



Episode #179:

**12-Year-Old Rylan on
Growing up with Tourettes & Autism**

October 15, 2019

- Debbie: I'm really excited. I was, you know, I get a lot of emails about people sharing what they're doing about the podcast and, but I got yours and I took one look at your book and I was like, I have to have you on the show. So.
- Gwen: Well thank you. That's so sweet. Yeah, we're pretty excited. It's turned out to be such a fun project for, for both of us. I think Rylan's like, why are we still talking about this book? Cause it was like a year ago that I did this, but you know, that's just.
- Debbie: Yes.
- Gwen: An issue of not understanding timing of publishing.
- Debbie: Yes. Oh goodness. Publishing. It's years and years sometimes.
- Rylan: Years and years. It's so much hard work.
- Debbie: It is. It is. But at the end you have a book.
- Gwen: An amazing book. We're getting started on writing his next book, just in preparation to keep this going. Cause all of his words are, you know, two years old now.
- Rylan: What I want to do for my next book is like the dragon. I want to make a dragon series where me and a Minecraft person named Steve go on this like awesome adventure.
- Debbie: I like it.
- Gwen: He's already written quite a bit of it.
- Debbie: That's very exciting. I have to tell you, Rylan, that I have a son who's just turned 15 years old. And how old are you Rylan?
- Rylan: 12.
- Debbie: You're 12. Okay. I think when Asher was about your age, 11 or 12, he wrote a couple of Minecraft themed little novels. Not about dragons, but in the Minecraft world. And it was such a fun project for him to work on.
- Gwen: Yeah. We are big Minecraft fans. He's sitting here with a Minecraft book, you know, just in case he gets so bored.
- Debbie: Yes.
- Gwen: Always have to have a plan B.

- Debbie: Yeah. And a plan C and a plan D.
- Gwen: And a plan E.
- Debbie: Yeah. Well do you, do you guys want to take a minute and you can both share, however you want to do this. I would love if you could tell the listeners about the book that you wrote together, *If I Squeeze Your Head I'm Sorry*.
- Gwen: Yeah. So I'm Gwen and I am the mom. And um, this book is a picture book. It's drawings that Rylan did about what it feels like to live in his brain. And do you want to tell everybody who you are?
- Rylan: My name is Rylan.
- Gwen: And what do you have to do with this book?
- Rylan: I'm the author. I um, well this is like based, sorry, based on my perception of the world.
- Gwen: Yeah. And so what do you live with? What are your, what we would call special needs?
- Rylan: Tourette's syndrome and autism.
- Gwen: Yeah. So Rylan did a bunch of drawings about what it felt like to live in his brain and then started talking about them and I just decided, well, this is better than any therapy we've ever done as far as learning what it feels like to be him. So I just started typing down what he would say. And it turned into just the most introspective, unique, imaginative way for him.
- Rylan: And it was all my idea, I wanted to do an entrepreneurial thing where I show pictures and it came up to this, I don't know why, but.
- Gwen: Yeah. We were living in Denver at the time, and I did a semester of homeschooling with Rylan and we were studying about being an entrepreneur and we went and interviewed, do you remember who we interviewed?
- Rylan: No.
- Gwen: Miss Lennon? Yeah. So she owned a cafe by our house that we frequented. We could walk there and he wanted to talk to her about her journey of being an entrepreneur. And then she said, Rylan, what do you want to do? And he said, well, I'm going to be an artist. So she offered up her cafe as a place that he could do an art show. So then of course we had to do an art show.
- Rylan: Yeah and then everybody after that wanted my art show.
- Gwen: Yeah. So we, Rylan wanted to do a Pokemon themed art show. And what did I say?
- Rylan: No.

Gwen: No. I wasn't willing to invest that kind of time into a Pokemon art show. So we settled on drawings about what it felt like to be him and to live in his very special and unique brain. And it evolved into what will soon be this book through just kind of a miraculous journey in publishing. So that was the origin and it has taken on lots of different shapes and we are pretty excited about it.

Debbie: I'm just curious, where are you in the publishing journey and when is this coming out and are you self publishing it or are you working with a publisher?

Rylan: We are in the nether of Minecraft.

Debbie: I know exactly what you mean.

Gwen: It is set to hit shelves in October, we're hoping at this point.

Rylan: But that's in the end.

Gwen: That that will be the end of the nether. Yeah. And it'll be at Amazon, Barnes and Noble. But yeah, it is, the book is about 99% done, so we're getting so close.

Debbie: Wow. Well first of all, congratulations because I am a published author and I know, oh gosh, it is a lot of work. It's so much more work I think than people realize. And what you guys have created, like I said, I got your email, I opened this up and was really blown away by the whole thing. I was blown away by the design and the art, but of course by Rylan's voice and insights. It's just such a special book and I'm, I'm so excited for it to be out into the world.

Gwen: Thanks. We are too. And we definitely had the help. It's been a team effort. So we have a co-illustrator, her name is Ellie McLaughlin and she's just really talented, a good friend of ours. And she has a little girl who has autism as well. And so she did a lot of the co-illustrations in the book. And she knows Rylan and it just turned out to be such a beautiful collaboration. It just shows when you're really invested and your heart's in something, what, what amazing results can come from that. So it was a, it was a trio for sure, making the book the way it is.

Debbie: Yeah. So cool.

Debbie: So Rylan, I have a question for you. You do such a great job of expressing what it's like to be inside your brain. I'm wondering why you felt it was important to share that with other people.

Gwen: He's thinking.

Rylan: Wait, what?

Gwen: Why was it important for you to share what it's like to be you with other people? He made some notes. He's looking at his notes. Well, just think about it. Why is it important for you to share with the world what it's like to be you?

- Rylan: Well, everyone would be mean to me because they wouldn't understand it. Other people might have special needs like me and get bullied. They can learn to be brave and teachers can understand their students better.
- Gwen: Did you understand that? Do you want him to say that again?
- Debbie: Yeah. No, I did. And so it sounds like you're gonna help other kids feel brave, kids like you who may not be understood. But you're also going to help people who just don't get it, what it's like to have Tourette's and to be autistic, to help them have a better sense of what it's like.
- Gwen: Does that sound right?
- Debbie: I mean, it's really, it's, that is so important because no one knows what it's like to be you. No one knows what it's like to be inside your brain. And it's just such a generous thing to share your voice with people.
- Gwen: Did you hear that? She said it's generous. Isn't that nice to say that it's generous?
- Rylan: I wonder if I can meet you in person some day.
- Debbie: I wonder that too. I, from everything I've heard so far, I think actually you and my son would get along quite well. He was also really into Pokemon when he was a little younger.
- Rylan: How about Yu-Gi-Oh?
- Debbie: Gosh. I don't know about Yu-Gi-Oh. I guess if, if he was, I would have known so.
- Rylan: Well, yeah the Pokemon that might help people understand about me is Slowpoke, because my mind is slow, Happiny because I'm happy and Celebi because the real Celebi is generous and offers other Pokemon fruit.
- Gwen: Generous. He's generous.
- Rylan: She.
- Gwen: Oh she, I'm sorry. Yeah, he likes that question that you proposed about the Pokemon.
- Debbie: Yeah. No, that's so, so interesting that, yeah, cause they, don't all Pokemon have different qualities and personalities?
- Gwen: They do. He knows, I don't know, all thousand of them and their evolution.
- Rylan: Well yeah, I guess. I might not know, I mean sometimes I forget about Pokemons.
- Gwen: But why did you pick Slowpoke?
- Rylan: Slowpoke, I told you already because my brain is slow.

- Gwen: Your brain is slow? Yeah. So Rylan's brain, he's twice exceptional. So he is really gifted in visual spatial and figuring out how things work and that intuitive sense but then his processing speed is the deficiency. Where it just takes a long time to think about what people are saying and to come up with, you know, appropriate responses. Sometimes it takes a day or two and then all of a sudden you get this flood of responses to something you were talking about the day before. So processing speed is tricky. So he definitely has creative ways of explaining what that's like to have that processing speed deficiency. A lot of the times it talks about being a Slowpoke, right buddy? But at least Slowpoke the Pokemon is a cute way to describe that.
- Rylan: I mean, Slowpoke is very cute, maybe search a picture on your phone.
- Debbie: Yeah, I'm actually gonna do that. Right now, I'm going to do it right now, but I will say that right now I'm looking at the page that says race car brain too. And you also talk about your brain being a tornado. And I just love that imagery. And a lot of people who listen to this show have kids who are twice exceptional. And that processing speed is one of the more common things. That lower processing speed, but then this brain that also is like going a lot faster in other ways. So, um, alright, I'm looking up Slowpoke Pokemon. Oh, Slowpoke is cute.
- Gwen: Do you want to tell her why you wrote the, the tornado? Why does your brain feel like a tornado? What do you mean by that?
- Rylan: It's because I'm confused. Really confused.
- Debbie: Feeling confused, you said?
- Rylan: Yeah.
- Gwen: What is it, what is it like a tornado?
- Rylan: Well, my mind is spinning like whoa, whoa.
- Gwen: You get super dizzy.
- Rylan: Yes.
- Gwen: Yeah. Because what kind of thoughts go through your brain?
- Rylan: Um, Pokemon, Minecraft, Yu-Gi-Oh, school, lalala, whoa, whoa. A lot of stuff.
- Gwen: Yeah.
- Debbie: So I'm curious then, Rylan, you said that screens help you feel calm. So do screens help with the tornado brain for you?
- Rylan: Mmmhmm.
- Debbie: Can you, cause I think there are a lot of people listening who that's really helpful for them to understand that screens can actually not be something that makes

their child more energetic or hyper, but actually can be very calming. Can you tell us a little bit about what it feels like when you're doing things on, on your screens?

Rylan: Well sometimes I get a little hyper and I jump and that makes me all sweaty. Well sometimes we'll watch movies and kind of makes me tired. Or it means like I'm calm. And usually, I don't know, I'm tired a lot at school and it's just hard.

Gwen: Yeah. He likes to come home and decompress.

Debbie: Yeah.

Gwen: Which you know, your parenting instinct is like, no, don't jump on a screen. But it really like, I really feel like his brain's on hyperdrive all day trying to attend and stay in tune and focus on what is expected of him. So we have really had to just kind of come to terms with the fact that coming home and spending some time on a screen does actually help him. You know, in, in limited, limited chunks of course. But it does help him to just have his own time to sit there and relax and let his brain stop the spinning, right buddy?

Debbie: Well, I was just curious, you said you feel tired and you talk about this a lot in your book that you feel tired a lot of the time. And is that at school because you have to pay so much attention or it just takes so much energy just to focus on what's happening?

Rylan: Yeah, I mean even during this interview I kind of space off.

Debbie: Yeah.

Gwen: Even during this interview.

Debbie: I get it.

Gwen: So what makes your brain the most tired?

Rylan: Well, I would say either gym or math.

Gwen: Yeah, but what about being at school makes your brain tired?

Rylan: You have to focus a lot and...

Gwen: You have to focus a lot, keep going.

Rylan: Um, and there's a lot of people going around being cookoo.

Gwen: Being cookoo? What does that mean?

Rylan: Like really, like crazy and people running around, whoa, whoa, whoa. Like making me dizzy.

Gwen: Yeah. So Rylan has auditory and visual processing struggles, so he hears like 125% out of one of his ears and he gets very visually overstimulated. So I spent a

lot of my parenting years trying to figure out how to make the school environment less stimulating. I think it's naturally overstimulating pretty much anywhere you go in a school setting and that just, he, he attends to everything he sees and everything he hears. And so to weed out the information he's supposed to be taking in versus everything else around him is, I mean it's pretty much impossible for him to do. So yeah, his brain is exhausted. I didn't, I don't know that I really understood that until we started doing this book and he started drawing pictures about his brain and then describing what that feels like. So it definitely helped me get more of a visual as far as when he walks into school, kind of what he's up against all day long. And it gives me just more patience as his mom when he comes home, understanding how exhausted he physically and emotionally and his sensory system is just kind of shot.

Debbie: Yeah. I think that's one of the gifts of this book is, you know, you had that experience of learning more and I think that so many parents are gonna end teachers are going to better understand the experience of some of their kids because of this, you know, and that's so exciting.

Gwen: I hope so. And we're doing a curriculum guide to go with the book that you can have as a virtual download. And that's where I can kind of have my piece in there talking to teachers about that, that parent perspective that, you know, it's just impossible to have. We can't expect that every teacher understands what his journey is like. Cause if it's not something you've lived, it's not something that you can fully grasp. So the curriculum guide just offers just big picture opportunities and questions and very sensory focused activities as it relates to the content of each page that they can dive deeper, you know, in like a 10 minute chunk. Cause I know teachers have zero time for anything extra. But it does allow for some sensory activities to get to know how students in each classroom see the world and process the world.

And you know, the things about them that I think are really vital for teachers to understand at the beginning of a school year. You know, we've just learned, we don't really care what his math skill is. We want you to understand him because if you can understand him, you can then speak into his ability to do these academic expectations. But if you don't understand him, you're, I mean, you're just, it's like, you know, walking backwards on a treadmill. There's just no, you know, it just doesn't make sense. So the curriculum guide is really, I'm hoping, going to be a helpful tool to work with the book for teachers just to have more dialogue in a classroom setting. And really K through sixth grade is what the curriculum guide is meant to speak to.

Debbie: That's so great. That is such a need. And that is what I hear from people all the time. You know that we're doing as parents this work and we are seeing our families thrive and our kids doing so much better, but there's so little understanding in schools and so I love that you're helping to bridge that gap. I'm super excited about that.

Gwen: Yeah.

- Debbie: So I have a question for you, Rylan. Believe it or not, you are the first guest that I've had on this show with Tourette's. And so I was wondering what would you like listeners to know about what it's like to have Tourette's?
- Rylan: Oh, I'm way ahead of you. I am the person right here. Everyone with Tourette's are just great people. Even if they're different, we're just normal people. It's not contagious. It's not like the bug. It brings you tired, tight and tired a lot.
- Gwen: Can you read that part again? This is my favorite part. Slowly.
- Rylan: It's not contagious and it's not like a bug. Like the bug.
- Debbie: That's great. Yeah. I think there is so little understanding and I bet people really just don't get it most of the time. Do you find yourself having to explain it to people?
- Rylan: Yes. A lot.
- Debbie: Yeah.
- Gwen: And quite often it's teachers that we have to explain it to because they're the one that kind of sets the tone for a classroom. And so we've had teachers say, well, he didn't do that tic yesterday, so he, that must not be a tic. And so there's just a lot of education that we need to do about Tourette's in general. You know, Rylan has never said a curse word in his life. It would be like the bane of his existence if he said a curse word. So it's not that stereotypical view that people are just screaming out vulgarities. You get that a lot, shockingly, just people assuming that that's what Tourette's is. And for us Tourette's, he didn't get diagnosed until he was like seven or eight because we just didn't know that that's what it was. So it's just the complex movements, for him it's mostly above the shoulders. So sometimes it's eye blinking or sometimes it's shoulder scrunching or he makes little squeaking sounds. But he also is an incredible sound maker. Like do you want to do your cricket kind of quietly?
- Rylan: [cricket sounds]
- Gwen: He is a really good sound maker.
- Debbie: That is true.
- Gwen: Some of that is Tourette's and some of it is just that constant need to be making noise. And so it becomes just a habitual thing. And that's tricky, right? When you're in quiet settings and in environments where you're expected to behave a certain way. Tourette's is a pretty tricky one to have to navigate, but he also educates all of his classes every year about his Tourette's at the very beginning of the year. And he'll use that video he did with Chris with special books by special kids. And that has been invaluable for teaching his classmates about what to expect with him. And then I think the, the most beautiful aspect of that is that it opens up dialogue within classrooms for other kids to talk about, you know, little things that might be unexpected about them that their classmates will see. And it

usually ends in teachers and myself just crying because the things that the kids are saying, you know, how else would you open up conversations like that other than just being vulnerable about your own idiosyncrasies. So that has been such a cool process to watch, the results of him opening up about his special needs.

Debbie: That's amazing. I am just, I'm so touched by that because I believe so deeply that that is what it's going to take for society to start seeing our kids in a, in a different light, in a positive light and embracing who they are. And that you're such a brave trailblazer, you know, to do that work Rylan, in the classroom. And I really think that's how it happens. You are being vulnerable and kids see that and it just changes, it changes everybody. And that's how real big change happens. So that's just so cool.

Gwen: She just said you were super brave. What do you think? Do you think you're brave?

Rylan: I don't know that much but.

Gwen: I think a lot of this comes natural for him.

Debbie: Yeah.

Gwen: He just, he doesn't see differences in people. And so he gets very surprised if somebody sees a difference in him. And that's one of the things we love about him the most is, you know, he'll see somebody in a wheelchair and he'll say, oh, well, yep that's her special needs that she wears. You know, he won't, he won't notice that she can't walk. And I think that his inability to see difference definitely has been an aid for him in just not seeing his own differences as a thing. He just does himself and he owns that and he's proud of it. And I think other people are really touched by that and it helps them to be more brave. Don't you think Rylan? That other kids are more brave when they see how brave you are. Do you think so?

Rylan: I don't know what to like expect. Like the dark, the unpredictable dark force.

Gwen: The unpredictable. Yeah. That's one of your pages in your book. Never know what to expect. And that can be hard. He had a couple pages that he really liked the most, Deborah, would you like him to read one of those for you? Would that be appropriate?

Debbie: Yeah, I would love that.

Gwen: Which one do you want to read Two Joys or The Wave of Relaxation?

Rylan: Umm.

Gwen: Okay. Two Joys is shorter. Just read it nice and slow for her. We are almost done, okay buddy. So this is a page from his book called two joys. And the picture, we can send a picture if you want to show the picture in notes.

Rylan: Sure, can you read it? Mom, can I ask you a question? You know like that movie Inside Out, what do you think my brain headquarters says when I have a tic? Tics are very important to me so they have to live in my headquarters. I think there's a monster hiding up there and he runs out, puts him in his shift that makes me have a tic. He's definitely not a friendly emotion. Then I think my anger and sadness join together they form confusion and frustration. Good thing I have two joys up there, mom. Mom, I think it really helps with my tics.

Gwen: Yeah. So we saw Inside Out and he, that movie resonated so strongly. Well, I think with a lot of people, but with him especially. So that's what he had to say about that movie that he thinks he has two joys up there because when the tic comes to hit his button in his headquarters, the second joy comes really fast to hit it again so that he doesn't stay frustrated about his tics. And I just thought, well, what better way for me to understand what goes on in your little brain than that?

Debbie: That's great. That's beautiful. Wow. Um, I really, I don't want to gush too much. I'm not really a gusher on the show, but I just, I just think this book is really fantastic. I'm, I'm so excited. I'm just looking at it right now. It's just beautiful too. I'm excited for listeners to check this out and yeah, if it's okay with you, I would love to include a page from it as an image on the show notes so people can get a sense of what it's gonna look like.

Gwen: Absolutely.

Debbie: If you, and either of you can answer this, if this book could do anything in the world, if it could change the world in any way once it's out and available, what would that be?

Rylan: What?

Gwen: If the book could change the world in any way, what would you want it to do?

Rylan: Make me famous!

Debbie: Got it.

Gwen: Anything else?

Rylan: No, nothing else.

Gwen: Nothing else. I think going through this, I really, I really had to evaluate why am I publishing this book? I have a background in marketing and the why, you just have to keep digging into that why. And I think what, what I came to is that the power of storytelling and learning each other's stories before making any judgments or assumptions is really going to be the way that we can make changes in the world. It's such a tough place to be for kids especially. But I, I just learned that the tens of thousands that we've spent, you know, special needs parents get that on therapy. If we would have just done this and just sat down

and listened to him share what it's like to be him, I mean this was more effective than anything we've ever done that we've spent money on.

So having this book out in the world and just encouraging people to do the same for each other, outside of special needs, just as human beings, just sharing our stories and listening to our stories and trying to understand why we respond the way we do and why we process the way we do is going to be what it's going to take. You know, that big picture, big picture level thinking of just really caring enough to walk in each other's shoes. I don't know how much effect we're going to have on the world if we're not willing to do that. So that would be my overarching hope for this book is that we just take time to give each other space to talk about what it's like to be us.

Debbie: I love that. So great. So any last thoughts before we say goodbye? Anything that we didn't cover or anything you want to make sure that listeners know about?

Gwen: Rylan, do you have, would you like to sing for her your Pokemon song? Rylan is head on the table right now. He's pretty mentally spent. This is our first podcast interview, so I'm taking lots of notes on if we do another one maybe having a Lego set or something here for him to work on so that he doesn't have to think so hard and get so exhausted. And I do, I do want to give props on here to Chris with Special Books by Special Kids because him coming to do what we were just talking about, he just shares stories. And he has shared so many amazing stories that never would have otherwise have been shared. And you can just spend hours and hours lost on his channel just listening to what it's like to be all of these different people who have differing abilities and different challenges and different gifts and...

Rylan: Different obstacles.

Gwen: Different obstacles, yeah. And his passion for doing that and the effect and the power of that video he did with Rylan, the effect that that's had on our ability to share Rylan's story has been really amazing.

Debbie: Yeah. Listeners, Chris Ulmer has, many of you probably have checked out his YouTube channel Special Books for Special Kids. I watched your video Rylan. It was awesome. And yes, I'm, I've actually been trying to get him on the show so maybe I'll mention, I'll mention your name and see if that opens the door for him to come and guest on the show. But yeah, he's doing great work.

Gwen: I hope you can get him. He is doing amazing work.

Debbie: Yeah, absolutely. Well, listen, I'm going to let you both go. I am so grateful that you took time to come and talk to me and I just think I want to be a part of helping to spread the word about this project.

Gwen: Thank you so much. We appreciate that.

Debbie: You're so welcome. So nice to talk with both of you and hopefully, yeah, Rylan, we can meet in person one of these days.

Gwen: Yeah. I hope, he promises he won't squeeze your head right away, but on the second meeting he might.

Debbie: Okay. Good to know. Awesome. All right, well have a great rest of your day you two. I'll talk to you soon.

Gwen: Thanks so much.

RESOURCES MENTIONED:

- *If I Squeeze Your Head I'm Sorry* by Gwen and Rylan
- *If I Squeeze Your Head I'm Sorry* (on Amazon)
- Living with Tourette's and Autism // Rylan on Special Books by Special Kids (video)