

Stories from the brainreels podcast transcript

December 4, 2013

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Introduction

CHERYL: Welcome to Stories from the brainreels. I'm your host, Cheryl Green, from StoryMinders up in sunny Portland, Oregon. This is a monthly podcast about brain injury and disability with a focus on art, culture, and disability pride. Contact me at info@storyminders.com with questions or topics and guests you want to hear on an upcoming show.

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My guest today for December, 2013 is Jackie Pilgrim. She runs several blogs including: autismslove.wordpress.com, a voice from the spectrum, where you can find her very dynamic, visceral poetry as well as some great resources. Jackie also has a Facebook community called Autisms Love: Making Connections, where you can find all sorts of stories, resources, and links to tons of video and articles of great interest. Jackie and I prerecorded our conversation.

Let me give you a few pieces of community and arts news, and then we'll dive into that conversation.

1. Lots of stuff about local artist Lavaun Heaster.

On December 8th, 2013, Lavaun will have a calendar release party for her 2014 art and food calendar. Each month features prints of her original artwork, multi-cultural holidays, and multi-ethnic recipes. Her art comes from her visions and storytelling. And it often reflects and celebrates aspects of society that are rarely shown in the media: multi-ethnic and multi-tonal families, people with disabilities, trans people, and many other people and ideas that are part of Lavaun's life and community.

The party is Sunday, December 8th, 2013, 6:00 to 8:00pm

Arbor Lodge Coffee and Community Space

1507 N Rosa Parks Way

Buy your 2014 calendar, view and feel some art, and enjoy live music by the wonderful musicians Camilla Rose and Lee Rice.

While you're there, my camera might catch you, cuz I'm making a short documentary about Lavaun right now!

Which leads me to Lavaun-based event #2. On Friday, December 13th, 2013 NW Documentary is hosting their Homegrown DocFest. My classmates and I from the DIY Documentary class will be premiering our short documentaries. Mine explores some of Lavaun's experiences becoming a disabled artist entrepreneur.

Friday, December 13th, 2013

7:00 to 9:00 pm

Mission Theater at 1624 NW Glisan Street

There are a few steps at the front door. You can call (503) 223-4527 when you arrive or have someone alert staff at the bar. They'll set out ramps for an accessible entrance.

#3, the Great Gifts Holiday Fair is a group arts fair organized and led by none other than local artist...Lavaun Heaster. This is a chance for artists with disabilities to share a space and sell your arts and crafts. Please contact Lavaun at inclusionandaccess@gmail.com or (503) 703-9983. All types of art (like painting, drawing, music if you have CDs to sell, sculpture, poetry) are included. If you're an artist with a disability with art to sell, be part of this! If you're anyone in the world who wants to buy some gifts and treats made by local artists and entrepreneurs with disabilities, no matter who you are, come to this!

Saturday, December 14th, 2013

11:30 am to 2:30 pm

Tabor Space at 5441 SE Belmont on the #15 bus line.

The venue is physically accessible.

Lastly, some news not about Lavaun! [The Yvonne Pierre Show on BlogTalkRadio](#) will have Leroy F. Moore Jr. on her show Monday, December 9th at 10:00 am Pacific/1 pm Eastern time. Leroy is a Black writer, poet, hip-hop music lover, community activist and feminist with a physical disability. He is Co-founder of the Sins Invalid performance project and the creator of Krip-Hop Nation. Binki Woi of Germany, Lady MJ Warrior of the UK, and Leroy started what is now known as MCEes with Disabilities, an international movement. Leroy formed one of the first organizations for people of color with disabilities in the San Francisco Bay area. And he is one of the leading voices around police brutality and wrongful incarceration of people with disabilities and has studied, worked, and lectured in the field of race and disability and social justice around the world. For more information about Krip-Hop Nation or Leroy Moore, visit http://poormagazine.org/krip_hop. That will be a great show to listen to: Monday, December 9 at 10:00 am (PST) / 1:00 pm (EST) Discrimination and Disabled Profiling with Leroy F. Moore, Jr., episode # 96.

Lastly, I want to share a small piece of "AMESSAGE BY MR NELSON MANDELA TO THE CONFERENCE FOR THE DISABLED (SCOPE), APRIL 2004"

"We have tried to give special emphasis to the rights of people living with disability. It is so easy to think of equality demands with reference primarily to race, colour, religion and gender; and to forget, or to relegate to secondary importance, the vast discrimination against disabled persons. It is not a question of patronising philanthropy towards disabled people. They do not need the patronage of the non-disabled. It is not for them to adapt to the dominant and dominating world of the so-called non-disabled. It is for us to adapt our understanding of a common humanity; to learn of the richness of how human life is diverse; to recognise the presence of disability in our human midst as an enrichment of our diversity."

So now on to my guest, Jackie. Jackie and I started our phone conversation with a little small talk. But really, I'm terrible at small talk. So I cut that little part of our conversation out of the recording because it's just plain silly sounding. So I know the recording starts kind of abruptly! We spoke on the phone on the day Daylight Savings ended. While that used to be a minor annoyance to me, nowadays it brings up lots of reminders of how terrible I am at using calendars, keeping track of time, and dealing with

changes someone else makes to my routine. So we chat about that and then launch into our larger discussions around race, class, disability, and Autism culture. Please enjoy.

The Interview

CHERYL: Did Daylight Savings work out OK for y'all?

JACKIE: It rarely affects us.

CHERYL: Mmhmm.

JACKIE: We're not very time-driven people in terms of having to keep up with a clock. It's more just getting things done within a certain block of time within a day, if that makes sense.

CHERYL: Yeah, it does make sense. I'm very time-driven. I'm terrible at telling time and using calendars. But I'm very driven by them. And then the cats. The cats don't do well with Daylight Savings changes [laughs].

JACKIE: Oh, they don't? How does it affect the cats?

CHERYL: They get fed at almost exactly the same time every day. And so they just sense it. And every 12 hours, they get extremely hungry and start screaming about it.

JACKIE: Oh, wow. OK.

CHERYL: But when Daylight Savings comes, they start getting hungry at the wrong time.

JACKIE: Ah, interesting.

CHERYL: Yeah, it's a little bit weird to me. I don't quite get it.

Room for flexibility

JACKIE: You know, it's kind of like that thing that I fight, with my son being Autistic, and the professionals originally told me that they had to have all these rigid schedules. And wherever you put his things, you always have to put his things in that very same spot. And I thought gee, that's kinda weird. Life doesn't happen that way. Nothing ever happens the exact same way every day. So if we are given to do anything the exact same time every day, we're kind of shooting ourself in the foot, more or less.

CHERYL: Mm.

JACKIE: Yeah, because then we tend to get trapped. We're trapped in that it's gotta happen in this point in time, or it's gotta happen this certain way, which leaves you no room for flexibility. If you have a more flexible, less-rigid way of doing things, you, #1 have a whole lot less headaches in your life. And you just tend to kinda just go with the flow better. Cuz that's the way I raised my son. I raised my son to go with the flow because you never know from one day to the next: it could be a tenant calling, we could have a flooding or anything, or something happened with the roof or whatever, or need an impromptu meeting on something. And we might have to stop what we're doing right on a dime and go deal with this other matter. And I can't afford to carry a screaming child with me.

CHERYL: Right, so if you get too rigid, then you are not ready--

JACKIE: Anything, right.

CHERYL: --some kind of natural change. And then you're probably more anxious if there is a change, right?

JACKIE: Well oh, of course you're more anxious. You're more anxious before there's a change. You're anxious at the anticipation, the thought, or the possibility of there being a change. Anything to throw your dynamic off. So you're in a constant state of rigidity.

CHERYL: I mentioned to you that I actually trained to become a speech therapist. And one of the things that we talked about a lot was making those very predictable schedules, making pretty--I wouldn't use the word "rigid", but--pretty set schedules, and making things the same and routine all the time because people with autism do best in that scenario. And I'm generalizing. But this is pretty much how we were taught to do it, was to help people with autism by coming up with a schedule that's not that flexible. But that's sort of the opposite of what you just said.

JACKIE: That is a myth, as far as I'm concerned, because the thing is, you're set up for failure if you think that way. Because why would you say that to help a person that you need to have a rigid schedule--or less flexible schedule, if you will--but then, on the same note, you're telling the person who's working with an autistic person that you have to teach them to kind of comply to the things that are socially acceptable? But the things that are socially acceptable are not rigid in terms of how things happen. OK, I'll give you an example. Oftentimes you hear people say or refer to autistic people as "anti-social" by social standards. OK, I get that. But if you take an autistic person, and they actually pay attention to what the social standard is, you'll find that the social standard is non-social. Typical people have the least amount of social anything as far as I'm concerned because it's like, you can walk into a room, and no one may acknowledge you. But if you're known to be on the spectrum, and you walk in the room, and you don't acknowledge those people that aren't acknowledging you, then you're the one who's deemed anti-social based on the fact that you have a diagnosis. Whereas the typical people who have chosen not to speak to you, that's normal behavior. And I mean, it doesn't make sense. Everything's a Catch 22.

CHERYL: Mmhmm. And I find those double standards, having been trained to become a speech therapist, but then I was a patient in speech therapy. I felt like I saw a double standard like that a lot where if I, let's say, messed up on a scheduling thing and emailed you, "Oh, I'll call you Tuesday" but then I had to email you back, "Oh, sorry. I mean I'll call you Wednesday," I would sort of get a little bit discipline for that. Well, Cheryl, you know you really need to learn how to use your day planner. But I get emails from people all the time where they messed up their schedule. And I don't see anybody saying, "You know Cheryl, I think I need to practice with my day planner too." But because they know I have the diagnosis of a traumatic brain injury, I do get gently disciplined on certain things that everybody does. And I don't see anybody disciplining themselves or each other.

JACKIE: Exactly.

When your diagnosis becomes everything to other people

CHERYL: They're sort of exempt from it. But once you have the diagnosis, and people know you have a certain kind of impairment, then that becomes sort of everything.

JACKIE: Yeah, and that's not OK.

CHERYL: And you're always in need of improving yourself. But other people aren't supposed to improve themselves [chuckles].

JACKIE: Exactly. And I find that fascinating, to be honest. I really do. I find that very fascinating because as an adult--I'm an adult. I have mild Asperger's, OK. Not many people would know that to look at me or talk to me or whatever. And that's fine. But if I choose to make it known that I have mild Asperger's, then automatically the person that I'm talking to, their demeanor changes. I have been in a doctor's office and, let's say a new doctor, and they pull up my chart, and they see the diagnosis "Asperger's." And prior to that, we were talking normal, talking fine and everything. As soon as they see that diagnosis, they forget about the person that they were speaking with prior to seeing the diagnosis. And they turn around, and they speak slower to me.

CHERYL: [gasp] Oh. What are some other changes in people's demeanors besides speaking slower?

JACKIE: Expectation level. I find that people are less tolerant. If you say that something bothers you, like if I walk into say, I take my son to therapy or something or to a doctor's appointment, and I walk in, and the lighting in the room is very harsh or there's something, the wallpaper's very busy, and it's kind of disturbing to me. If I mention that, without it being known that I have Asperger's, then people talk about, "Oh yeah, that worries me" and blah blah blah and blah blah blah. But if I mention it, and it is known that I have Asperger's, it's more or less "get over it."

CHERYL: Oh. I have the opposite experience around brain injury. If I say something is bothering me, then people sort of feel like, "Well, it's not that loud, Cheryl. Come on. Don't complain about that sound." But if I say, "Oh, my ears are sensitive because of my brain injury," then people are, "Oh! Oh! Uh-oh! What can we do to fix this? Oh!" So that's so weird that people have the opposite response.

JACKIE: Right. But then again, there's another facet too because if it bothered my son, then perhaps the response would be more likened to what you get because he's more obviously autistic.

CHERYL: OK. It sounds like people have more patience, maybe, with brain injury or autism than they do with Asperger's, you think?

JACKIE: Than they do with anything that appears to be typical, I would say. It doesn't have to be specifically Asperger's. Because my traits are hidden behind what appears to be normal. I don't have any obvious signs, right?

CHERYL: So it's almost like if you deviate from the "norm" only a little bit, then people don't believe you, or they disregard what you're saying you want and need. But if you deviate a lot, then people, "Oh! OK, well that person's disabled. I better help."

JACKIE: Exactly. If you deviate a lot, there's a little bit more concession for you. I feel like for a person like myself that appears to be normal, and if I'm speaking to someone who considers themselves normal, and I say I have this difference, it's almost as if I've offended that person. It's almost as if to say how dare you say you have this issue, and you act like I do? Cuz I don't have any issues.

CHERYL: Ah.

JACKIE: You see?

CHERYL: Mmhmm. We talked about this a little bit the other day. And now I'm having trouble remembering how you described it to me that people sort of get scared like oh, wait. If there's something wrong with you, is there something wrong with me? Did I remember that right?

JACKIE: Exactly. If something's possibly wrong with you, then what you're saying is there could possibly be something wrong with me. And I know there's nothing wrong with me. Because you don't look Autistic. You look like a normal person. And if I don't fit that mold of whatever their pre-conceived notion is, then it's often just rejected.

CHERYL: Right. Now, if we can unpack for a second the idea that if you have Asperger's or you're Autistic, that there's actually something wrong with you. Cuz I don't agree there's something wrong with you. Wouldn't you say the same?

JACKIE: Oh, absolutely. There's nothing wrong with us. I mean, I know that there are some cases where there are some severities. And I don't know exactly what might trigger the severities. There's a lot of different arguments out there, which I don't even really want to bring up because it's such a sensitive area. I don't think there's anything wrong with having Asperger's. I don't think there's anything wrong per se with having Autism. I think the only thing is, is that we're just different. But our society doesn't handle differences well. Anything that's deemed different is considered abnormal, which means that it's already tagged as being wrong. Just to say that you have a diagnosis, no matter how mild, is already deemed a mistake, if you will, or a disparity of any kind, just by the nature of the beast. Instead of people just looking and saying, "Oh, this person, they're neurodiverse. They have feelings, but they show their feelings differently. Or they express themselves differently." There has to be some sort of deformity, or it has to be something less than. And I don't know if you've seen any campaigns like Autism is not less than; it's different. They see differences as less than. And so that's why I don't like to use the term "special needs" or "disability," because we've already put ourselves at a disadvantage with the first word that we've spoken about ourselves.

CHERYL: Mmhmm.

JACKIE: I like to think of it as we have unique abilities. Because everybody's abilities are different. It doesn't matter where you are, if you have a diagnosis or not, your abilities are gonna be different from your neighbor's.

CHERYL: Right, right.

JACKIE: So what's the big deal if I do things differently than you?

CHERYL: Right. And you're making me think of something that, just again, with the training that I have-- and to be clear, I've never practiced as a speech therapist because I was a patient in speech therapy, and that didn't work out so well. And I decided I didn't wanna practice. I think I mentioned that to you. One of the things from the speech therapy training side that you learn is that when it comes to Autism or even brain injury, people are very rigid, very inflexible with their thinking. And yet, who's being more inflexible here? If I tell you I have this certain diagnosis, and you put me into a box as to how you think I'm gonna communicate and how well you think I can do things, and by hearing a diagnosis and automatically assuming, oh, that means there's something wrong, there's some kind of defect, the person is less than, that's pretty rigid thinking.

JACKIE: Exactly. That goes back to what we were saying earlier about the Catch 22 situation. What is deemed so different and so negative or whatever for a person with diagnosis is something very normal for someone who doesn't have a diagnosis. So they don't seem themselves as being rigid. We're the rigid ones because we have the diagnosis.

CHERYL: Yeah, it's interesting. I hadn't thought about it this way before. I like it. This is good. I tend to be a somewhat inflexible thinker myself [chuckles].

JACKIE: I'm inflexible about some things yes. But my background may be different than some. I come from a very harsh background, a lot of abuse. So I was forced to have to be able to really look at bigger pictures and be aware of inflexibilities and abnormalities of what was happening to me on a daily basis.

CHERYL: Right.

Asperger's as an asset it getting through an abusive childhood

CHERYL: And you've mentioned to me before that you felt that your Asperger's actually played a really great role in helping you just get through that childhood and process it.

JACKIE: Yes, yes, because my brain process is very literal and logical. And so because I wasn't thinking so much emotional, I could look at my parents and their behavior towards me and process it in a logical way, which made more sense than looking at it out of an emotion of pain. So it's like with my Asperger's, I could literally set that emotion to the side and focus on what was literally happening in front of my face and process it that way. And that way, I was able to, like a lot of children who have been victimized oftentimes, they're caught up in the emotion of being victimized and feeling like the victim. In my case, even though I was being victimized, I did not take on the role of victim because I was too busy processing what my parents were doing. And I saw them as the victims victimizing me, but I was not the victim. I was just a matter of circumstance.

CHERYL: Mmhmm.

JACKIE: Does that make sense?

CHERYL: It does make sense. It's a way of describing it that I haven't heard of before. But certainly, you can say that you had quite an advantage at being able to say, "OK, I'm not a victim. And I'm not going to be overtaken by my emotions around this really painful situation."

JACKIE: Well, it wasn't quite that much of a thought process in terms of I'm not gonna take on the emotion because the emotion wasn't really thought of until well after the fact.

CHERYL: Ah!

JACKIE: When I look at it, I have to now think of what emotions did I feel and try to connect with that emotion and then attempt to describe what I felt.

CHERYL: Oh, OK.

JACKIE: So I didn't feel. And so during that time while I was processing it, my thought process was I'm looking at two very angry people. These two people are beating me, yelling at me on a regular basis. And my father was also brutally raping me on a regular basis. And with that being said, logically speaking, instead of looking at I know I felt pain. But my Asperger's allowed that pain to be diverted elsewhere. It

was kind of like it was just stuck in a box and put on a shelf where it was felt but not dealt with in what would be considered a normal way. Yes, I felt pain. But it did not really compute as pain because my effort was going into what is causing my parents to do this. What level of whatever are they going through? Why are they so angry when I haven't done anything?

CHERYL: Mm.

JACKIE: So now that I'm in therapy about my past, it is now that I'm actually addressing whatever emotions I had tied to that time. I remember feeling things like starting to cry and then all of a sudden, that pain or whatever that feeling that made me cry, the way I describe it, it was reabsorbed. As I felt it coming up, it was like I just mentally reabsorbed it and just sucked it in, and everything stopped. That's pretty much what it was. It was kind of more of just surviving as opposed to feeling.

CHERYL: Mmhmm.

Autism and racial/ethnic expectation myths

CHERYL: So you brought up something that I wanna ask about, which is--and maybe tell me if this is a myth or not a myth or somewhere in between--that people who are anywhere on the Autism spectrum can't put themselves in someone else's shoes or try to imagine someone else's emotions or what they're thinking.

JACKIE: I can't speak for all people.

CHERYL: [laughs] I'm glad you said that!

JACKIE: I have a wonderful imagination. I know several Aspies that have wonderful imaginations. We can talk about, I think there are several actors and actresses that are on the spectrum that clearly can step into the role of someone else. Let's say Darrel Hannah, who's just recently come out. She's an excellent actress. I mean, she's able to go into these roles, and she's very memorable in her roles. She's claiming to be on the spectrum. If she wasn't able to put herself in someone else's shoes, then how could she act?

CHERYL: Mmhmm.

JACKIE: Again, that's another myth because a lot of times people on the spectrum are associated as not having feelings or not being able to show feelings. And in some cases, we do have difficulties with that. And in other cases, we can wear emotions or we could wear the persona of someone almost like a cloth and just kind of put on a persona and take it off. And the more typical you behave, the more that you find that you do that because you are in situations where you have to act more typical than you really are. You have to learn how to be typical. You have to script your language so that you respond properly and everything. You do that enough times, then you kind of pick up a rhythm, and you pick up on patterns of behavior that you can adopt.

CHERYL: Mmhmm. The way you're describing it sounds, at least on the surface, a lot to me like the way people of color are demanded to do kind of the same thing about how to act right and how to talk and that you are judged if you are not talking the way white, middle class culture talks. I mean, do you see a similarity there too?

JACKIE: Yeah, I think that's a very--I'm glad you brought up that point because I think that is, to me that's a phenomenon. Especially with my being "African-American." I don't really like the term. I just go by

Black because I feel like I'm a Black woman, and Black is a very powerful thing for me. And I don't need an exorbitant label to express who I am. But I have been told growing up--I think, largely because I went to a private school growing up for six years--and was told by people in my peer group that did not attend this school that I was not Black enough. And when I questioned why was I not Black enough, it came down to very superficial things like how I spoke, even how I sat when I rode a bicycle because I didn't bend my back; I sat with my back very straight. The fact that I was a very informative child, which again, was part of my Asperger's, because I was a lover of sharing information and a lover of getting information. So with that being said, I thought that was very odd because I came from a family that spoke proper English. That didn't just start in school; that was in life. My family is Black. I come from them. I'm a biological child of theirs. So obviously, if I have two Black parents, then I'm gonna be a Black child. And I speak the way that I've always been spoken to, even prior to school. So I don't understand how the way I spoke or speak defines who I am racially.

CHERYL: Mmhmm.

JACKIE: It doesn't equate to me, and I don't understand how we, or how cultures or how different races, can look at a person's dress and say, like if I see an Indian person--Eastern Indian person--in Western type clothing, the Western type clothing doesn't make them any less Eastern Indian to me. It's just a person, a Hindu or whatever, that's wearing Western clothing. Yeah, if I dress hip hop, does that make me any more Black than just putting on a regular shirt and jeans?

CHERYL: [chuckles] No, it's a really good question. And I think the same is true also for being on the spectrum or having a traumatic brain injury or lots of different kinds of things that may be impairments or may be called disabilities is that people tell me all the time I don't have a brain injury. And I think well, I kinda remember getting it, actually!

JACKIE: Right.

CHERYL: But I don't act the way they think I should act with a brain injury.

JACKIE: Exactly. And that's the whole thing that again, if you mention a diagnosis, there's typically a preconceived notion of what you're supposed to be within that diagnosis based on a limited amount of information. Human beings are creatures of habit. Typically, we project what we have been exposed to throughout life. And if we've been exposed to a very narrow way of thinking or a very narrow band of information, then that narrow band of information is what we are going to project.

CHERYL: Mmhmm. So what are some of the things that you think people automatically expect when let's say somebody knew you had Asperger's before they met you. What are the things that you think, like the stereotypical things, they're gonna expect you to say or act like?

JACKIE: They're going to look for a mild speech impediment. They're going to look for--like in my facial expressions--they're gonna look for more of expressionless expressions, if you will. They don't expect you to smile big, or they expect you to go overboard, but nothing in between. My movements, they would expect my movements to be more robotic, that sort of thing. Perhaps I would not speak fluently in terms of if you ask me a question, then I just answer a question. Yes, there are times that I have to think about it. I tend to be a little bit more on the chatty side. So oftentimes, I just blurt out answers, and then I think about them after the fact and wish I'd said something different.

CHERYL: [laughs] Me too.

JACKIE: Basically. But I have been told these things. It's like, "Oh, your speech is this. I was expecting it to be more like that." Or "You smiled." And I'm like, "Yes, I can smile." You know? So it's things like that. It's very, I don't know, it's almost as if, and even though I tell them it's mild, I'm very mild in terms of my diagnosis, it's still, it's almost as if because I have this diagnosis, that any ability I have has to be kind of dummed down to a "lower level."

CHERYL: Yeah, and I'm trying to imagine all the people in the world with Asperger's, that how could they possibly all fit into that list of descriptions you just gave?

JACKIE: Exactly.

CHERYL: It doesn't make any sense that everyone would fit in.

JACKIE: Well, of course it doesn't make sense, especially when you talk about it being a spectrum disorder. I don't know if people understand how big a spectrum can be. Because when they talk about spectrum disorders, I see a very narrow spectrum within the research of Autism. It's like you've got to fit into this mold in order to be considered on the spectrum in one branch of research. And then, in another branch of research, it's like oh, hey, look. Guess what. They can think, and they can feel. And then another branch is, oh wow, look. They can get married and have children and raise families. I mean, it's just like it's almost as if when people study people on the spectrum, it's like they are just amazed that we are people.

CHERYL: Wow.

Autism research not including Autistic people and getting diagnosed

CHERYL: Do you feel like research or work around the Autism spectrum actually includes people on the spectrum in positions where they're actually running the research or producing this information?

JACKIE: No. No, I think if that does happen, I think it's very rare. I think what it is is that you have a lot of people on the outside of the spectrum looking in at the spectrum trying to unravel the spectrum. But they don't want to talk to anyone who's actually on the spectrum because we don't know what we're talking about, is what I think.

CHERYL: Mmhmm.

JACKIE: I feel like our opinions are not valued. And I feel like if we are on the spectrum, but we are capable of really communicating what we feel, that we are dismissed because we must not be on the spectrum enough.

CHERYL: Just like you're not Black enough.

JACKIE: Right.

CHERYL: You're not on the spectrum enough.

JACKIE: I'm not on the spectrum enough.

CHERYL: Uh-huh. Or I hear that I obviously didn't really get a real brain injury cuz I'm not that impaired.

JACKIE: Exactly. Oh, you just had a tap on your noggin, basically.

CHERYL: [chuckles] Right.

JACKIE: Yeah.

CHERYL: Right. Or if I, I have testing from the neuropsychologists that proves, at least, well, let me back up. It doesn't prove anything. But I certainly have testing from the neuropsychologists and different kinds of testing from different experts that show the impairments. But I forgot what I was gonna say. Never mind [laughs].

JACKIE: But I know where you're going from cuz I'm thinking about when I went through the process. And I actually went to a person who was a behavioral specialist, a person who specialized in spectrum behavior all across the board. So from the very minute to the more severe. And this person took me through grueling tests. It was this massive written test. And I had to come back several days to do things that, and I didn't know exactly what to expect any day. I didn't know what was being tested or whatever. You just, I mean, it's not clear. It's not like they come and say, "OK, we're gonna test you for this behavior, that behavior, or whatever." You just come in and just do whatever they say. And you don't know what they're looking at. But it doesn't really matter because if you have any of the behaviors, they'll see it. And if you don't, you don't.

CHERYL: Mmhmm. That does sound grueling.

JACKIE: It is grueling, but it was necessary. And the whole thing was, like many Aspies, especially my age--I'm 48 and a mom--and I've talked to other women who have gotten late diagnosis. And it all kind of stems from one thing: either there was a series of questions that we had from our past as to why we were treated in certain ways, or the biggest tie is our children. We see our children, and our children remind us of us.

CHERYL: Mmhmm.

JACKIE: Even if it's something that we don't do now, they may remind us of what we were like when we were kids. And then we begin to question ourselves. Yeah, and then sometimes if you're brave enough, you may actually branch out and go for an assessment.

CHERYL: Uh-huh. You got a formal diagnosis later in your life, not as a child.

JACKIE: That's right, because as a child who knew of Asperger's? I'm 48 years old.

CHERYL: That's right. Mmhmm.

JACKIE: Right, so it would've been impossible for me to get a diagnosis, especially also being Black, you know. Cuz you have to think about it: when I think about, when I look at Darrel Hannah, and I read an article that she was diagnosed as a child. And Darrel Hannah, I think, is about my age if not a couple years older. And I thought to myself, gee, that's kind of odd because the word "Asperger's" was not really well known at all. As a matter of fact, when she was very young, the research done on Asperger's wasn't even translated into the English language yet.

CHERYL: Oh!

JACKIE: It wasn't even translated into the English language until she was old enough to be a young adult. So unless her parents, you know, maybe she came from an affluent background. Or perhaps, if you

come from a affluent background, maybe she went out of the country to get assessed or something like that. I would see, then, how she could get a diagnosis of Asperger's specifically as a child. Other than that, I don't understand how she would've gotten that diagnosis prior to the age of say 18, 20 years old.

CHERYL: Mmhmm. I wonder, is it possible she maybe had a mild Autism diagnosis, and then later changed?

JACKIE: If so, then she should have stated that, or that should've been stated in the article. But it wasn't stated that way. It was stated that she had an Autism diagnosis. She was diagnosed as a child.

CHERYL: Mmhmm.

JACKIE: Which again, like I said, I find that most interesting because when I look at my information, here we go: Asperger's became a distinct diagnosis in the United States of America in 1992. The original papers were translated from I believe it was German to English in 1991. It actually became a diagnosis in the DSM in 1994.

CHERYL: Huh.

JACKIE: So that's why I said in this country, I'm not understanding how you could get a childhood diagnosis of Asperger's prior to 1992 unless they went out of the country. Perhaps they emigrated. And I can't say because the article did not specify how she got her diagnosis, exactly when. It just said "as a child."

CHERYL: Right.

Race, class, and diagnosis disparity

CHERYL: Now, one thing you mentioned--you mentioned two things--when you were talking about Darrel Hannah. You mentioned race, and you mentioned class and what those two things, the roles those two things might play in who gets a diagnosis and when they get a diagnosis.

JACKIE: Well, I'll just put it this way: research has shown that typically non-white children and children of any other ethnic background other than white, especially African-American, get diagnosed later than most white children or Caucasian children. Caucasian children typically get diagnosed I'd say anywhere between 18 months to 2 years, 2 1/2 years, whereas if you look at diagnosis for African-American children or children of other ethnic backgrounds, it's typically maybe 3 1/2 years to 8 years before a diagnosis of Autism is given. Largely in African-American populations, the diagnosis of ADHD or ADD are given. And there's a lot of things that are very similar to Autism.

CHERYL: Mmhmm.

JACKIE: Mmhmm.

CHERYL: And I know that within--I don't know about all non-white communities--but certainly within the Black community, I know that people are given diagnoses of mental illnesses and behavioral disorders at a huge rate compared to the white population.

JACKIE: Exactly, exactly.

CHERYL: And that may have nothing to do with disability at all. That may be purely around race and class and misinterpreting people's communication and expression and misinterpreting a whole lotta things.

JACKIE: Exactly. Well, my experience, let me give you a little information about me. I was raised in a "middle class" environment and remained in that until having my son, and I was kind of talked out of that when my husband left, and I ended up being in more of a low income situation because I couldn't work for a while. I had my son very early, and I stopped working to stay home and take care of him. So that was my first real taste of being "low income." And I saw that the treatment, the difference in treatment between being considered middle class and being considered low income was vastly different. And I had constant reminders. One thing, when my son was in the hospital as a preemie--he was born at 27 weeks--one day, actually, and he spent three months in the NICU. And I would talk to the doctors. I spoke with them frequently. I was at the NICU every day, and if I wasn't at the NICU, I called every hour on the hour. One of the things that one of the doctors told me, one of the leading doctors, was that he was gonna tell me something. I told him, "Tell me exactly everything that's going on with my son. Do not worry about what I can or cannot understand. I will tell you if I don't understand you."

CHERYL: Mmhmm.

JACKIE: When I said that to him, he had this huge sigh of relief and said, "OK. I'm gonna tell you everything. But I'm gonna tell you, usually we don't tell parents everything." And I'm just gonna use "parents" loosely because he didn't really specify race. But it was kinda like understood in the conversation, the way that he looked at me. So he said, "I don't usually tell parents everything because I don't have the time to explain it. And usually, they're not gonna understand what I'm saying anyway. So I just tell them, a lotta times we don't tell them everything." And I thought that was very interesting, that you would assume, you could look at a parent and assume that they're not gonna understand you. You're not going to try to explain anything. You're just going to tell them something or a little bit of what's happening with the child and leave everything else a mystery.

CHERYL: Wow. Even though it's your child.

JACKIE: Even though it's your child. But they don't have the time. In essence, they don't have the time to sit down and hold your hand and teach you the language. So they just tell you a little bit of something. They don't like, really, talking in laymen's terms. If they can use the regular, medical terminology, they're more comfortable with that. So I mean, this is my understanding of that exchange.

CHERYL: Uh-huh.

JACKIE: And I've thought about it over the years. My child is now 14. I still think about that exchange, and I think about it a lot just to make sure that I'm right about what happened. But it just seemed to be, it seemed to kind of follow us along the way even up into my trying to get--I noticed that my son starting changing at 2 1/2, even though he was already diagnosed globally developmentally delayed based on the fact that he was so very premature, he lost a third of his gut when he was a week old. So he was failure to thrive because he didn't have enough gut to absorb his food properly. So he had to eat by mouth and NG tube. It took so much work to get my child to gain even an ounce, let alone a pound. So we went through a lot with that, which of course, affected him neurologically because of the amount of nutrients that was getting into his body. It was more going to his head than his body. And he was not yet at the age of one year, he was 11 pounds and could not sit up by himself.

CHERYL: Oh, tiny.

JACKIE: He was very tiny. Language did come in. It was slow, but he did have language. He had language, but he was not able to walk, but he could crawl. He crawled later in life. He crawled after he was a year old. He started walking around 2 1/2. But as soon as he started walking, his language went away. Everything changed. It was like just as I was, my child was like really coming up and doing. Then all of a sudden, it was like my child went away.

CHERYL: Wow.

JACKIE: And the words that he had, he never said anymore. He stopped looking at people in the eyes. He stopped responding to me when I called his name. Everything stopped. And so I looked it up. I didn't know what was happening. I didn't know what to call it. So I just put the traits that I noticed into the computer, into Google, actually, and Autism popped up on my screen. And that was how I learned about it. And I read this list of traits. And they had 10 common traits. My son had, he was exhibiting eight of the 10 traits.

CHERYL: Uh-huh.

JACKIE: So I took that information to the pediatrician and told him about it. The pediatrician said he didn't see Autism with my son. OK. So then I went to every entity in the town where I live to get my child assessed. And everywhere I went, I was told--after I gave them a whole spiel and the whole history and everything--I was told my son could not be Autistic because he could interact with me and because he blew a kiss to me from across the room and because he stayed engaged with a stranger who was playing toys with him. And then, so I went on to further say, well, as soon as I saw what I saw in my computer and read everything I could read on Autism, I started working with my son to combat this thing called Autism, while I'm trying to get him assessed. So in the meantime, I'm playing games with him to teach him how to look at my face. He doesn't have to look in my eyes, but he needed to learn to look at my face so he could learn facial expressions. I had to work with him to get him to respond to me when I called his name. I had to work with him on getting him to utter a word or a part of a word. And I'm doing all of this. And so when I explained this to the therapist that was assessing my son, she turns to me, and she says, "Well, maybe you shot yourself in the foot by doing so much."

CHERYL: Mm!

JACKIE: "Maybe that's why he's not gonna get the diagnosis of Autism," is what she said.

CHERYL: What a process!

JACKIE: Right.

CHERYL: I don't even know how to respond to that story. Oh my gosh.

JACKIE: Yeah.

CHERYL: That's amazing to me.

JACKIE: Yeah.

CHERYL: And talk about rigid [chuckles].

JACKIE: Exactly. And so how I ended up getting the diagnosis: I kept going to everyone I could go to, and I finally came to a psychologist who was willing to see my son and assess him. She assessed him for multiple days. I filled out all kinds of information. She confirmed that information with his pediatrician and his physical therapist (PT), everything. She confirmed everything and came to the conclusion that my son was indeed Autistic.

CHERYL: Just for information, what is the value of getting the diagnosis?

JACKIE: The value was getting the label on paper so that I could tap into the resources to help my son. Because if he doesn't have that diagnosis, he's not gonna be able to get the resources. Autism is like an exclusive club. You don't get Autism treatment until you have the formal diagnosis.

CHERYL: Mmhmm. In your experiences, are the Autism treatments that are available, that you and your son have tried, do those seem to be very racially-based or class-based, or are they kind of universal for kids?

JACKIE: OK, well, this is the difference, I think, in terms of what resources you tap into, what you can afford, what you're privy to in terms of knowledge. If you take a situation where a person doesn't feel-- and how do I put this--held back by certain things like their socio-economic situation. And I say that because in this culture, if you come from a "low income" situation, as I have been in and have experienced, the assumption is that you do not have nor are you interested in tapping into these resources. When they look at your socio-economic background, they lump your education. You can't possibly have--I'm saying based on what society has shown me--you cannot possibly have or aspire to obtain higher education if you are comfortable or in this level of living.

CHERYL: Mmhmm.

JACKIE: OK? But if you, say, are not in low income, say maybe if you're working class or above, anything above that, then perhaps you may be privy to some things like perhaps you actually go to a library, or perhaps you would have a computer in your home. This was before all the cell phone range. You don't have to have a computer in your home anymore; all you need is a device, and you have instant access to the internet. But at this time, devices were not popular. So most of the time, it was a matter of having a laptop or a table top in your home or having access to that by way of library or school or whatever. So they look at it, the more education you have, then the more likely you may tap into information. Whereas, if you maybe just only had high school or maybe didn't finish high school, and you come from a lower income background, it was "assumed" that you may not have access to these things.

CHERYL: Mmhmm. When people see you or know about your race, do they make an assumption about how much education you have and how much access to things like the internet that you have?

JACKIE: Typically, if someone has not seen me, if they've only spoken to me on the phone, a lot of times--and I've been told, and I don't really quite get this, but--I've been told I have a universal sound, which means I could sound like I could be from anywhere, more or less, because I do not have a distinct ethnic pattern of speech, according to them, or I do not sound in a particular way, according to them. Or people might say they liken it to, "You have the voice of a newscaster. You have a very plain, ordinary way of talking that could span across any race or culture." So if they're talking to me, they will speak to me one way on the phone. And then, once they see me, they will speak to me differently once they've actually seen me.

CHERYL: So you get that both around race and around Asperger's.

JACKIE: Yes.

CHERYL: That people will change the way they communicate with you once they find out this information, these different qualities about, these different parts of you.

JACKIE: Exactly.

CHERYL: They'll just change their demeanor around you.

JACKIE: Exactly. And in some case--not in all cases, of course, but in some cases--yes.

CHERYL: I mean, I get it. But I don't get it. I don't get what that is.

JACKIE: Because it shouldn't matter, but it does matter.

CHERYL: Yeah. I'm sorry. It just infuriates me. It infuriates me.

JACKIE: Yes.

CHERYL: Humans are humans.

JACKIE: Humans are humans.

CHERYL: There is not value, there is not benefit to behaving that way and to lumping people together and deciding this lump is valuable, and that lump is not valuable.

JACKIE: Right.

CHERYL: Why is it so hard? Why are we, as a culture, so resistant to changing our views around race and class and discrimination? Why is it that we, as a culture, love discrimination so much?

JACKIE: Well, I ask myself that all the time. But whenever I ask myself about culture or human nature, I always take it back to the beginning. In the beginning, if you looked at this land and the Indigenous beings that were here, they had their own set up and hierarchy and everything. But basically, it was about keeping the territory and maintaining your strength within your grouping. And you had the different groupings, which were defined by whatever the defining things were for those groups. And then you have this outside group coming in, OK. Because these groups, they had hierarchy. I don't think it was a matter of my group is better than your group because my group has more of this or that, other than maybe some land or something. But it's more like a hierarchy as you have your king, and then you have your people that work closely with the king, and then you have your general people, and blah blah blah. OK? So you have another grouping of people come in. And this grouping of people may have been considered the outcasts. They came from a social situation where the hierarchy was you had these high people too that were the untouchables. They got the best of everything, and everybody else got nothing. And then you go to another land, and you're building a society based on that. You're basing it on hierarchy. So now that you're in this land, you become, you have put yourself in the hierarchical position. And everybody else just gets whatever you decide they get. And I feel like that's what this country's been built on, because that's the way our society functions. You have the Haves and the Have

Nots. You have the ones who feel that they are privy to have, and they get. And then it trickles down, and it trickles down based on however they decide it trickles.

CHERYL: Uh-huh.

JACKIE: Does that make sense?

CHERYL: It does make sense. And there's a myth that everything will eventually trickle down, and everyone will get their fair share. But it doesn't, it doesn't.

JACKIE: No, there's no such thing a fair share.

CHERYL: Trickle down doesn't actually work.

JACKIE: No, cuz it has to move laterally, not down. I mean, even common sense: if a drop of water hits a ledge, and it starts to roll downward, that drop of water gets thinner and thinner and thinner unless it's bumping into more water and collecting and growing bigger along the way. Otherwise, it's just getting smaller. So when you're going down with a trickle-down theory, you're leaving something behind. And then, whatever hits the bottom is just a remnant of what was at the beginning.

CHERYL: That's a beautiful way to bring that metaphor to life.

JACKIE: You have to have something for it to build on. If there's nothing to build on, then it's just gonna dissolve.

CHERYL: Mmhmm.

JACKIE: I think what I find to be so damning, if I'm allowed to say such a word, is that it doesn't have to be this way. It is this society's choice to be this way and to uphold this. Even though it doesn't work, even though it's unfair, there's no willingness for change. And that's the part that I find very heart-wrenching in terms of dealing with human nature, humanity, and society, and all that other thing, is that there's no willingness to change. And I find it absolutely mind-blowing that now that we are in a time where we have more information than we could ever take in in a lifetime at the tip of our fingers, that we are still such an ignorant, ignorant grouping of people. You know, we such an ignorant group. How can we not know, if we want to know? That's the whole defining difference. If you want to know something in this time, it's just a matter of pressing a button. If you don't wanna know, if you don't feel affected by, if you don't care, is the only reason I can really say that you don't know. Because, if you wanna know, it's there.

CHERYL: Mmhmm.

JACKIE: And you have to feel like you can obtain it, whatever the information is.

CHERYL: Right, right.

JACKIE: Be it Autism, be it brain injuries, be it anything, if you wanna know.

Getting to know something about disability and culture

JACKIE: When we talked the other day, I knew some information about brain injuries because I have a couple close relatives that have had brain injuries, and I know what it's like for them personally. But I

hadn't really looked into "brain injuries," and I started reading up on it and looking into everything. And I learned so much about it because I find learning about people and learning about different cultures is fascinating to me.

CHERYL: Yeah.

JACKIE: And so now I feel like I know a little bit more, and I feel like I can talk to a person who sustained a brain injury. Or I can be able to communicate better because I know that you may forget something in the middle of a statement, and it's OK.

CHERYL: Right.

JACKIE: We all forget at times. Yeah, it's OK. It's no big deal. Either I'll try to help you remember, or we'll find something else to talk about.

CHERYL: Right, right. That's exciting. I didn't know you had gone out and looked up brain injury. That's really cool. And when you said "culture," you reminded me of--So this morning I was looking at one of your blog posts on neurodiversity. And there was a link to an article about Autism culture. And I just ate it up. I loved it! It's very exciting to me when I read things or talk to people or hear about things that are related to we'll say a disability or a diagnosis, and they use the word "culture." Because when you've got that word, "culture," then you've got, I believe, then you've got pride.

JACKIE: You do. And tangibility.

CHERYL: Yes. And I would love to hear, if you wanna share stories or ideas you have around Autism culture or a culture around the spectrum.

JACKIE: Well, I've always felt from my limited knowledge prior to even having a son and anything, I've always felt what little bit I've known about Autism, I've always viewed Autism as kind of a like, I see it kind of like a little club. This is this cool grouping of people that they seem to be a mystery to many except to themselves. And what I find most fascinating about this grouping of people is the way they think. [Son yells in the background.] Hunter, thank you. Please. That's my son in the background.

CHERYL: Yeah, I heard him.

JACKIE: He's watching a very riveting movie. So I find that when I watched this grouping of people, I was fascinated because of the movement of this group. The sense that I saw in this group of people, how their senses work, how they react to regular stimuli, how they communicate with each other, things that bother them, how people react to them: it was like a world within a world to me. So I had a sense of seeing a culture present before the terminology ever came about. Because in all cultures, cultures move--to me, in my way of thinking--in a globular kind of effect. You have a grouping of people that are kind of adhered to each other based on how they react or how they perceive or what their general ideal of what things are. And they move in that collectively, which creates culture. And then you have cultural differentials, of course, as they spread out and learn and absorb things from other cultures. But it always comes back to the root, and it always brings them back to that home culture. Well, Autism is pretty much the same thing. When you're born with Autism, you come into the world. You don't really know that you're different. You don't know that you're different until somebody tells you you're different. But as you get around people, and that's a fact. I think it's such an interesting question. When people ask me like, "Well, what led you to believe or what showed you that were different or you had Autism or you had Asperger's or whatever? Or how did you know or when did you realize?" Well, I realized something

was different based on how people treated me. If they treated me one way and treated my cousins, let's say, a different way, then I wanted to know what caused the difference. You know, that kind of thing. So anyway, getting back to the cultural aspect of it. So when you look at Autism, or when you look at say maybe a grouping of people like not just people with head injuries, but let's get even larger and say people that are wheelchair bound, that is a culture. It's a culture because you move, the defining things that have you moving are how you function in your wheelchair. Your wheelchair becomes a part of you like an extremity. And that wheelchair, even though it's nuts and bolts, actually it's almost like it becomes flesh when you're in it because you have to learn how to navigate, and it has to get you around and do things. And there's an understanding of height and width and need and access that someone who's not in a wheelchair wouldn't understand.

CHERYL: Right.

JACKIE: So that creates a culture. You have a cultural movement of people who are wheelchair-bound. So the same premise goes for people who are on the spectrum. Even though it's not the same, we have some general things that link us. And within those general links, we have built a culture. And our culture is based on our neurodiversity. And that's what sets us kind of apart from other people, is our neurodiversity. We're very different in that.

CHERYL: Mmhmm.

JACKIE: So we're told.

CHERYL: So you're told, yes.

JACKIE: And I say that because, like I said, I see people being anti-social all the time that are "not on the spectrum."

CHERYL: Mmhmm. And for various, various reasons that change all the time. There are a lot of reasons and individual person might not say hi to someone who walks in the room. But we don't try to label them unless we know you have a diagnosis, and then we'll label it.

JACKIE: Exactly, exactly.

Autism and the medical model

CHERYL: And this article that I was looking at this morning sort of made a binary. It said there's the medical model, which says Autism comes with symptoms. And then there's the cultural model, which says Autistic people or people with Autism have certain traits that may be in common or that we can share. I don't know. To you, is it helpful to sort of break it up into those two ways of looking at it? Or do you think there's more ways?

JACKIE: I think there's always more ways because what we're looking at when we're looking at those two subsets is simply a group of people's perception of what they're seeing. And they just happen to write it in books or put it in papers and put it out there to the universe. Any person can look at a group of people and see something different if we choose to. We can either look and say, "Let me look at this with my own eyes and determine what I'm seeing," or we look at a group of people, and we see what we know in terms of knowledge of what we've read or what we've heard. So I think, to answer your question, yes, there's multiple ways that you can look at this. And yes, I do think it's helpful to look at it

in the two subsets that you talked about. But I also think that you learn those subsets, and then you expound on them. Don't just stop at them.

CHERYL: Yeah, yeah. And one of the things that's difficult to get that perspective out is that when you have groups--let's say like Autism Speaks--that have a lot of money and a lot of airtime and a logo that everybody recognizes--that little puzzle piece--they have sort of one main perspective that they deal with. And then, if somebody doesn't, say, meet you or meet someone else on the spectrum and get to know them and get to hear information from the inside, then a lot of people can easily start to believe that a group like Autism Speaks is telling the whole story and giving you all the information you could get.

JACKIE: That's right, and I've found that to be a truth in what you're stating, because when I talk to my friends that are less familiar, and all they ever hear is Autism Speaks. I don't think--even though there are hundreds and thousands of other organizations, they're all eclipsed by Autism Speaks. When my neurotypical friends talk about Autism Speaks, they talk to me, and to them that's just like the best thing since sliced bread: Oh, you've got this great Autism Speaks. And I say, "Yes, we do. But I have a problem with the organization because I don't see representation of people on the spectrum within the organization. I do not see employees or hear of employees that are on the spectrum or have children on the spectrum. I have not heard of any Board members being on the spectrum or having children on the spectrum." When I look at organizations like The Arc, when I call them, they are largely made up of people that either are on the spectrum or have disabilities of some sort or have children that have disabilities. So they live and breathe and not just work in this environment, whereas when I speak to someone at Autism Speaks, their knowledge is very limited. It's really more rhetoric from research as opposed to from experience. And that is a severe lacking. And then, when they talk to someone like me, they get excited that you know, oh, I'm talking to someone who has a diagnosis of Asperger's and whatever else. But if I don't say or speak their language the way they want to hear it, then they are less inclined to want to hear me, I find, in my experience.

CHERYL: Mm. Because you won't be a good token for them or diversity for them.

JACKIE: No, not me. No, not by any means. And I'm not one who's going to lend myself to fill their heads with knowledge and then be dismissed.

CHERYL: Mmhmm.

JACKIE: Because I think that's not good either.

CHERYL: No, no. And if, as an organization, if they wanted your perspective and your information and your knowledge, then they would also want the perspectives and opinions of a lot of people on the spectrum and would give positions of leadership and power to people who were on the spectrum.

JACKIE: Exactly, exactly.

CHERYL: They wouldn't ask only one person for some talking points.

JACKIE: Or a couple people, yeah. And basically what they do is they don't really ask. They offer you some information, some community forum of some such thing, and oh, you can get in contact with this person that's in your general area and talk to them. But still, you're not involved in the deeper levels of Autism Speaks; you're on the very outer crust where you're stay until you flake off like dead skin.

CHERYL: Mm. It's painful. But I think it's something that you and I talked about before where, when you talked about people from Europe moving to this continent, they weren't the cream of the crop. They were the bottom.

JACKIE: No, they weren't.

CHERYL: They were the bottom of the barrel who came here.

JACKIE: Exactly.

CHERYL: And they brought with them their experience of being on the bottom of the barrel. And they said, "No more. I'm gonna put someone else on the bottom of the barrel cuz I don't wanna be there anymore. That's why I came here."

JACKIE: And that's why they're so good at it.

CHERYL: Yeah, they got to experience it first hand and then turn around and put it on someone else. And I think, well shoot. Now I don't know where I was going with that. Sometimes I get really hung up when people use analogies and metaphors because I get so into the imagery that I forget the real thing that it was referring to. And it doesn't matter. I think I was just trying to recap something you had already said.

JACKIE: I get it cuz I did too. Cuz my thoughts move faster than my mouth, is what I say.

CHERYL: Yeah! Mmhmm.

JACKIE: And I think of things, and my mind is going 1000 miles a minute. And I've got all this information coming in, and then I'm trying to get this point. But then I've got so much information that I wanna share. By the time I start sharing that, I've lost my point.

CHERYL: Yes!

JACKIE: And then I lose the information.

CHERYL: Right.

JACKIE: Yeah, I get it.

CHERYL: [chuckling] OK, good.

JACKIE: [chuckles]

Blogging and poetry for self-expression

CHERYL: When you say that, it makes--I wanna ask you a question about, you have several different blogs that you keep. And I was thinking well, gosh, is that what's behind having several different blogs? Would you tell us about the different blogs that you keep and why?

JACKIE: OK. Well, I do have several blogs. I have two blogs that have the same name but two different purposes: Autisms Love. One is [Autisms Love: A Voice From the Spectrum](#). And the other one is [Autisms Love: Living, Learning, and Coping on the Spectrum](#) kinda thing. The Voice From the Spectrum is more kind of the poetic side to my Aspieness and how I kind of see things, just my perspective on some things as an Aspie, whereas the Autisms Love: Living, Learning, and Coping is more about teaching, working

with my son on some things or maybe talking about neurodiversity, which I really wanna get more into on that blog. But the reason I have several blogs and also have a Mentalizations blog, which is another artsy side of me--the reason I have so many different blogs, it's because it's hard for me to generalize a specific direction because I do feel like I have all this information coming from so many different ports inside my brain. And I don't know, I have it all labeled and categorized in my brain. But when it comes to putting it on paper and putting out where someone can read it, it's very difficult for me to categorize it because I tend to touch on so many different things sometimes. Or I start off talking about one thing, and then I veer off the beaten path and have gone awry in another direction as I tend to do in my communication. So I have all of these different blogs because I feel like I have all of these different facets that I have to somehow make sense of outside of my brain.

CHERYL: I was really enjoying looking at them. And I found the poem that you read to me on the phone the other day.

JACKIE: Yes.

CHERYL: And I like the way you use different fonts for that poem because that helped me distinguish the different voices. Because when you read it, you used the different voices. But the different fonts gave me those different voices back, and I really appreciated that.

JACKIE: You're welcome. That kind of came when I actually hired a couple actors to go with me to the studio because I wanted to bring this poem to life, as I mentioned to you the other day, to possibly use as maybe an installation for a couple art pieces, or maybe even in a PSA about child abuse. So in order to try to communicate to the actors what I wanted, I read the poem for them. But I wanted them to feel or get a sense for the flow, if they could look at it, because I knew that I was gonna mail a copy of these words to them. And just plain words on a flat piece of paper, especially when you're talking about an emotion at that level, you're never gonna pick that up, just looking at regular just black and white piece of paper. So I thought if I read it to them and gave them the different fonts and the colors and then put a little key at the bottom so they knew which font was for which character, then maybe in their mind, as they're practicing, they could find their flow. So that's how that actually all happened. Another form of a bridge of communication, trying to convey something to someone that doesn't know you so they could have somewhat of a clue of what you're trying to convey to the masses.

CHERYL: Mmhmm. I don't like the question why, but tell me about why you write poetry or what role poetry or art has for you.

JACKIE: It all has the same role: it's all communicating. It's all about making sense of what's inside of me and finding some way to purge that information so that my head doesn't explode. So in some ways, it's just about real basic technical information, very dry and droll. In other ways, information comes out more vibrant, vivacious even, which is more the form of poetry, with more fluidity and movement in those thoughts, as opposed to just sharing general information or fact. So I use these different things. And the same thing with my art: the art is another form of expression. It's a story that wants to be told. And even though I can't even begin to tell you what the story is when I sit down with the paper, the story kind of reveals itself, and I'm just the one who gets to bring it to life on the paper. But the story tells me when it's finished. I don't tell it.

CHERYL: I was gonna ask if you exhibit your art publicly, or is your art on your blog?

JACKIE: Not yet, not yet.

CHERYL: Did I miss it?

JACKIE: It's very hard because I'm very funny about--It's very personal. And that's on my blogs, actually I was about to write to you today to thank you for looking at my blog. I wanted to show you my appreciation and tell you how elated I was and how scared I was too because it's one thing when a complete stranger reads your work, and they know nothing about you, and they do not communicate with you even though you're communicating with them. And it's another thing to actually talk to a person or actually know a person, and they read your words, and they connect those words to what they know of you or what they sense from you. And it's such a very private exchange. And it's kind of daunting to pour that out of yourself and to offer that to someone to partake of.

CHERYL: Mm.

JACKIE: And so it's a necessary thing, but it can also be a very painful process too.

CHERYL: Oh.

JACKIE: I love when I'm able to purge thoughts. But I don't necessarily like the process of purging.

CHERYL: Oh! That is fascinating. You know, it's so, I mean I never would've thought of what you just said because most of the connecting I do with people is through technology. I mean, I will talk to people face to face, and I will often have a good time with it. But I really prefer to be connecting to people through a computer. And the phone is fine. I'm happy to use the phone. But I prefer writing and reading to communicate with people, whether that's a long email or whether that's a short thing on Facebook. But since I've become a blogger, I've started loving reading other people's blogs. And I feel like I connect to them so much through blogs. But I've never stopped to think about that difference between putting your blog out there for the anonymous anyone, individuals or masses to find, versus someone who you're also connecting with personally because I just always feel like no matter whose blog I read, I feel like there's an instant, complete personal connection.

JACKIE: And there is.

CHERYL: I never think about that sort of anonymous thing.

JACKIE: Yeah, because the anonymous aspect of it is a safety net. That's why communicating through technology is vital. I mean, it's crazy because you have that safety net. You can be anything you want to be, say anything you want to say and still be able to keep people at a distance.

CHERYL: For whatever reason, it eliminates the distance for me.

JACKIE: Because you're open. But see, that's the thing. You get to set that. It's just like me telling a friend of mine some time ago, she has some difficulty with dealing with people in her personal space. So I told her to picture herself as the planet Saturn or Saturn-like. And all of these rings around her are levels of relationships, ok? And she is the nucleus; she's the actual planet. Well, when people come, they come to your planet, they hit that outer ring first. You keep everybody at the outer ring. And then, as you deal with the people, based on what you learn of them, the knowledge of them kind of causes them to filter through. So as you bring people closer to you, in the closer rings, they're going through a filtration process. You're choosing. If you feel more comfortable and more open and receptive to people through that means, then you are more open and ready and available to have that kind of very open and honest exchange, whereas some people use that means, as like say in gaming rooms, as a cloaking device. It

cloaks and masks who they really are, and they can take on another persona and be something else or someone else.

CHERYL: Mm, mmhmm.

JACKIE: It all depends on how you choose to use it.

CHERYL: Yeah, I do forget that. I do forget that people are using the computer and using the internet and all these different sites as a cloaking device.

JACKIE: Right.

CHERYL: I just always assume this is what is allowing people to be more open and honest.

JACKIE: No, people tend to lie more.

Online gaming and connecting to people

JACKIE: I like to play games. One of my favorite gaming rooms, I like playing games in Pogo.com because they have a large variety of games. But what I find most interesting--and I call it Pogoville because again, it's like a sub-set of humanity, OK? You go into this gaming room, you're given this little picture of a person, and you can design that person to either look like you or not look like you. You can dress this person, give them all kinds of hair, you can add family members, pets, you can change backgrounds, whatever, OK? When you're in Pogo, this is what people see of you. They can go and read whatever you put into your bio. But what they see when you're gaming, is they either see your badge--covers that you win from games--or they see this caricature of you that you've created. And I find that the exchange with people based on what they see in this caricature is absolutely fascinating. I got approached by a person in Pogo, and he liked my caricature. And he mentioned something to the fact that he liked how I liked, and he gave me this gift outfit for my caricature. It was like a red leather biker chick kinda thing.

CHERYL: [chuckles]

JACKIE: And I thought to myself how odd that he would say, "This would look good on you" as if it was a piece of clothing that I was actually going to wear on my person.

CHERYL: Mmhmm.

JACKIE: So when I talked to him, and he said "I thought this would look good on you," I was like, I think that's very strange because you're looking at a cartoon caricature. All of your human senses are responding to a cartoon caricature that's not real.

CHERYL: Uh-huh.

JACKIE: I was like, why are you doing that? And that's just my curiosity, you know being very literal. And he just kinda laughed, did the LOL thing. And he's like, "How odd for you to say that." But my thing is, snap back to reality. This is a gaming room. We're just here to play games. This is not a love fest, sex fest, whatever you're turning this into in your mind. Whatever purpose you're serving, it's not working for me. But I find that these people go in, they go into these gaming rooms for very specific reasons, and that's to live out a fantasy.

CHERYL: Rather than heightening their reality, maybe, yeah.

JACKIE: Right, because my thing is I do my character to depict the fact that yeah, I'm a woman, and I have a child, and I look however I look, and that's it. And we have a dog, and that's what you see [laughs]. And then I play my games.

CHERYL: Uh-huh.

JACKIE: You know, I don't try to--I'm wearing t-shirt and jeans, which is basically what I wear in life all the time. That's just it. But I'm just there to play games, and it's cool if you meet friendly people and you can enjoy playing games together. But this other grouping of people, they actually seek out to have relationships and affairs and different kinds of exchanges, very fantasy-based exchanges.

CHERYL: Uh-huh. I've played games a bunch on Pogo. And I would still play them, but I forgot about Pogo, which is that's the only reason I don't play games there [laughs]. Totally forgot it exists.

JACKIE: [laughs] It drains your brain anyway. It really, it's such a waste of time. But it's a nice distraction when you have some time, or you just wanna take some time to kinda just not have to deal with reality, yeah.

CHERYL: Yeah, yeah, it's great to be able to play games to take a little break from the daily grind, yeah. But then you got people giving you red leather jackets.

JACKIE: Yeah, red leather outfits and things. And then there's a large grouping of people, I also find, that are in the community of "disabilities" that often speak about these things. And a lot of times, when they're home-bound they're or they're less receptive to getting to know people in real life because of...whatever their reason is, and they feel like they can communicate better in these gaming rooms. They tend to spend the majority of their time in these rooms. It's like a real life for them.

CHERYL: Mmhmm. I've heard some criticisms outside the disability community of people who say, "Anybody, anybody, anybody who spends a lot of time online is not living. Those are not real relationships, and those are lesser forms of relationships than what you get in real life. People need to learn how to get out and do things." And I find that that can be--it's not always, but it can be--very ableist because some people can't get out of the house for various reasons. I have a friend whose wheelchair broke. Well, how's he gonna get out of the house when his wheelchair's broken? So don't tell him he should be outta the house unless you're gonna go buy him a new wheelchair.

JACKIE: Exactly.

CHERYL: But then there are also different emotional reasons that somebody's not leaving the house. And with or without a disability, there's always the chance that you might overdo something, to make a choice that has a negative impact on you. But I think to say that across the board, everyone who socializes and interacts online as their primary interaction, to say that they're not fulfilling human potential as much as other people, it's very ableist. I used to have more face to face interaction with people than I do now. But since the bike wreck in 2010, I have more interactions through the computer or the phone than I do face to face. And I don't think I like people telling me that I'm now having lesser forms of communication. That feels bad.

JACKIE: Well, again, it's based on that narrow perception. Remember I was telling you that limited thing that we're exposed to coming up, growing up, and carry that into the latter years of our life, it always goes back to the beginning. If we are less receptive to being open minded about communication, if we

think that communication has to, as we see in therapy and what not, has to fit a format, then we tend to be more comfortable with the format that we're familiar with.

CHERYL: Mmhmm.

JACKIE: Because, if you haven't had the experience, or if you cannot fathom what that experience is like, then you're making a judgment out of ignorance. And my thing is, when you go into these virtual worlds, you go in, and you can have any level of experience from the simply I'm just here just to hang out and play a game for a couple hours and go on, to that virtual world being a lifestyle for you, and you developing very real relationships that are romantic relationships, family-based relationships that may stay within that virtual world. Or you may elect to bring them outside of the virtual world. I've met some lovely people in Pogo and have had long-standing friendships with them on the phone. We haven't met in person because of distance. But we speak frequently, and we know about each other's families and lives and we communicate about things. We talk about child-rearing and pet issues, just like I was talking to my neighbor next door.

CHERYL: Mmhmm.

JACKIE: In any facet of life, in any aspect of any life, regardless to whatever limitations you may have, it's all up to you what you choose to do with what you're able to do and what your perception of it is in the end.

CHERYL: Mmhmm.

JACKIE: There's no right way or wrong way. There's no one size fits all.

CHERYL: Right, right. And that's that very open-minded view that OK, that's how you do it. Great [chuckles]. Rather than, no, I don't like the way you're doing it. So it must be wrong [chuckles].

JACKIE: Right. It's like looking at lifestyle choices. People will grumble about people's lifestyle choices. I'm like, their lifestyle choices have nothing to do with you. Then why are you upset? You know?

CHERYL: Uh-huh.

JACKIE: It just doesn't make sense. The only time I get really disgruntled about a choice, if a bad choice is harmful to people or the person who's making the choice.

CHERYL: Mmhmm.

JACKIE: If you're hurting someone, that's a problem. But if you're just making a choice and just living your life, then live your life.

CHERYL: Mmhmm.

JACKIE: Yeah.

CHERYL: Yep, yep. Do you wanna bring up a topic I haven't brought up or expand on something?

JACKIE: I'm not good with open-ended questions.

CHERYL: I hear ya [laughs]!

JACKIE: Right. You have to ask me specifics, cuz if you leave me to my own devices, too much information comes in, and I can't get it out.

CHERYL: Yeah, you know, if you had asked me the question I just asked, you would just hear crickets. I don't know. Yeah, cuz those questions are painful to me when they're really open-ended like that.

JACKIE: Yeah.

CHERYL: I just, I don't think I get a flood of information. I think all the gears just grind to a halt. But I can understand if there's a flood, how do you pick which one you would bring to your mouth to speak about?

JACKIE: Right.

Faith

CHERYL: But we actually touched on everything on that list expect for faith.

JACKIE: Oh!

CHERYL: So do you wanna talk about faith?

JACKIE: I can because my personal faith is what I perceive as what has gotten me through the darkest, most deplorable days of my life. Had I not had some form of faith, I don't really know how I'd be able to really see myself in another day, if that makes sense.

CHERYL: It does.

JACKIE: Because when I talk about my life, my childhood, and all that I went through in my childhood, and it's even more difficult. I have one--that I can remember--I have one living person who witnessed a lot of what happened to me growing up. She's my cousin, and I talk to her about it periodically. And we actually go through those times and relive them together because they were horrifying to both of us. If I did not have a measure of faith or believe in a higher power or believe that things could get better in time, I don't think I would still be here.

CHERYL: Mm.

JACKIE: And I attribute my being here to my having faith or a faith-based life. I attribute it to my being able to handle the trials of having differences and how people treat me in that, and just going through life in general, day by day. I have faith practices that I live by that I feel help me get through my days and to be able to maintain a smile in my day or be able to cry and survive crying in that day. And I don't uphold one practice over another. Generally, when I talk to people, and I talk to people from all walks of life and all kinds of faiths or no faith backgrounds, and I just simply tell people the main thing is to love yourself and to love people and be kind to people, you know? Even if you can't necessarily trust people, just be kind in your interactions with people, and that says a lot. For people that are curious about faith or curious about my faith--and I happen to be Christian, by the way--but I'm not the typical Christian, however you wanna see that. I enjoy going to visit churches. I enjoy studying my Bible with people all over the world. I don't really like going to a building, the same building over and over and over again because I feel like I have kind of encapsulated myself with this small group of people, and I'm just dealing with their perception and their practice, when I feel like faith should be something that can span all across the world. And it should touch all people. When I feel love for myself and people, that means I

feel love for all people, not just people at this particular place. When I share my stories and my testimonies, I share them with all people, not just people at one particular place because I believe that my God is all over. So wherever He goes, I wanna go, you know? And that's just how I live, and that's my choice. But I believe my faith helped me to deal with my son being very, very sick early in his life, you know, have hope that he would overcome that. Because I had doctors that were telling me to give up on him and to let him go.

CHERYL: Oh.

JACKIE: But my faith said hold on because God is giving you something really, really special here and not to give up. And all my life with my son, I've gotten the same thing: never give up. When the professionals tell you to give up, when they tell you "he can't" or "he won't," don't give up. Because they don't have final say. And living that way, believing that and living in that, has shown me you're right. They don't have final say. Everything that they told me that my son could not do, would not do, he does. Because I don't give up. Anytime someone says, "Oh, your son will never be--" I've had people tell me, "Your son will never get potty-trained. If he's not potty-trained by a certain time, just give up. Do what you can for him. Teach him how to change himself and what not and blah blah blah." And I did. My son became potty-trained at the age of 10, not for lack of trying. I tried all kinds of things. But I fault a certain TV psychiatrist, if you will, psychologist--I will not mention his name--whose show I used to watch. And he said when you're potty-training your children, when they have a success, give them a party. I did that. My son looked at me as though I violated him and would not use the potty again.

CHERYL: Oh, wow.

JACKIE: Yes. And I had the confetti and everything.

CHERYL: One size does not fit all.

JACKIE: No, no it does not [chuckles]. It was quite a detriment in my situation. So I literally started potty-training my son as soon as he was two years old and spent eight year working on potty-training him. It finally came down to three months, after those eight years of just being completely and totally beside myself and dealing with an infinite number of diapers. And I just said three months: we're gonna lock ourselves in this house, we're going to potty-training boot camp, and we're not opening up the doors until you are potty-trained. And that's what happened. In three months, he was potty-trained, not fully at first, but to the point where he knew he could wear real underwear, and he knew to get up and go to that bathroom. He might have had a couple mistakes, or he might have not gotten up in the middle of the night. But I knew in time, with prompting, that that would change. And now my child is fully potty-trained. But I was told that he would never be potty-trained. And I had to choose not to give up.

CHERYL: Mmhmm.

JACKIE: So that's what faith means for me. It means stepping outside of the situation, being aware of your situation. Be fully aware of your situation, but to be able to step outside of that and say you know what? There are choices outside of this. There's a life outside of this. There are goals and happiness outside of this. And if I can take this very ugly thing or this very painful thing and use this to help someone else come out of their painful thing, then it's all worthwhile.

CHERYL: Mm, mmhmm. And it's connecting, and it's building community.

JACKIE: Yes.

CHERYL: Mmhmm. What a wonderful conversation! Thank you. Thank you, thank you for talking to me today [giggles].

JACKIE: Thank you. Thank you so much. I enjoyed talking.

Wrap up

CHERYL: Jackie and I talked briefly about some difficulties around Autism Speaks. For more information and perspectives on how some people are troubled by how Autism Speaks represents Autistic people and Autism itself, there are some very nice recent blog posts.

Beth Ryan wrote on her blog Loveexplosions.net a post called [Why why why?](#) on December 4th, 2013.

John Elder Robison, who wrote the book "Look Me In The Eye" shares his perspectives about why he resigned from working with Autism Speaks at jerobison.blogspot.com. The blog post is "[I resign my roles at Autism Speaks](#)" from November, 2013.

[music]

CHERYL: Thanks for joining me for another episode of Stories from the brainreels. Find more handy info on brain injury and disability art and culture on my disability arts blog, WhoAmItoStopIt.com.

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