

Sivan Hong: Parenting neurodiverse children

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SPEAKERS

Katy Weber, Sivan Hong



Katy Weber 00:00

I've interviewed quite a lot of women who had come to their diagnosis through their children. So I'm curious about that. But I also am fascinated about the fact that you wrote your books before your diagnosis, right? Like, you're sort of like, Yeah, I'll get to that eventually. But let's start with. So you have two sons, who were one of them. They're both neurodiverse. So let's usually I ask kind of what made you first think you had ADHD? And what led to your diagnosis, but I feel like you kind of backed into yours. After doing so much. So let's talk about kind of what made you really get interested, I guess, in neurodiversity, and as a topic for children's books?



Sivan Hong 00:44

So yes, all of that, oh, that there's a question in there somewhere. There isn't, I found it. Um, my eldest son, he's 10, was diagnosed with autism around two. And at the time, I knew nothing about autism. But I had known that there was something development totally different about this child pretty early on, and he was my first and I still had that, like mommy instinct that said, to me, something is different. And I took him to therapist, the therapist after therapist to try to find out what was going on. And oftentimes, they said to me, he's just a gifted kid, it's okay. And, you know, in your gut, that that's just not, right. Like, it's nice that you think I want to hear that, but that's not right. And finally, we got him diagnosed with autism. And what used to be Asperger's. And I recognize that at that point, we had to do a lot of work, to help him get on the path that he needed to be on. And so I left my job and, and I just did what people with ADHD do. And I hyper focused on this idea that I needed to know everything, I needed to talk to everybody. And, and I just went in, like, I just dove into it. And I know that there's kind of two different kinds of parents, when their kids get a diagnosis, one like me, who's like, I need to know everything, I need to do everything, I need to try everything. And then the ones who put their heads in the sand and are like, Ah, I don't want this to be happening. I'm not that kind of personality. And so in doing so I realized how plastic the brain is, when there too, and how much I could do if I really was able to work with him. On getting him more comfortable to be around kids. He had all of these crazy spikes, where you could give him a date and say, say November 18. And he would say, Oh, well in 2075. That's a Tuesday. And he'd be right. Right?

Like he had this brain that I couldn't understand. But my husband and I stepped back. And we're like, we could have this really, really smart, eccentric child who can't survive in the world, but could graduate Harvard when he was 12. Or we could have a kid who had a chance at a somewhat normal and happier life. And we chose B. And so instead of trying to work on those kinds of spikes, we tried to normalize his brain. And, and I say this, because that's a hard thing to talk about. Right? Like, I wanted him to be able to be comfortable in a room full of kids. And, and, and never take away who he is, as a person never take away the quirks that makes him who he is, but still be able to function independently in society. And that's what we did, like we worked tremendously hard. His entire life was going to therapists and for us working on things with him. And he's gotten to the point where he has friends, and he can function in school. And he doesn't now know, November 18, in some random years is going to be a Tuesday because who needs to know that but he also knows about his autism. And we've talked about it with him from day one. We called it his special brain, and that he saw the world differently than other people did. And he would tell people about his autism. And when he actually started to make friends, he would share this with them even though you know, kindergarteners, they don't really understand what that means. And with his autism diagnosis, I started to pick up on the ADHD. And people had told us early on that there's the No, no, he doesn't have ADHD, it's just autism. And again, like, the more you dive into it, the more you know, your kid, like, this isn't just the autism, there's something else going on. And I got him diagnosed with ADHD in second grade. And it's interesting, because there it is a Venn diagram, there are overlapping pieces to ADHD, and to autism. And I keep thinking about neurodiversity as this spectrum, that's not just the autism spectrum and the ADHD spectrum. But none of our brains are wired the same way. And so he got this ADHD diagnosis. And then I started to see it in my younger son. And I was like, no, no, I know what this is. I've seen this movie before. And we were able to get him diagnosed in first grade. And the whole time, my conversations with those kids have been, this is really cool. You have this different brain, it makes you see the world differently. And, and my first grader once said to me, he's like, I'm not going to tell any of my friends I have ADHD, because I don't want to brag. And I'm like, That's right. That's what we want. Like, this is something to be proud of. And everybody kept saying that this is genetic. And I'd always say to my husband, I'm like, where did all this come from? Who could have possibly had this and he would laugh at me, but not say anything. And so finally, I realized, it dawned on me, I'm like, wait a minute, all of these characteristics that I'm seeing in my children, I can see in myself and it never crossed my mind. And so I talked to my kids about it. And for my 47th birthday. Wait, how old am I now? Maybe my 48th birthday? Sorry. This is not the way my brain works. Um, I told my husband, I wanted to get a diagnosis. I wanted to do a full neuro psych for my birthday. And that's because I wanted the actual diagnosis. And I went in and I did it. And the doctor is like, yes, of course, you have ADHD, like it wasn't even close. And I came home. And I told my husband and he starts laughing. And he's like, I could have told you this from our first date. I'm like, I know. But now it's like, it's official. It's like, I can literally say, This is why all of this stuff happened. And I've heard women on your podcast, talk about what it feels like to actually get the diagnosis and what you go through. And I went through this phase of anger and sadness, and joy, and it's all happening at the same time. Because it explains so very much.



Katy Weber 07:56

Yeah. Oh, my goodness. Yeah. I think, you know, it's funny, I was talking to my kids, just this morning, in kind of mentally preparing for this interview. I was saying, like, you know, I've been talking about ADHD, basically, non stop in, in our household. But I didn't come to my diagnosis through my children, right. So I came to my diagnosis through my therapist and the pandemic. And so, but I do talk a lot about how difficult but I was growing up, and, you know, the, the

issues that I had in school and how, you know, I do kind of talk about it very openly in the terms of the negatives and the positives. And an AI, neither of them has been formally diagnosed, I have a 10 year old and a 14 year old, but I, you know, I talk about it with them very openly about like, I don't think it's not that I don't think you have ADHD, or that you are neurodiverse I just haven't gotten you diagnosed yet. Because we are, you know, I'm learning we're learning we're dealing we're coming up with our own kind of lifestyle changes, etc. And you know, and I also feel like I want to get it right when I do the diet, you know, when I don't want to just go through the school district because like, neither of my kids is terribly physically hyperactive, they're not disruptive. They don't have a lot of the stereotypical traits that would get kid pulled out of the classroom and get them a diagnosis through the school district or so like I you know, I'm just like, I think you know, because I've been learning so much about it like I want to be super I just want to get it right and so but of course procrastinating but so I sent it I asked them both individually this morning, but you know, I was like, do I you know when i What do you think like do you feel like ADHD is something that is a gift or do you feel like it is something terrible, you know, because like I was worried I was like maybe I do painted in such this terrible picture. What because I talked about how you know, living The Life undiagnosed and being convinced your whole life that you just like something was off and everybody got the manual, but you and why can't I do certain things? And why am I not trying harder? And all this? You know, I know, I'm bright and all that stuff. And, and they both had very satisfying answers, which was like, you know, my daughter was like that, and I, you know, you I think it's, it's, I think you credited with a lot of the great things in your life. And, you know, I understand that, you know, you wish things had been differently, and that's fine, and that you're trying to do right by us, etc. And my 10 year old was like, I think you're overthinking it was like, it was like it is what it is, you know, it's just a thing. And I know, there's parts about it, I like there's parts about it that you know, are probably difficult, but at the end of the day, it just, it is what it is. And I was like, Alright, I can live with that. But, you know, it's certainly like I, I, I get worried that when I talk about ADHD, and I talk about the struggles that so many of us face, you know, we can't help but talk about some of the shame and the grief around not being diagnosed. And then I stop and I'm like, Oh, God, am I painting this terrible picture of what a life with ADHD is actually like? So anyway,

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Sivan Hong 11:23

no, I, I know exactly what you mean. And I feel like, there's always this part of me that projects my own personal school experience onto what my kids are going to experience. Right? Because it's this, this fear that you don't want them to go through the same things that you and I went through, right that that self doubt, and that, that inability to understand what you were missing. My I had my youngest had a 504 meeting this past week, and I didn't sleep for literally weeks, my husband just saw me break down before this meeting. And because I was so nervous that I wouldn't be able to get him the accommodations that I knew he needed. And I didn't want him to have to experience school, the way I experienced school, and how important it is for those accommodations to be in place so that he can feel good about who he is as a learner. And normally, in meetings like that, I'm the one who talks right. Usually, my husband doesn't even come because I'm like, here's what I need. And like I go through it. But in this meeting, I have to have him weak. Because I remember second grade, I remember failing spelling over and over and over again. And I remember my teacher humiliating me in front of the classroom because I couldn't spell the word Sox. And it was like, Am I really like this person that can't do these things. And so I project that on to my son's experience worrying that that's

what he is going to go through and how much I want to protect him from that. And I think for me, getting them diagnosed was my way of saying, I'm not going to repeat this experience, even though I hadn't actually been diagnosed yet myself.



Katy Weber 13:23

Yeah, absolutely. And I think that's kind of what I'm what I'm keeping a keen eye on to which is like, at what point will a formal diagnosis lead to then that the accommodations that are needed, but I'm also Yeah, get like, I would be the same way with a Bible for because I'm also sort of, like, I don't really know yet, what they need and what they don't need. And, and so, you know, we're really just and with COVID and so much of the at home learning from last year, like there were a lot of things that I was able to pick up on and help with. And it was such a mindset shift of in terms of, you know, no longer like, I've, I think I've talked about this with my son before, right, like so he's in fifth grade now. And then he was never a straight A student, my daughter always came home with straight A's. And he didn't he came home with like, you know, twos and threes out of the four chart and, and I always took that mindset of like, well, you know, not every kid is good in school, the same thing my parents did, which was like look, I'm not going to pressure them I'm not going to become that crazy parent who's like you have to come home with A's but at the same time, like my mindset totally shifted when I saw how what he was capable of with the help that he you know, getting the appropriate help he needed. Because I was basically his full time tutor and assist last year. And so it really shifted for me where I was like, instead of always just being like well I don't want to pressure him to get A's you know, not everybody has to get A's to like what do you need to get your a right? And and but I off you know, but again, I'm on I'm still worried as a parent where I'm like, I don't want the emphasis to be on getting A's because I don't necessarily think that is right. But I also know how so much of your sense of self and self esteem is wrapped up in getting the A. So we need to do everything we can to find figure out what you need to get the A, and I still don't really have an answer, like, I'm not sure. Which way is the best way. I just know that like, I want, I want my children to feel like we have done everything we possibly can to help them succeed, as opposed to just being like, Oh, well, you're not gonna succeed at everything. But I also think you don't get succeeded there. Like that's, I don't know, that I go back and forth all the time, because I'm like, I don't expect my children to succeed at everything. And I also know that like, when you are neurodiverse, you, you tend to put a lot of pressure on yourself to succeed at everything. And is that because you tend to be good at things? Or is it because we grow up in a society that like, pressures you to be consistent at everything? I don't know,



Sivan Hong 16:00

for me, the five of four that combinations are about leveling the playing field, right? My son being at grade level without a 504 does not level the playing field to me, to me, it's what does he need in place so that he could have the same opportunity to achieve as any of the other kids that are not neurodiverse? And so if that means he needs extra time, okay, if that means he needs headphones in the classroom, so he can focus, you know, during the time where they, it's loud in class? Absolutely. But it's, it's not an accommodation in my mind to be like, you have to get straight A's because these kids with ADHD, just like us are super perfectionist, right? And like, to me, it's not about that. It's it really is this idea of, you know, putting in the ramp for the wheelchair, right? Like, could the kid make it up the stairs anyway? Sure. Would it be hard and terrible and painful? Yes. So let's put in the ramp. Right? Like, that's how I think

about it. Um, and it's hard because, like, you like this idea of wanting your child to be the best they can be without putting that pressure on them? Because it's there already, like, how do you scale that back? And how do you have those conversations about, about that kind of pressure that they're putting on themselves? Right? And how do you identify the things that are hard for them and the things that are gifts, and also identify the stuff that's just hard for them that has nothing to do with the fact that they have ADHD? Right, like, it's not everything. It can't be everything, it's here, the things that are you're good at, because you're good at it's not just because you have an ADHD brain. But I, I because it's not this homogeneous experience for all of us. We don't have that clear path. We don't have that clear guideline that says, Here are the steps you need to take in order to level the playing field for your kid. And I think they keep changing on us, right? Like every day they grow up, it's just something else happens to make me change the plan. If they would only just freeze in time, I could do a much better job as a parent.



Katy Weber 18:31

Yeah. And I also sort of feel like, you know, I, I look back at my parents and how they kind of dealt with me growing up and I you know, I can't fault them. I think they did the best they could and I move on from that. But then there's a part of me that's also like, well, what am I not seeing, you know, where's the ramp? Where's the wheelchair ramp that I'm not putting in and what could else could I be doing? And it's like, parenting?



Sivan Hong 18:58

Right? Like, we can't wait every one of these things that we're just so hard on ourselves about. And the neurodiversity piece adds that level of additional complexity to something that's already super complex. Yeah, I agree. All right,



Katy Weber 23:00

so let's backtrack a bit because I want to talk about the book. So you started writing these children's books during lockdown, right?



Sivan Hong 23:09

I did. So when my older son was in kindergarten or even earlier than that, and we talked to him about autism, and he'd have to wear headphones in the classroom or things like that. There were not a lot or any that I could find children's books with illustrations that showed neurodiverse kids, right, the chairs in the classroom all looked like normal chairs. Kids were not playing with fidget toys they didn't have headphones on. And he would ask me, you know, why do I have to wear headphones? Or why do I have to sit in a special seat. And children's books, particularly picture books are so great at being mirrors for young kids so that they can see themselves so that they can feel normalized, and that their experience is validated. And watching my youngest son, you know, get diagnosed with ADHD over COVID, you know, like, we're locked down and all that I'm like, I need to create a tool for other parents. So that this exists, right? There's a gap to me that was missing. And with my hyper focus, I sat there and I

wrote two children's books in like, the span of a month, and I illustrated them because I'm a control freak, and I have to do everything. Um, but more importantly, I wanted to make sure that the illustrations were not distracting, right, like so often with my kids when I read a book and they have these beautiful illustrations and I would love them. My kids would be like, Well, why is that you know, book on the bookshelf green and completely forget the focus of the story. And so my illustrations are very simple and very clean and only show what needs to be shown? The font is, is dyslexic friendly, so it doesn't have any curly cues, the spacing is wide. It's really, really simple. So that nerd diverse kids can follow along. And so the books are designed in such a way to appeal to this type of kid so that they can see themselves. And then they're also a great teaching tool for parents to explain to the other kids in the classroom. Why is that kid wearing headphones? Why do they get a special seat? Why do they get to chew gum or have a box of fidget or whatever accommodations those kids have, because we're not in the classroom with those kids, it's hard to be able to talk to them about the differences that they are seeing, particularly when kids are so young. And so I created these books as a tool for neurotypical parents to



Katy Weber 26:01

that's awesome. Oh, that's so beautiful. I love that. And and so, after you show you've written three, are you writing more?



Sivan Hong 26:12

And I'm working on making lots of money or you know, there's some article at NPR for a couple years ago that that pretty much made it seem like an author was super successful if they could pull in \$10,000 a year. So if this is the line of work, you choose you, you need, like I keep telling my husband, he's my patron because it's it takes a long time to bring in when you're an author, but



Katy Weber 26:45

I have the same issue with podcasting. My husband is right What are you gonna What am I what do I get to quit my job I've like never just this is really a part time hobby.



Sivan Hong 26:55

I call it my midlife crisis. And like it was this are getting a portion of this is much more meaningful. But I'm, I'm working on the fourth book. Now. It's, it's about the end of school. Because, you know, we always think about the end of the school year, I'm so excited about summer 100, diverse kids are not going to change. And this is change. And it's scary. And so it addresses some of those concerns that kids have at the end of the year. And if you talk to Special Ed teachers, or even, or even regular ed teachers, the kids are a little nuts at the end of the year. And part of that is the same anxiety over the change that summer is happening and what will next year be like so that's what this book is about. All of my stories are actually true stories that have happened to my kids, or that have happened to other kids that I know about. So they're all based on true stories. And they're written in a structure of a social story. So in

special education, a social stories, a teaching tool, to help a child understand their emotions, and what steps to take to face a challenge. And these books are written in the very same way. So this book, again, will will will help children deal with their fears about the end of the school year.



Katy Weber 28:19

That's so incredible. And I think, you know, the book that you wrote about transitioning and the Emily, Emily D and the fearful first day, right, that is something I wish I had had for my son when he was younger, because he is has a really difficult time with change and transitions. And he experiences a lot of anxiety at the beginning of a school year with a new teacher. And so it would manifest as you know, he would feel physically sick, he would feel nauseated, because like he and he would try to explain it to me where he's like, I can't go to school, I'm sick. And that, you know, and I'd be like, Okay, well, what's happening how, you know, you don't have a fever. And he and and we would get to the point where he would say, you know, I'd be like, do you feel like you were on a roller coaster? You know, or do you feel sort of like the is that what the feeling is? And he's like, yeah, like, I feel like I'm going to throw up. And then he would get worried about throwing up at school. So he didn't want to go about that. And I'm like, you're not actually going to throw up. I mean, it's possible he could, but we had to, we had to have a lot of conversations about like, what anxiety feels like. And I think it's really sort of helped him become more in touch with his physical, the physical manifestations of anxiety, right. And so I think that that is something that like, we aren't very good at. As either as neurodiverse or ADHD adults. Like I feel like we had to have that conversation with a lot of guests about like, how we kind of tamp down our intuition a lot of the time because a lot of the things we think and a lot of the things that we do, or we're told they're wrong, so much as children and so we stopped listening To our instincts. And I think that that is such a disservice. Like, I feel like it's so important to teach kids to listen to all the different sort of wisdom areas that are happening in their bodies,



Sivan Hong 30:13

right? Because little kids feel stress and anxiety, right? Like, we don't think about that. But they do. And particularly now, after lock downs, and COVID, and whatnot, the level of school anxiety and school refusal is just going through the roof, right? School feels like a scary place to kids right now. And one of my books, George J. And the miserable Monday is about school anxiety, and the fact that every Monday feels like a battle for certain kids, because they've made it through the week of school, and then the weekend happens. And for young kids, that change can be feel really dramatic. And that fear that school is not going to be like it was last week, everything's going to be different, is really, really hard and and look as an adult Monday's can be hard for us, right? Like, that's not just a kid problem. But giving kids the tools to talk about what those feelings are and, and respecting and owning the fact that those feelings are real, teaches them about how to deal with it when they're older, before they can turn to who knows what to try to deal with those feelings. And so I think that recognition that they can really feel these things, and those feelings are real is so important.



Katy Weber 31:43

Oh, my goodness. Yeah. I mean, I noticed that with Zoom, when they were doing zoom

schooling last year, like my son would just as soon as he would get off zoom, he would burst into tears, right? Because it was like you're holding it together. And I saw the degree to which he was like, working. And it was like he was just holding his breath the whole time. Right? Like really trying to concentrate really trying to focus really trying to do all these things where it's like the the sensory world was working against him. And he would just fall apart the minute he got off of zoom. And then I was so excited for him to go back to the classroom. But like you said, like school? Yeah, it doesn't feel like a safe place. And so I was picking my kids up last year. And as soon as he would get in the car, he would just burst into tears, it was like the whole weight of the day would just, you know, he would just unravel as soon as he got into a safe space. And that was sort of, you know, and so this year, we have him in like, you know, what was the word of preventative therapy, where we started getting him to see a therapist, just, you know, we wanted to hit the ground running this year with making sure he had somebody to talk to you, but also like, his therapist was sort of like, what's wrong, what's wrong, like, there was a sense, even with therapy, because just Okay, I'm getting tangled up. So basically, we wanted to get him in a situation where he could normalize therapy, right, where he could see where the idea of therapy was not like there has to be something seriously wrong with you, in order to go to therapy, that therapy just exists as an outlet. And that we needed to normalize like verbally processing things and talking about things with adults that aren't necessarily your parents, but like, you know, getting it feeling like there are places where you can talk about this stuff. And it doesn't, you know, or not like that's the other thing, you don't have to like, always come to therapy with some dramatic trauma event that you have to go over. Like, we just wanted to have it available to him as a way of normalizing therapy in his life as opposed to feeling like they're, you know, therapy was something that you only did if there was something seriously wrong with you, which is I think most people think of therapy that way, right? Like couples that don't go to couples therapy, unless you're on the brink of divorce, and you don't get you know, and I don't think I feel like that is a terrible way to look at therapy. So we have him doing that. And it's I don't know what they're talking about, like I you know, he doesn't tell me anything, I don't really pry, but like he is in such a better place just from having one hour every other week to like, I don't know what like just to be in that space. It has made such a tremendous difference in terms of his ability to like cope this year.

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Sivan Hong 34:30

But I'm a big believer that preventive medicine is important. And we do it for our physical health, but we need to do it for our emotional health too. Right. My kids have been in and out of therapy since they could speak I think. And it becomes another grown up that they can talk to and feel safe with and discuss their feelings. And even you know the school psychologist, it's Cool. I asked my second grader, I'm like, Well, you know, what did you guys talk about? And he's like, That's private. And I'm like, Okay, that's good. Right? And so, um, because I want them to be able to turn to therapy throughout their whole life. And if it's only something that you go to and something's on fire, doesn't really work the same way. Yeah.



Katy Weber 35:25

I know, right? Yeah. And one, the other thing was like, the school counselors are so overwhelmed right now. I mean, last year, the very end of the year, their teacher who was really holding a lot of these kids together, had to leave for a medical emergency. So she was gone for the last month of school. And there were a lot of kids who just unraveled without her

presence there. And one kid started biting other kids. And so like, I called the principal and I called those the guidance counselor was like, Look, my son doesn't feel safe in the classroom, like, what do we do? And, you know, and the guidance counselor's are so, you know, they spend all of their time dealing with the extreme cases, the behavioral cases that like, they don't have a lot of resources or time for the quiet kids who are in the corner holding it together, until they get home and are just sort of like, you know, even if you were to even if the guidance counselor was to take my son into her office and ask him how he's doing, he probably would have been like, I'm fine. Everything's fine. You know, because he doesn't want to be disruptive because he's that kid. So like, I really, you know, it really sort of felt like, so much came to the fore last year in terms of like, yeah, how kids are dealing with these stresses that, you know, as grown ups, we're not dealing with very well. So I really do hope that we're a lot of this the way in which we're talking about mental health, the way we're talking about depression since the pandemic, like the you know, being so much more open about it, and, you know, being able to answer the question, how are you doing and just being like, I'm not okay. Like, I feel like that I feel like, as adults, we've been able to normalize that a little more over the last year and a half. I'm hoping it really trickles down.

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Sivan Hong 37:08

Well, and I, I hope that the resources that the schools are trying to funnel to mental health stay the focus, right, because that could be a huge benefit from all of this, that the resources are there, the social and emotional learning focus is there that it's not just about learning algebra. That that would be a great perk. That would be a great positive thing to come out of all of this awfulness.



Katy Weber 37:39

Yeah. Put that on the put that on the bucket list. Okay, so then when you were just diagnosed, I guess, you know, we've sort of talked about this a lot, you know, here and there in this conversation, but like, are there some things in your past where you look back? And you're like, the signs were there? Oh, I know what I want, you know, scrap that question, because I feel like we've already talked about that. But I was curious, like, what was the reaction from your family when you came out? And you know, when you were diagnosed,

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Sivan Hong 40:30

so my husband looked at me like, yeah, of course. And he laughed. And we, my husband is very hyper rational, like, I call him a Vulcan, because he is as anti opposite ADHD as a human being can possibly be. And, and sometimes I feel like we live in, in like, different universes that are just overlapping, because the way we see, he's like you in the boys are over there. And I'm over here. And he's like, sometimes you just stop, and I watch you guys. And he's like, I can't even believe what I'm seeing. And in my mind, it all feels perfectly normal. But so he was very supportive. And, and the kids loved it, like they high five to me. And it felt like we had this special club. And I'm not sure my mom fully believed it, because I was a kid in the 70s. And they diagnosed some boys with ADHD. But goodness me, they would never diagnose a girl with ADHD. And I had done well academically, and I had done well professionally. And I don't think she saw the extent of the struggle. Because again, it manifests itself differently in girls than it

does in boys. And particularly in my case, but I live in a community where we have a very strong group of special education, parents who lean on each other. And I talked to them about it. And everybody was really supportive and was able to then, you know, relate their own experiences. And I think having that support network is huge. The place where it's interesting to me where I get the greatest level of pushback is on social media. And social media is not something I'm very good at, or did before becoming an author. And whenever I write something positive about my ADHD experiences, or positive about neurodiversity, I'm floored by the number of trolls that come out of the woodwork and feel like because my experience overall has been good, why look at kind of the gifts that it has given me. That it diminishes their experience. And that, to me is the hard part, right? But that I look at my life and my life comes from a place of privilege. And I've been able to get my kids all this therapy and do all of these things. That my positive outlook is a bad thing. And so to me, that's the place that's a bit interesting. But otherwise, it's been nothing but good. For me, it explained that internally, it explained is like, this is why I couldn't read books, right? Like I wrote a dissertation, and I still couldn't read books. And as soon as somebody came up with a book on tape, that was like my, the greatest thing anybody could have invented. And I remember listening to Warren Piece in the car, doing like a drive and being like, this is what literature is finally like, I had that like aha moment. And this is why people like to read, because I could never digest it in any other way before that. And I walk around the house and I constantly have an earbud in my ear listening to a book like non stop because it opened this door to me audio books and and understanding that that is because of my ADHD it like made perfect sense because for the longest time I couldn't understand why I couldn't really read the way other people would sit there and read. I know I totally digressed from the question.



Katy Weber 44:50

No, but you brought up an interesting point, which I think has been such a huge mental transformation for me since my diagnosis which was how you No recognizing how much I love to learn and how I've always been like that, you know, I would always sort of joke about the fact that, like, if I could just go to school and, and like learn things, whenever I have to take tests or be graded, I wouldn't be in school forever, like, all I do is take courses and certifications. And yeah, like I'm listening. You know, I listened to, you know, multiple books a week, but it'll take me six months to read a book, and I've just given up on reading books now, unless I have absolutely no choice. But like, you know, this idea that like, I never thought about how much I was obsessed with learning because I had such this negative relationship with academia. And so it was like, such a huge shift for me in terms of my self esteem, to real to really say to myself, like, my experience with academia is in no way a reflection of my intellect. And like, I had to, like, give myself that permission, because I didn't realize how much weight I was carrying around believing that I was dumb. You know, even though there was all this overwhelming, you know, evidence to the contrary. And I think that was really what brought me to the diagnosis was my therapist saying, like, look at all that you do, and think and talk about it, you know, and yet, at the end of the day, you think so poorly of yourself. And so I get, like, you know, and I've had people reach out to me, too, and have said, like, everybody on your podcast is so accomplished, and so wonderful, and doing all these things, like, where are the real ADHD people who are struggling? And I'm like, No, that's the point. Like, the struggle is behind the scenes, right? Like, that is what I think is so important to talk about when we you know, when it comes to how lonely we feel with this with undiagnosed neurodiverse agencies, which is just like, so many of us really are, you know, do put out this, this identity of being very,

like, high performing and intellectual, but like, there's just so much struggle and work behind the scenes that nobody is seeing, and that you can't talk about, and you don't know how to process or what to do. Yeah, I don't, I don't remember what I was talking about.

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Sivan Hong 47:17

And part of that is like, I blame society, right? Like, the expectation that we're all the same. And we come out of an education system that is designed for a cookie cutter education, that's just bogus, right? And so there are plenty of things I'm terrible at as we said, spelling. And to this day, I still can't spell an even with spell checker, I have to change what I'm writing because even with spell checker, I can't figure out how to spell a word. It there are things I'm terrible at. But those are not the things that I choose to focus on. Right? Like, I'm going to focus on the things that I do well, I'm creative, I write books, like, I do these things that that make me happy as a person and whether I'm neurodiverse or not, like, that's my choice to look at the world through that lens. And that is not a neurodiverse neurotypical issue, there are plenty of neurotypical people who are unhappy with their lives and unhappy with their success. That is the way you look at the world. But I do think the reason why so many of us have struggled and have had issues with our self esteem. And our self confidence is because our education system does not value the things that we can bring to the table and does not allow us to show them those things. Right. That I IQ tests that are given to kids are not designed for kids with ADHD, right? They are designed for neurotypical kids. And so we are judging our kids based on a criteria for a different kind of brain. That's crazy. That would be like giving, you know, looking at a cat and being like, Well, why aren't you functioning like a dog your failure as a cat? Like, that's not okay. So those are the things that I think we should be outraged about. Those are the things where I feel like it's time to change the way society views us. And in order to do that the positivity has to come from us. We're the ones who have to say, No, we're worth it. We're just as good. We're just as smart. In fact, there are places that we're even smarter. So then society can start looking at us and being like, oh, yeah, you're right. You are just as good as you say you are. We should change the education system to be able to start recognizing the value you bring to the table. It's not to positivity just to be positive. We're not human. We're not talking about ADHD, and women and the success women have to make ourselves feel good. We're making this message to everybody so that people start seeing these gifts. Right?



Katy Weber 50:11

Yeah. So beautifully said, I really appreciate that. Because, you know, I think I think you you do when we start talking about the gifts of ADHD, and you know, I talk a lot about the problems, the problems around terms like ADHD being a superpower. And you know how there is a lot of sense that, like you, you know, when you start talking about it in this aggressively positive light, you really are brushing aside so much of the inherent privileges, that, you know, start to, you start to see the cracks in the system in terms of privilege, and what children, you know, especially children of color, who are treated very differently, and then you think of women of color, who are treated even more different, like you think about all the ways in which we are treated in society, and how, you know, how difficult it is to, to have accommodations, based on who you are, and where you're growing up, and where you're living. And I think so much of the, you know, so, so much of changing the face of what this looks like, and how we are treated is, is being able to advocate for ourselves, right? And being able to really understand deep down, there's nothing wrong with me, if something if I can't, you know, like, I love the cat dog

analogy, right? It's like, if I can't do this, it's not because I'm a failure is because I haven't, we haven't, we don't have what I need to be successful. And I think, you know, this, the ability to advocate comes from an understanding of yourself, and also a certain level of like confidence in order to, you know, bring that to the table, bring that advocacy to the table and say, No, I'm not going to just sit by and let you, you know, tell me, I'm stupid, or, you know, tell me, I can't do that thing. But I also but then at the same time, the ability to advocate, you know, you need a certain level of privilege to even get to that point, and then some of the, you know, then we end up in this like hamster wheel of like, yes, society needs to change, and we need to change it. But that's a tall order for, for a lot of members of our society. And I guess, I guess my point is, like, you know, advocacy on all levels is so important. And having these conversations is so important, and recognizing, recognizing privilege, but also, like you said, like having those conversations and acknowledging it, but at the same time, like, what can I do with my privilege? What can I do? Can I, can I help other people? Can I talk about this? Can I open up conversations? Can I make changes in schools, I don't know. Like, let's try, you know, a lot of that as opposed to just being like, every man for himself. Take what I can and run with it. And if you can't, if you're not doing as well as me, sucks to be you, which I think is a distinctly American viewpoint, as somebody who grew up in another country and moved here, you know, that, that, that I feel like is a very distinctly American mindset of like, well, everybody succeeds on their own. And, you know, if anything smacks of socialism, we're gonna we're gonna shut it down. But that's a whole other tirade.

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Sivan Hong 53:21

Yes, the the myth of Horatio Alger continues on that we all start with the level playing field and we don't. But just the fact that we talk about neurodiversity is such a change from 10 years ago, right? Like, the it was coined in the 90s. But it hasn't really caught on. And this idea that people are starting to say that, that brain differences are okay, that they're biologically significant and have been around for so long, for good reasons. You see, in kind of the autism rights movement, this pushback, again, some of what Autism Speaks, has been talking about in terms of in terms of finding a cure for autism, this idea that autistic individuals say, you don't really get the right to cure me. Right. Can you imagine if we tried to cure Michelangelo, right, like these are, these notions are new, and I think it will take time for society to catch on, but at least we're talking about them, at least for raising them at least we're saying, you know, these differences are okay. They're part of society, they're part of humanity. They're they're biologically normal to have our brain differences as as much as having a skin color difference or a height difference, right, that that, that these conversations are happening in and of themselves. I think this is what's going to start shifting society.



Katy Weber 55:03

So that's a good segue to my question. I like to ask about renaming ADHD, because you know, we talked about neurodiversity and the Venn diagram. So if you could rename it to something a little less confusing and problematic for so many of us, would you would you call it something else,

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Sivan Hong 55:20

I would take away that the, the kind of the disorder piece, I think it's really a negative framing, I

struggle with what to call it, I do believe, kind of putting in some concept of a spectrum is really important, because we are not one size fits all my ADHD experience looks different from your ADHD experience. And, and, and having that, that, understanding that it manifests still differently, and everybody I think, legitimizes everybody's own experience, I think that's an important piece to it. When I talk about it with my kids, it's all positive, right? Like we don't use, they don't know what it stands for. I mean, at some point, they'll google it, and they'll figure out that I've been lying to them this whole time. But um, but I taught you know, the H for them is high speed, and the A is about being accelerated. And it's all about this idea that their brains go so fast. And their problems stem from the fact that they haven't figured out how to work them yet. They don't know how to downshift. And part of learning about how to deal with ADHD is figuring out what tools for you allow you to then slow down, control your brain and then step on the gas when you want to write and I have boys. So the car analogy works. And I'm being super scary, sexist and stereotypical there, but whatever. It's working for my kids. And so for me that the the notion of a spectrum is the most important piece that we're missing right now.



Katy Weber 57:03

Yeah, I love that. I know, I have these moments with my son where he'll say things like, yeah, my brain was moving really fast. And my hand couldn't catch up. And so I like I saw that there were all these words missing in the paragraph. And that's but you know, that's just how I am. And I just love that. Like, there's this just utter lack of judgment when he has those moments where he's like, Yeah, this is how I am as opposed to, you know, what's wrong with me? I can't do that thing. Right, which I just like, those are those moments where I'm like, Okay, you're doing something, right. Because he's looking at these things as like, you know, like he said, You're overthinking it, Bob is like, this is just it is what it is.



Sivan Hong 57:41

And he's having these incredible thoughts. And so what if his hand can't keep up just yet, right? Like, the fact that those incredible thoughts exists? That's the gift. Right? Right. We need to come up with a technology that's going to allow him to speak fast enough to be able to get those words transcribed. So his idea stay, right. Like, it's not his hand. That's the problem. Right? It's not his brain. That's the problem. It's the connectivity between the two of them that he needs to



Katy Weber 58:12

figure out. Right. So yeah, it always comes back to that, like, what do you need to help you succeed? Yeah. Oh, my goodness, what a lovely conversate conversation. Thank you so much. I was so excited to talk to you about so many of these things. So thank you.



Sivan Hong 58:27

Thank you for having me. This is this every time I talk to another woman who's been diagnosed, kind of when I've been diagnosed, it's just so refreshing because despite the fact that it manifests itself differently in all of us, we have so many shared experiences

