lamb 15:29:48

Thank you