

Sarah McConnell: These days, autistic people and their families are coming up with new ways to understand autism's unique gifts and challenges. To these advocates, that means making the environment more inclusive for people with different minds and bodies.

Lydia X Z Brown: To understand what disability justice means, to incorporate that into our work means not treating our lives, our community as a single issue, it means recognizing the whole humanity of every person.

Sarah McConnell: That's Lydia X. Z. Brown, an autistic activist, organizer and lawyer. They spoke at the Colorado Trust, an organization that focuses on health equity.

Lydia X Z Brown: It's not merely about checking the boxes, do you have sign language interpreter? Do you have the ramp? It's about making sure that individuals in your communities and in your work actually feel welcome without having to check pieces of themselves at the door.

Sarah McConnell: From Virginia Humanities, this is With Good Reason. I'm Sarah McConnell. Today we talk to autistic adults, plus parents and educators of autistic young people about how they're building a more accessible world. Later in the show, how designing classrooms for autistic students can benefit all students, and how children's museums can include autistic patrons in their exhibits.

Sarah McConnell: But first, when she noted that her young daughter had delayed speech and dramatic meltdowns, Professor Jen Malia went looking for answers. She discovered her daughter was autistic, but she also discovered something else, that she was also autistic. Now she has written a children's book that stars an autistic girl. Jen, you have a book coming out next year. The title is Too Sticky!: Sensory Issues with Autism. Why too sticky?

Jen Malia: Well with my own experience as a child, I had some sensory issues. Too sticky was just something that I think a lot of kids that are autistic have trouble with. Both myself and my daughter, we have trouble touching sticky things and want to wash our hands constantly. I thought that would be a good sensory issue to write about for children.

Sarah McConnell: The book is loosely based on your own experience.

Jen Malia: Yes, I didn't know I was autistic when I was child. I wasn't diagnosed until I was an adult. But when I was looking for children's books for both myself and my kids, I had a lot of trouble finding books that were representing autistic characters in a way that was positive. That was one of the reasons that I set out to write a book.

Sarah McConnell: What do you now realize about the young you that had symptoms of autism?

Jen Malia: Well, when I was younger ... In my generation, now I'm 43, but in my generation, unless you had a severe case of autism, normally you would not have been diagnosed. At that time, I was very shy as a child, I had difficulty communicating, I had often sit in classrooms being completely silent and not interacting much, unless I was really comfortable with a couple friends that I had. But for the most part, growing up, I knew that there was something wrong, but I didn't know what it was. I knew that I had these sensory issues, I had trouble walking on hardwood or tile floors, and just a lot of sensory issues and difficulty communicating.

Jen Malia: Also as a child, I used to line up all of my toys, not even realizing that alone could be an autistic trait. But now that I know that that's something that's pretty common, what I did was I actually learned how to play with toys from my ... I had a brother growing up and he taught me how to play with his Star Wars toys. That's how I learned how to play.

Sarah McConnell: How can we understand it better? How was what you experienced not tidiness, fastidiousness and shyness?

Jen Malia: Right. I think that there's not really a look to autism. A lot of people have a stereotypical view of what autism is. I have to admit that until I got diagnosed, which was about three years ago, I myself had a very stereotypical view of autism. It was what I saw on Rain Man. That's what I had, a vision of someone that's very isolated and doesn't really communicate much with the outer world.

Jen Malia: Also statistically, for every four boys that are diagnosed, only one girl is diagnosed. Autism presents differently in females. Now there are a lot of girls and women being diagnosed that weren't or wouldn't have been in the past.

Sarah McConnell: What prompted you to have a diagnosis of autism so late in your life?

Jen Malia: At the time, I was looking to figure out what was going on with my daughter. I have three kids and my second child, when she was two years old, I noticed there was a lot of behavior issues, but also these sensory issues. She had a language delay. But when I would take her to doctors to try to figure out what was going on, I was constantly told that she had just a language delay. I knew there was a lot more to that, so what I started doing is I researched. Being a PhD, one thing I was good at was research so I spent a lot of time reading hundreds of medical articles. It's not my field, but I knew that I needed to do that to figure out what was going on.

Jen Malia: What I discovered was that the only thing that kept coming up with all of the things that I noticed that was going on with her was autism spectrum disorder. Then I realized, probably a couple hundred hours more of research, that well, I was on the spectrum too.

Sarah McConnell: What did you see in your two year old that went beyond what you thought was language delay?

Jen Malia: Well we would have these ... She had a lot of episodes, what a lot of people refer to as autistic meltdowns where she would be crying, and kicking and screaming. I could tell that there was a lot more going on than just a tantrum. The main thing that I think is different with a tantrum, which she was two years old at the time, which is pretty common for a two year old, and a meltdown is that it was a lot more severe.

Jen Malia: It wasn't the type of thing where if she wanted something and if you gave her that, let's say she asked for a toy, a two year old can have a tantrum if you take that toy away. But with an autistic meltdown, even if you give the toy back, there's going to be a continuation of this emotional breakdown, a sensory overload because at that point, if I gave my daughter the toy back, it would be too late because she can't control or emotionally regulate.

Sarah McConnell: Your forthcoming children's book, Too Sticky!: Sensory Issues with Autism, in that you're trying to help children, parents, educators really understand autism better. Is that right?

Jen Malia: Yes. I would say that the main purpose that I have, or main goal that I have with this book is not only to raise autism awareness, but also acceptance. I think that second part is really important because I, for one, consider autism part of my identity. I like to refer to myself as an autistic woman, autistic mother, not just a person with autism, which is person-first language, is actually preferred by the medical community, but a lot of the autistic community prefer identify-first language because we can't separate the autism from who we are.

Jen Malia: My experiences are all through an autistic lens. Every experience that I have ever had has been based on my own experiences with having autism. When I think about one of the goals that I have for writing the book, it's specifically is to write a book for the autistic community, for autistic children who want to see some part of themselves in the book and can identify with the character who is going about her every day life, which is exactly what we need to do every day.

Sarah McConnell: Are there many other children's books about autistic children?

Jen Malia: There are some other children's picture books that are written by neurotypical authors, but there are very few that are written from the perspective of someone who is living with autism.

Sarah McConnell: You must have so many people come up to you, through all your writing in The New York Times, The Washington Post, Woman's Day. You must have so many people saying, "Thank you. I so relate, both for myself and my children."

Jen Malia: Yeah. In fact, I have a lot of readers that reach out to me. They'll message me on my Facebook page and tell me that they were able to get diagnosed, or they were able to get their sons or daughters diagnosed. I even had someone that I went to school with in middle school who reached out to me. He just happened to come across an article he had read. This was recently. He sought his own diagnosis. It was something that for him, he had gone through therapy as a child, but also was not diagnosed. Then he's looking into potentially getting his daughter screened as well.

Sarah McConnell: What advice would you have for parents and children to recognize these character traits in children and colleagues, and account for them, be more understanding and accepting?

Jen Malia: Yeah, I think that a lot of times, especially if my kids are more on the mild part of the spectrum and I am as well, I think a lot of times the reaction that I get when I mention that either myself or my kids are on the autism spectrum, it's something like, "Well, you seem to be doing fine. You're a professor and your kids are interacting really well with other kids here at the school."

Jen Malia: A lot of times, that's great that we are able to do all of these things, of course, but sometimes it pushes to the side the fact that we are having a lot of challenges that we have to deal with and to dismiss as well. Sometimes I'll hear things like, "Well everybody is a little autistic aren't they? A lot of people who have PhDs and are studying intently, and have hyper focused interests and things like that."

Jen Malia: That is true. Sometimes there are definitely some people that are on the spectrum that are getting PhDs, that may or may not want to pursue a diagnosis or just have autistic traits, but if you're on the perspective of someone else like myself who is diagnosed and does have significant challenges, and my kids do as well, acknowledging that we are different and we do need accommodations sometimes. Even if we look like we're doing just fine on the outside, sometimes there is things that we're holding in on the inside that are really difficult for us.

Sarah McConnell: People are afraid to assume a work colleague or a child has autism.

Jen Malia: Yeah, I think that's true that there's still a lot of stigma about a lot of people I know don't actually want ... There are writers who don't want to identify that their children are autistic if they're writing about them. I have treated it with my own family. I've been very open, of course, and are writing articles about it. Also all of my colleagues, they know because I go to readings and I read about being autistic. But I have treated it as something that I'm proud of.

Jen Malia: I know that everybody has their own preferences as to whether or not they want to be openly autistic, but for me, as I said, it's part of my identity. I don't ever want my children to feel ashamed of being autistic, I want them to also be proud.

Sarah McConnell: Well Jen Malia, thank you for sharing your insights on autism on With Good Reason.

Jen Malia: Thank you so much for having me.

Sarah McConnell: Jen Malia is a professor of English at Norfolk State University. Her children's book, *Too Sticky!: Sensory Issues with Autism* will come out in the Spring of 2020.

Sarah McConnell: Coming up next, how museums can design autism accessible spaces.

Sarah McConnell: Jackie Spainhour is a museum professional and the mother of an autistic son. Now she's working on a research project about how museums can improve accessibility for autistic children. Jackie, you recently had a bad experience taking your three year old son to a children's museum. What happened?

Jackie Spainhou: I did, actually. My three year old is on the autism spectrum, and my husband and I thought that the best place to take him would be somewhere already suited for children. We decided to take him to a local children's museum and there were a number of barriers there that we weren't expecting. Children who have autism tend to dart, they're a flight risk. When you go into a space that doesn't have areas that are blocked off or that don't have doorways, then your child is really free to run, and dart and roam everywhere. As a parent, you end up literally chasing them throughout the facility and then they're not really learning anything or getting much from that experience other than you getting a 30 minute workout.

Jackie Spainhou: Another issue that we had is they have this wonderful bubble room that I can remember going to as a child. I knew my son loved bubbles and would love that room. Unfortunately, children with autism tend to zone in on one particular thing that they are fixated on. There was this large place where they had the bubble liquid and they had multiple wands in that particular area. Each wand had a different color and had different shapes that it made.

Jackie Spainhou: The first time that we went in, my son zoned in on this particular wand and that's the only wand that he wanted to play with. He had a great time, but then when we left that area and we came back, there was another child playing with that wand. You can imagine the meltdown that ensued because all of those wands were different and he wanted the pink one with the triangles, instead of the yellow wand with the circles.

Jackie Spainhou: What ended up happening is we just had to remove him from that situation and we ended up taking him to a part of the facility that was actually designated for infants. He was a little old for it, but that particular area had a door. We ended up staying there in a spot that really wasn't great for his learning and didn't allow him to use the space wisely. We were very disappointed with the

experience. I don't think that it accommodates children on the spectrum very well, that particular facility. To be honest, I'm not really sure if we'll go back.

Sarah McConnell: That's so interesting, a place where you had gone and loved as a child did not work for your own child.

Jackie Spainhou: Yeah.

Sarah McConnell: What's another example of something common in children's spaces that doesn't work for a lot of kids on the autism spectrum?

Jackie Spainhou: Sure. When I went to the children's museum, one again there was a section that had these tubes that children could climb into, which of course we all associate with childhood. We remember playing in those tubes at a McDonald's or some other place as a child. It's not a great place for your child with autism because a lot of children on the spectrum do not either know their names or they are unable to communicate when they get stuck. My child was climbing in these tubes and getting in the very back of them. I, as an adult, would have had a very difficult time trying to get to him if I needed to.

Jackie Spainhou: Those, although they work well for neurotypical children, children with autism, it's a little bit more difficult. You really have to think about safety with children with autism, and you have to make sure that you're thinking about how parents can have easy access and line of vision with their child at all times. I was surprised that we had that issue again at a children's museum where you would think these accommodations were already in place.

Sarah McConnell: I can see how museums could get it wrong and never realize it.

Jackie Spainhou: There are some museums that are working really hard to make accommodations at their facilities to ensure that children on the spectrum are able to come and be comfortable. There's been some museums that I've been to that have started creating spaces with different types of seating for a children's reading group. Or places, when they are doing crafts, they are more mindful of the fact that children with autism who are younger tend to explore with their mouths and they'll eat everything, so they have bigger beads or they have pipe cleaners because they're better for dexterity, as opposed to having a piece of string that you have to actually have to tie a knot.

Jackie Spainhou: There are some facilities that are trying to incorporate those things and are getting them done well, but I personally have not visited a children's museum that I feel like is really doing it well.

Sarah McConnell: Name one that you've come across that was doing it the best you have seen so far.

Jackie Spainhou: I have been writing a book called Museums and Millennials. As part of that research, I interviewed someone from the Mosaic Templars Cultural Center. They are a relatively new museum that's out in Arkansas. They have a variety of families, specifically African American families, they're an African American cultural center, that are coming to their facility almost daily. They are serving them very well. They realize that they had a lot of children that were coming that were on the spectrum and that they needed to make changes so that those families felt comfortable.

Jackie Spainhou: They are the ones that I've personally talked to that are really just doing wonderful. They're doing trainings constantly with their staff, but they're also recognizing that children with autism have difficulty staying on task and they have difficulty following directions. When they are having an event or something, they actually used colored duct tape and they put it on the ground to tell the child, "Follow the yellow duct tape," and then they'll end up at a Stop sign and then they'll do an activity. Then at that point they'll say, "Please follow the blue tape," and they'll go to another Stop sign. They're doing a really nice job of using nonverbal cues to communicate with a population that has a lot of nonverbal people.

Jackie Spainhou: Honestly, if you work for a museum facility and you don't know where to start, the best thing to do is to find your local autism community. You can do that by calling a developmental pediatrician's office. They often can direct you to all of the local resources. There's many national groups that have local chapters. The best thing to do is to educate yourself in order to make those accommodations and ask that group what they need so that they can come in and enjoy your facility.

Sarah McConnell: It's so interesting to hear you talk about this because I know how much parents love reading hours at libraries for children, children's museums, places where they can take their children and have a blast, and get outside the home. If you need that for children without the sensory needs, just imagine how much the parents of children on the spectrum extra need it, right?

Jackie Spainhou: Right, right. I'm part of a number of Facebook groups and things. Daily, I mean daily, multiple times a day, I'm seeing people post about their young child and how they are unable to find anything social for them to do. We love getting our children together who have sensory issues, but still again, our main fight is for inclusion. I think if we keep segregating our children with autism, and ADHD, and down syndrome and all of these special needs from mainstream children, then we're really doing a disservice to mainstream children and families because we have so much to teach them, they have so much to teach us.

Jackie Spainhou: As we're living in a world now that is so politically charged and there's this huge lack of compassion, wouldn't it be wonderful if we could get all of these kids to grow up together and realize that different is beautiful, and to ensure that all of our children could grow up in a world where compassion was king?

Sarah McConnell: Jackie Spainhour is Director of the Hunter House Victorian Museum in Norfolk, Virginia.

Sarah McConnell: Like museums, schools can sometimes be inaccessible for autistic learners. Radford University Professor of Special Education, Leslie Daniel, wants to change that. She has some techniques for designing more autism friendly classrooms.

Leslie Daniel: Some of my favorite strategies, and I have a few go-to ones, using visual supports is probably one of my number ones. That includes giving somebody a visual schedule, whether that be with pictures, or just written words or a combination to let somebody know, "Hey, here's what's happening through the day." Sometimes we think, "Oh, they get it now. The person with autism doesn't need the visual anymore."

Leslie Daniel: They don't on an average day, perhaps. But then comes the out of the average day. There's a snowstorm and they've got a two-hour delay to get to school, so when they get to school, there's no breakfast served. Well they're used getting to school and having breakfast. People with autism often rely on routine. A visual can help them see, "Okay, we got here late so this is where we are on the schedule now."

Leslie Daniel: Another favorite for me is using wait time. Wait time is when you ask a question or give a direction, and then shut up. If I say, "Pick up your pencil," usually teachers are like, "Come on, John. I said pick up your pencil. Where is your pencil? Don't you have a pencil?" Well the kid with autism is processing. They're still on the first one, and now you've said it three more times and they got to process it. They're not being noncompliant, their brains are slowly processing what you said, and particularly if you've gotten louder or angrier, they've got to process, "Wait, there's another voice. It's a different voice. What does that mean?" I teach my students, as a rule of thumb, to wait for 15 seconds.

Leslie Daniel: Now most teachers wait a little less than two seconds before giving redirect. Fifteen seconds can seem like a long time, so I teach my students to count their Mississippis. A good rule of thumb I like to teach my students is to wait for 15 seconds, counting their Mississippis, letting the person process.

Leslie Daniel: Now some people, and what I teach people is to pay attention to when did they process. It might be that the person needed four seconds. Or I've worked with somebody who had a five-minute processing. Now you can't wait five minutes in a classroom. You can wait 15 seconds, particularly if you're preparing all the students, "Hey, we're going to wait until everybody's had time to think."

Sarah McConnell: Let's try it out. I just want to see what that feels like. Let's just do 10 seconds.

Leslie Daniel: Okay. So that's five, and that's 10.



Sarah McConnell: Wow. That's a big pause. It's actually nice, isn't it? It's nice to have a pause.

Leslie Daniel: It's nice. Going back to I try and teach my students, not just that it's good for people with autism, but it is good for all kids because we don't give enough think time in general.

Sarah McConnell: You've also said one of your soapboxes is about friendships, how teachers can work to build relationships between neurotypical students and students with autism.

Leslie Daniel: Yes. I don't like fake friendships. I don't want to say, "Oh, you have to be this person's friend today." But I like building opportunities for friendships to grow a little more naturally. But people with autism might need a little help to get to know other people. They don't necessarily know the rules of certain aspects of friendship. The thing is, kids need to be with other kids to learn those rules, but somebody who doesn't know the rules doesn't have an easy time being with other kids, so they're caught in a catch-22 sometimes.

Leslie Daniel: I like building groups, I like building varied groups. In my own college classroom I change up groupings on a very regular basis. Sometimes you should get to work with your friends or the people you're sitting nearest to, and sometimes let's let you get to know somebody else and learn a little bit about them because they won't necessarily be so other if you've been in a group, and you've gotten to talk with them and you've learned their name. Teachers can be mindful of helping people foster relationships.

Sarah McConnell: Isn't it a big problem if the children don't realize this other children is coping with autism and instead just feel bothered?

Leslie Daniel: Sure, absolutely. Sometimes with parent permission and child permission I have, when I was in a K-12 classroom, said, "Okay, here's what's going on with this person," but only if I have parent and child permission because you can't disclose somebody's disability. If I can share more about that and then share also from the perspective of, "We all have differences. I wear glasses, for instance, I'm also very tall for a woman," talking about how that impacts my day.

Leslie Daniel: Then talking about what autism is. There's some wonderful storybooks that people can get and read with classes, again, with family permission, and with and without the person with autism there. Sometimes you might want to have a more difficult conversation that the person would rather not be around for, but as much as possible, I like to celebrate. Autism comes with a lot of strengths.

Sarah McConnell: I'm super curious about the strengths.

Leslie Daniel: Yeah. Some people with autism have an incredible focus, an incredible eye for detail. I had one former student who could look down at the ground, and see a

four-leaf clover and pick it up. He became incredibly popular on the trip to Monticello one year when in about two hours, he found nine four-leaf clovers. I've never once in my life found a four-leaf clover, though I have looked. He can just bend down because that's his eye for detail. He can see in a field of green clovers the one that is four-leaf.

Leslie Daniel: I know a lot of people with autism who would not do without their autism. I am not somebody who wants to cure autism, I like people with autism. But I do want to help people with autism be comfortable in the life that they choose to live and to have the skills that they want.

Sarah McConnell: Well Leslie Daniel, this is fascinating. Thank you for sharing with me and With Good Reason.

Leslie Daniel: Thank you for having me.

Sarah McConnell: Leslie Daniel is a Professor of Special Education at Radford University and teaches in the Autism Studies certificate program. This is With Good Reason. We'll be right back.

Sarah McConnell: Welcome back to With Good Reason. From Virginia Humanities, I'm Sarah McConnell. Temple Grandin was first diagnosed with autism when she was two. She was nonverbal until the age of four. Back then, many autistic children were institutionalized. But Temple Grandin says her mother worked tirelessly to teach her how to interact with the outside world.

Temple Grandin: My mother had parties. When my mother had a party, I had to greet each guest, and there was no calling them by their first names. It was, "Good evening, Mr. Wood," shake hands, learn how to shake hands, "Good evening, Mrs. Wood," and I'm going to serve the snacks. Everything socially, as someone on the spectrum, has to learn like being in a play.

Sarah McConnell: Now so many years and hurdles later, Grandin's autism has helped her become a national leader in the livestock industry. With Good Reason Producer, Allison Quantz, traveled to the University of Virginia, College at Wise to hear her speak.

Allison Quantz: At this point, pretty much everyone has heard of autism. It's a developmental disorder characterized by certain behaviors, including a common inability to connect socially. Yet Temple Grandin, who was diagnosed with autism at age two, connects with people and animals everywhere she goes.

Temple Grandin: My name's Temple Grandin.

Allison Quantz: I met Grandin at the University of Virginia, College at Wise in far Southwest Virginia. So small and far from major cities, at first glance, Wise is perhaps an unlikely stop for Grandin and yet ...

Temple Grandin: You got lots of good beef cattle around here.

Allison Quantz: ... immediately she connected.

Temple Grandin: This is prime country for raising cows and calves. You ever gone out and just watched them?

Allison Quantz: Grandin is not known simply for her autism. She's known because despite her autism, in fact probably because of her autism, she's had a remarkably successful career in the livestock industry. She designed a humane slaughter house system that processes more than half of the beef eaten in America. That's a lot of hamburgers.

Temple Grandin: I feel very strongly, we got to give the cattle and the pigs we raise for food a life worth living.

Allison Quantz: Grandin often talks about how her autism became an asset in the livestock industry.

Temple Grandin: When I think about something, I get pictures flashing up in my mind. My mind works like a language-based visual search engine. You give me a keyword and then I get pictures.

Allison Quantz: This visual-based thinking she argues allows her to see what animals see, and in a way, think how they think. But as I said, Grandin doesn't just connect with animals. Everywhere she goes, people come to hear her unusual ability to share what it's like inside an autistic mind. Here she is speaking to the audience at Wise.

Temple Grandin: Now I see movies in my imagination. Now I realized that my thinking was different when I asked people about church steeples. How do they come into your mind? I was shocked to find out a lot of people see this generalized thing. In my mind, there is no vague generalized one, there's only specific ones.

Allison Quantz: Grandin's message is that people with autism are different, not less.

Temple Grandin: What we got to do is we got to really help them to be successful because you wouldn't even have computers if it wasn't for a little bit of autism. Half of Silicon Valley probably has a little bit of autism. Einstein, who had no language until age three. Maybe Steve Jobs, kind of a weird loner, brought snakes to school.

Allison Quantz: Chris Scalia, English professor and Chair of the Lecture Committee at UVA, Wise, says there was an instant response from the community.

Chris Scalia: As soon as we announced that she was coming, people started phoning our publicity department and wanting to get more information about it. People

came from Kentucky and Tennessee to hear what she had to say, and to ask her questions directly.

Allison Quantz: Scalia said that Grandin's talk was the most widely attended he had seen yet.

Allison Quantz: Regan Stiltner is the mother of a young boy with Asperger's. Stiltner was one of many to give thanks for Grandin's presence.

Regan Stiltner: When my son got his diagnosis, I didn't have any light of hope. It was just the broken-heartedness. Then once I saw her and saw the hurdles that she had gone over to reach what she has, it made me realize that he could do the same thing.

Allison Quantz: Jimmy Burleson is a Special Education teacher. He came to UVA, Wise to ask Grandin about what should be prioritized for autistic high schoolers.

Jimmy Burleson: To hear her speak about it in such clear words helps put the puzzle together, I guess you could say. As far as seeing things daily in the classroom that you may not understand or a problem you might be working through with a student, she's able to clear that up.

Allison Quantz: Grandin's not ready to give up her work with animals, but she feels a hefty responsibility to the autistic community.

Temple Grandin: I think it's important that I continue to have a job that has nothing to do with autism, because I get a lot of satisfaction in life through my work. I also get satisfaction, people come to me and they say, "Well my kid went to college because of your book," or, "My kids is getting and keeping a good job," because of something they learned in one of my books. That makes me happy, doing things that actually improve the world.

Allison Quantz: Temple Grandin is one of the most important leaders in the livestock industry. She's worked with major companies, including Tyson, Smithfield, McDonald's and Whole Foods. She's been a Professor of Animal Sciences at Colorado State University for more than 20 years. Last but certainly not least, she's a much sought after expert on autism.

Allison Quantz: For With Good Reason, I'm Allison Quantz.

Sarah McConnell: For decades, movies and books have shaped the way we think about what autistic people can and can't do. But most of the time those representations have not been created by autistic people themselves. For example, Dustin Hoffman, who is not autistic, plays Raymond Babbitt, whose face shows little emotion and who could memorize vast amounts of information.

Raymond Babbitt: Sally Dibbs. Dibbs, Sally. 461-0192.

Sally Dibbs: How did you know my phone number?

Charlie Babbitt: How'd you know that?

Raymond Babbitt: You said read the telephone book last night. Dibbs, Sally. 461-0192.

Charlie Babbitt: He remembers things, little things sometimes.

Sally Dibbs: Very clever, boys. I'll be right back.

Charlie Babbitt: How'd you do that? How'd you do that?

Raymond Babbitt: I don't know.

Charlie Babbitt: You memorize the whole book?

Raymond Babbitt: No.

Charlie Babbitt: You start from the beginning?

Raymond Babbitt: Yeah.

Charlie Babbitt: How far did you get?

Raymond Babbitt: G.

Charlie Babbitt: G?

Raymond Babbitt: G. Gottsaken, William Marshall. Gottsaken.

Charlie Babbitt: You memorized G?

Raymond Babbitt: Yeah, G.

Charlie Babbitt: A, B, C, D, E, F, G.

Raymond Babbitt: G. Half of G.

Sarah McConnell: But some argue that portrayals like this can narrow our understanding of autistic peoples' experiences and even reinforce harmful stereotypes. What's changed in the 30 years since Rain Man? What happens when autistic people write their own stories?

Sarah McConnell: Christopher Foss is a Professor of English at the University of Mary Washington. He's looked into how autism is portrayed in literature and film. Chris, are there many movies where autism is a theme or the main character is autistic?

Christopher Fos: I don't know if I'd say many, but there certainly are enough to teach a course on them. The older films, usually you would tend to see autistic characters being relatively minor characters, simply to advance the plot, or to enable some sort of realization or movement for the major characters.

Christopher Fos: For example, Elvis Presley's last major feature film, Change of Habit from 1969, features a young autistic child who is a patient in Elvis' inner city clinic where Mary Tyler Moore has been volunteering to work with him. It is in their work with her that they come together romantically. That's really her purpose in the plot.

Christopher Fos: You also see in that movie a much older understanding of autism, the refrigerator mother theory where the child is autistic because of some sort of rejection on the part of the parent, the mother in particular. The way Elvis and Mary Tyler Moore treat her is to try to somehow get her to get all of the rage that's inside of her out. That's what's caused her to withdraw into her own world.

Sarah McConnell: Refrigerator mother being the cold mother who withdrew her love?

Christopher Fos: Right. Exactly.

Sarah McConnell: Now what do we think about autism?

Christopher Fos: Now it's a lot different. You can still find plenty of cultural scripts that are out there that still see autism in terms of a disease, something that needs to be cured, that you want the individual to somehow recover from or emerge from. But increasingly, there is a competing storyline that emphasizes autism as human variation and difference, as neurodiversity. The emphasis there becomes on society learning more about autism and accepting autistic individuals for who they are, and working on accommodation and adaptation, rather than on an emphasis on some sort of pathological cure.

Sarah McConnell: Starting with film then, when did we first start to see autism depicted in film? I can think of Rain Man, and when was that, late '80s?

Christopher Fos: Yup, that's '89.

Sarah McConnell: Dustin Hoffman, Tom Cruise.

Christopher Fos: Right, exactly. As the brothers Raymond Babbitt and Charlie Babbitt. That film, in many ways, was way ahead of its time. Rain Man features an autistic character as one of the two major characters. He's really treated with compassion and with a sense of humor so that you really feel like his humanity has been respected. At the same time, you can see his character subtly reinforcing the more widespread responses to disabled individuals. He's pretty much a perpetual child, he's helpless and dependent. Ultimately in the plot you

can also see him as simply being the vehicle for his brother's redemption. His brother's a self-centered jerk at the beginning, and it's having to go around with Raymond that teaches him something about himself, gets him to open up.

Christopher Fos: There are all these ways in which, and most of those characteristics I'm talking about are coming from a disability study scholar named Paul K. Longmore who has worked on traits that we associated with the old telethon poster child. You can see Raymond's character, as in many ways, reinforcing the notion of the disabled individual or the autistic individual, as someone who's in need of our pity, in need of our charity.

Christopher Fos: It's when you move more into our own decade with films like, for example, Snow Cake from 2006 which stars Alan Rickman and Sigourney Weaver. Sigourney Weaver is the autistic character in that movie. She is living independently on her own, in a home and she does have help from her parents. But she's living independently on her own, she has a job, she is a mother, in fact. That's how the two characters have come together.

Christopher Fos: But you see her as someone who definitely has her quirks, a lot of the typical issues we've talked about for autistic individuals, but you also see that she is very smart. You understand why despite some of the difficulties, the Alan Rickman character comes to really appreciate his time with her.

Christopher Fos: For example, in one particular scene where the two of them are play Scrabble, you think about the difference between the interactions from Charlie and Raymond Babbitt where Raymond, he does seem in some ways as if he is this perpetual child figure. But in this scene, you see Sigourney Weaver definitely getting the best of Alan Rickman in terms of this relatively challenging, I think anyway, board game.

Christopher Fos: At the same time, even this movie ultimately still is participating a little bit in some of the more problematic aspects of those earlier movies. Ultimately, I think even though Sigourney Weaver and Alan Rickman are two major characters, the movie, the script moves us to seeing that Alan Rickman is really the major character. It's his story, he's trying to deal with the loss of his own son, the fact that he has been involved in this accident with Sigourney Weaver's character's daughter. Ultimately it's about his coming to terms with his own guilt, his own grief. Her character is helping him to do that.

Christopher Fos: You still see that vehicle of someone else's redemption going on, that this other individual who is different from the rest of us somehow is able to get to us and tell us something we needed to know about ourselves in a way that someone else hasn't.

Christopher Fos: Another more recent movie that I think is doing a much better job, one would hope so, almost a couple decades after Rain Man, is 2005's Mozart and the

Whale. That's a movie that's actually based on the real life love story of two individuals with Asperger's syndrome, which is autism spectrum diagnosis.

Christopher Fos: As you might expect, the two major characters here both have autism spectrum diagnoses. They are the two major characters, they are the love relationship, they are the two love interests. We get to see them interact with each other. They both also are, they're setting up house together, they're living out in society, trying their best to hold down jobs. The fact that this is a whole feature film where all of the major characters are autistic is really a significant advance.

Sarah McConnell: Tell me about representations of autism in literature. Are these mostly parents writing about their children, teachers writing about their students?

Christopher Fos: Most of them are either parents, but actually autistic individuals themselves make up a very substantial ... Again, that's one of the old perceptions was an autistic individual was someone who's sitting, rocking and can't really communicate when in fact there are many highly articulate individuals with autism out there. A number of them are telling their own stories.

Christopher Fos: What I've seen in the literature is the shift that we've talked about, away from the sense of a story about recovering from or curing the condition, to embracing it as a part of one's self-concept or one's identity. You can take Temple Grandin, for example, is a professor out in Colorado. The first book that she wrote was in 1985 and it was entitled, *Emergence: Labeled Autistic*. In that book, she's talking about emerging, to some extent, from the label of autism. She says that she's writing it in part to disprove the notion of once autistic, always autistic.

Christopher Fos: Even just a decade later in 1995, when you take a look at another one of her books, *Thinking in Pictures*, you can see that she's already moved away from that sense of the story of recovery or emergence. Instead, she's focused on adaptation. She says in that book, for example, if she could snap her fingers and be a non-autistic, she wouldn't anymore because it's part of who she is. That, I think, is a pretty dramatic shift in terms of how a lot of these writings are representing autism.

Christopher Fos: You can take a look at Barbara LaSalle has a book called *Finding Ben* from 2003. She's a mother. It's about her son. Dawn Prince-Hughes has a book, 2004 I think, *Songs of the Guerrilla Nation*. 2007, John Elder Robison who is the brother of Augusten Burroughs, the *Running with Scissors*, which was a popular book not too long ago, *Look Me in the Eye*.

Christopher Fos: All of these accounts are very much ultimately getting to a place where they want to insist up on their autism spectrum diagnosis as essential to their self-concept, and something that they can actually embrace and celebrate, or rather than something that they wish they could somehow be cured of or emerge from.



- Christopher Fos: Again, the same sort of thing you see in film. You're starting to see a different trajectory, a more positive one that's allowing both society in general and autistic individuals themselves in particular to have a much more healthy understanding of how they should respond to their diagnoses.
- Sarah McConnell: What have you noticed about the change in how autism is represented in literature and film over time?
- Christopher Fos: I do think that there is increasingly more of an opportunity for stories again that are focusing more on acceptance of autism as human variation and difference rather than a pathologizing of it where the emphasis is somehow on the autistic characters as definitely very different from the rest of us, and potentially defective in some way, in need of a cure. I think that in both film and literature, you can see. Not that the older models aren't still there, but you can see increasingly new possibilities for autistic characters or autistic individuals being represented in these two media, to be represented in this different, I would say more welcome, more positive light.
- Sarah McConnell: If people are interested in reading one of these books, is there one in particular that you would highly recommend?
- Christopher Fos: It depends on what you're looking for. I think that the Temple Grandin books are usually the best place to start.
- Sarah McConnell: That is Emergence and ...
- Christopher Fos: Thinking in Pictures. She has a number of other more recent ones as well.
- Christopher Fos: If you're an animal lover, you might appreciate the Dawn Prince-Hughes book because it's very much focused on her powerful connection with guerrillas that she works with as part of her advance degree work.
- Sarah McConnell: What is the name of that one, again?
- Christopher Fos: Songs of the Guerrilla Nation.
- Christopher Fos: The John Elder Robison book that I mentioned, if you're a rock and roll fan, for example, he's someone who's diagnosed later in life as is Dawn Prince-Hughes. He's spending a lot of his life trying to figure out why he seemed so different and why people respond to him so differently from others.
- Christopher Fos: But he goes through a number of jobs. He designs computer games. He ends up designing all kinds of special effects for KISS and is going on tour with the rock band KISS. That's a narrative that it's not as much explicitly about giving you all kinds of information about autism, but it's a narrative that's focusing on John Elder Robison the individual, and his Asperger's syndrome diagnosis is part of

who he is, but it doesn't have to be the whole book. Again, that's something that I find refreshing.

Sarah McConnell: Why did you start getting into a study of autism in literature and film? Why did you care?

Christopher Fos: Well first off, I did grow up in a family with two brothers and a father who lived with chronic illnesses, and as a consequence with multiple disabilities. But my interest in autism in particular really came about a number of years ago when a loved one received an autism spectrum diagnosis.

Christopher Fos: By reading a lot of this literature, watching the films, I have been increasingly realizing the extent to which I personally have been pathologizing some of the traits, especially negative traits of my loved one. There's this sense of always looking beyond the here and the now, the moment with the person right in front of you toward some moment in the future where through occupational therapy, sensory integration work, social skills work, speech therapy, any other sort of magical fairy godmother, suddenly you get to a point where you have someone who is more normal, more fully human.

Christopher Fos: What I've been realizing is that I have been buying into that myself. I think that I'm the one, to some extent, who needs to be cured of this ... I'm the one who's been locked inside the label of autism, not my loved one. My loved one doesn't need to be cured, my loved one doesn't need to somehow get to a point in the future where he or she can somehow pass for normal.

Christopher Fos: I always joke, very few people who know me I think would apply the adjective normal to me. Is that the goal anyway? Really what my loved one needs is better services, better healthcare coverage to be able to have what all of us really want, the opportunity to live a full life, and with as many opportunities for self-realization as any of the rest of us.

Sarah McConnell: It sounds like you think we're getting closer to that.

Christopher Fos: I think so. There's still a lot of work to do. I think one of the things when we were talking about the literature, you still see some of the older models. For example, maybe the most popular autism book right now is Jenny McCarthy's, *Louder Than Words*, which also came out in 2007. The subtitle of that book is *A Mother's Journey in Healing Autism*. Autism is seen in that narrative as something that steals the soul of the autistic child, that somehow, I think in many ways, somehow prevents one's full humanity from being realized. It's very much seen as the enemy.

Christopher Fos: Certainly Jenny McCarthy has gone through a tremendous amount of suffering, not to minimize that in any way. She also has, through the media blitzes, appearing on Oprah, Larry King, etc., more people have heard the word autism, and have started to think about it because of her and her book. But at the same

time, when you focus so much on the sense of we need to find a cure for autism, instead of we need to, again, work on better services, look at education, look at healthcare, then I think that ultimately you're in real danger of sliding back into that older model of defectiveness, rather than as simply human variation and difference.

Sarah McConnell: Chris Foss, thank you for sharing your insights on this with me today on With Good Reason.

Christopher Fos: Thank you very much for having me here and for giving me the opportunity to talk about it. I really appreciate it.

Sarah McConnell: Christopher Foss is a Professor of English Linguistics and Communication at the University of Mary Washington. He's also co-editor of the book, Disability in Comic Books and Graphic Narratives.

Sarah McConnell: Major support for With Good Reason is provided by the law firm of McGuireWoods, and by the University of Virginia Health System, pioneering treatments to save lives and preserve brain function for stroke patients. Uvahealth.com.

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Sarah McConnell: I'm Sarah McConnell, thanks for listening.