

## [“Neurodivergent individuals challenge society to question exactly what normalcy is, if it even exists to begin with”](#) –Interview with Gaby from A4A

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Transcribed by Julie Ann Lee

(Theme song - soft piano music)

**Anne:** Gaby received her BA in Biological Anthropology from the University of Toronto and currently has taken some time off to look after ill family members. In addition to contributing to the critically acclaimed anthology *All the Weight of Our Dreams: On Living Racialized Autism*, Gaby is one of the founding members of Autistics For Autistics Ontario, the first provincial autistic self-advocacy group in Ontario and an international affiliate of the Autistic Self Advocacy Network. In addition to being diagnosed autistic in early adulthood, Gaby also holds other identities – such as being multiply neurodivergent and the first in her family to attend university in Canada.

Hi Gaby! Thanks for coming on the show.

**Gaby:** Thanks for having me.

**Anne:** So, your family came here from Central America in the late 1980s and I’m wondering: in your experience, how have autism services and schools been doing in terms of outreach and communication with newcomers?

**Gaby:** First I’ve got to start with my experience, because it’s the one I’m obviously most familiar with, but in short summary, when it was one of my siblings who had gotten a diagnosis of PD-NOS- I mean their labels have changed over the years, but the very last one to finally stick was at the time what was called PD-NOS, so ‘not otherwise specified.’ Basically in lay terms, like ‘we think your sibling’s autistic, we’re just not sure *how* autistic’ --for lack of a better word. And the same thing goes with services and accommodations. We had *no idea* what was out there. Surprisingly, ABA was not offered to us, which I am pretty glad about. But there really was no long-term plan for what my sibling could do after school.

It was always more in the moment, like ‘how do we get so-and-so to know the basic skills’ and from what I’ve heard from a few contacts in the community, things have not changed so much. If anything, things in Special Ed have been stagnant pretty much.

**Anne:** Yeah.

**Gaby:** Very little information, and when it’s available it’s usually gloom and doom, like ‘your child will never do this or be independent or go to university’. Which again is pretty disappointing because I think we can do much better than that.

**Anne:** Mm-hmm. Yeah, and isn’t there a disproportionate number of students of Colour that get tracked into Special Ed, right?

**Gaby:** Yeah. Me and my sibling went to separate schools because their needs were much more complex than mine...and at the time I was undiagnosed. I was never picked up for assessment or anything. But even then, when I was in the so-called normal stream, I saw many kids being isolated from everyone else. At a certain hour every day they would be taken out of the classrooms to go into a separate room. And to me--I mean as a kid--I thought it looked just really weird. It looked almost mysterious, like *where were they going?* And now, again hearing all those stories as an adult and when I hear of abuse incidents or ABA, in retrospect, that's what was happening with these kids.

And yes, I did see a lot of students of Colour. Of course, my sister was also one of them. And even in the so-called normal streams, kids like me who were still struggling in at least one or two subjects, they were kind of subtly telling us 'you're not meant to go into this stream, why don't you try this type of math class or that type of English course? – We don't think you might be able to handle the university style work-load.' So, again, it's like very subtle but if you've experienced it, you would know.

**Anne:** Right. And then the social work system, did your family have interactions with them? Because it seems like a lot of people that get diagnosed in Ontario end up being kind of put into a social work stream.

[4:52]

**Gaby:** It's really interesting to me that I hear of that happening to quite a few families but, again with mine, no- nothing of that sort out there. It was as if we got the most basic services and that was it.

**Anne:** Were there bilingual people available?

**Gaby:** No. Our first language is Spanish, maybe if our first language was French things might have been slightly different cause we do have a French school system as well. But, for another language I don't think that would've been possible, and that also brought up another issue: my parents were encouraged to speak to my sibling only in English because the professionals told them, 'you know if you speak to your child in both languages they're going to be so confused, they're going to fall behind' – and now modern research says that's not the case, and actually that's a huge **advantage** to know more than one language. But that's what my parents were told. And my parents, I don't blame them, they went with what they thought would work at the time. And they saw how I was already struggling in the first place, like I spoke the language, I spoke the language at home first, and I was having difficulty in learning English, and again, I had no ESL help at all whatsoever. So, it seems like we were thrown out there with no assistance whatsoever.

**Anne:** Right. This wasn't really that long ago, when you think about especially for your sister. Right?

**Gaby:** Yeah.

**Anne:** My perception is that not much changes in schools ...and that any change that happens is really, really slow.

**Gaby:** Yep, yeah.

**Anne:** And, as you said, when we were talking before the interview, school staff and social work staff, special education staff – they never really *look* like the people they're supposedly helping. Can you speak more about that as well?

**Gaby:** Yes. I was talking with you beforehand on that. What I've noticed is that in every place that I've gone in to for services, whether it was medical attention, or whether it was an assessment, or even something simple as looking to what's being offered in the community – the social workers, the city workers, anyone who's behind the front desk – did not look like me. Or did not look like any other resident in the neighbourhood that they were supposedly serving.

And I'm not saying that we should hire someone just because, you know just to fill quotas or whatever, but there is a problem for me for when an outsider is coming into this environment and they've never taken time to know the community, they don't know what the community needs, they don't know what other challenges are facing that community, whether it's carding, unemployment, or like lack of available safe spaces for youth – they just look at all of this as just numbers. Like, they don't see the human factor behind all of these issues.

**Anne:** Right. I mean, the social work system, the system of getting diagnosed, the system of getting services, the school system – we've seen investigations by journalists here in Ontario that have exposed there's a major racism problem in our provinces' social services system. Families of Colour are treated with bias and then those experiences foster a distrust in the system and there's no way to know each other or trust each other in the way this system is set up, with this endemic racism happening within it.

We talk a lot about *access* to services in this province such as access to diagnostic hubs and things like that, we hear about it all the time but after someone gets diagnosed or even while they're getting diagnosed, what happens to them in the system is going to be determined by their intersectional identity, and the biases they face in that system. So, that raises a bigger question for me- what does *access* really mean in our province?

**Gaby:** Well, I don't think there's an easy answer for that. However, for me *access* is definitely not being left out in the cold after you get your diagnosis, for one. Taking into account people's histories when doing the assessments, understanding cultural differences especially, because again another occurring theme in many autistic narratives is the eye contact issue, for example. In many cultures, eye contact is considered very rude. And it's these little things that definitely don't show up when pursuing autism assessment. Or it also gets misinterpreted too. Now try being autistic and from that culture.

Like when I was growing up I did have quite a few teachers accuse me of basically ignoring them or being rude. But, I was taught that if you look at your elder straight in the eye, you're basically challenging them to fight. And, I thought well for me, I was being respectful of my teacher not looking them directly in the eye, but they interpreted that pretty differently.

Another definition of *access* for me would be definitely letting the kids who come from families who do not have the resources or the privilege to get these accommodations. I'm sure you've noticed in the media that most of the people in the protests for ABA and the Ontario Autism Program...I don't see many parents of Colour in the protest. I see mostly people who are professionals, who could *afford* to get the diagnosis for their kids in the first place, and I'm looking there going – *well where are the others?* Where are the working class parents, where are the parents of Colour, you know? It seems to me that the people who should be prioritized are not being prioritized.

**Anne:** Right, I mean there's a certain kind of, if you think about what autism looks like in our media, it's basically the face you see for autism is a white mom.

**Gaby:** (laughs)

**Anne:** That's whose face it is! It's not the autistic person's face, and it's not a person of Colour's face. The first person that you hear from, the first person that you see, the pictures that you see - it's white women. I think we were gonna talk about the media today, and I'm going to bring it up. It's an awkward topic-

**Gaby:** (laughs)

**Anne:** (Laughs)- yeah so, we have to talk about it because there is a *lobby* that has a lot of access to the media and it doesn't represent the majority- it doesn't represent autistic people *at all*, and it doesn't represent the majority of families. And, the family that you see in the media is not the average family that has autistic members.

One thing that really shocked me is when the Toronto Star writer **Lori Monsebraaten** described when the autistic representatives were put on the government's autism consultations...she described them as '*outsiders*'. She was describing *autistic people on an autism panel* as the '*outsiders*' on the panel... and you know, it's (sigh)- What's your reaction to that?

**Gaby:** as a founding member myself, I was very upset and that's putting it very lightly. I mean, I am one of the members who don't publicize the fact that I helped found A4A. But, it's still very much felt like an attack – It felt like an attack on *all of us*. I helped put in this hard work that we've been doing, and I'm really proud of what we've accomplished so far. So, for this particular writer to make us out to be this fringe group, it was like a slap in the face, really.

**Anne:** Yeah. It was just so blatant... to be labeled that way. And then, I don't know how you really fight it.

I mean, the way that we're kind of dealing with it and I think a lot of autistic self-advocacy organizations deal with this marginalization within the media, is to use *social media*. And I think that's something our groups are pretty good at, so it least, you know if you start to compare social media versus the mainstream media, I don't know what's more powerful. I think our social media is really powerful for us.

**Gaby:** For social media, I see a lot of potential. For instance back to the coverage of us in the *Toronto Star*, I do remember you sharing a meme online, it showed a picture of dogs, and it said basically 'look at all these dogs talking about feline health care' right?

[15:01]

**Anne:** (laughs)

**Gaby:** And I just about died laughing, because that's pretty much what's going on now in the autism debate. You have all these neurotypicals making these decisions, discussing autism without bringing in us into the room.

**Anne:** Right, right.

**Gaby:** It's like again, back to that meme, you would not do this with another group. Or maybe, then again other groups have had this happen to them, like for example men making all these laws about women's health. But, you know, it's the same thing anyway. So that was one example.

I definitely have noticed that memes and gifs have been pretty much the main tools used by a lot of autistics to express things that would not be considered acceptable.

**Anne:** Right.

**Gaby:** The same way NTs would express stuff, it's just that we do it online.

**Anne:** Right

**Gaby:** Overall, it has this power to make things travel much further than mainstream media.

**Anne:** It never stops, so that's like a risk...

**Gaby:** Yeah.

**Anne:** I mean for me, like sometimes I don't go to sleep when I'm supposed to go to sleep at night, then I'm tired the next day. I might be up really, really late, and I know that there's like the UK [autistic self-advocacy] people are waking up so I can talk to them, you know. But it's also this way to connect that's really amazing because, especially with written text because that's more a comfortable platform- often it's a more comfortable platform for me and a more comfortable platform I think for a lot of neurodivergent people. And, someone was saying to me like when you really look at social media it's really a form of AAC as well.

**Gaby:** Yeah. Especially with the memes. (laughing)

**Anne:** (laughs)

I wanted to bring the discussion over to a paper that you wrote for a course a few years ago which was looking at neurodiversity through the lens of anthropology and you point out that "impairment gets interpreted through different cultural lenses". So how do we determine what problems are caused by the actual condition and when the problem is really just not being seen as worthy of full inclusion, or capable of self-determination. You write that in pointing to these questions, "Neurodiverse individuals challenge society to examine itself and question what exactly normalcy is- if it even exists to begin with."

And you've written about this sort of way that things get hierarchized. In the anthology *All the Weight of Our Dreams* you talked about the hierarchy of disability and I wonder what your thoughts are on how disability gets hierarchized across cultures too, depending on who's asking or who's judging, like how these hierarchies are made.

**Gaby:** Well, the way I see it is certain disabilities appear to have this hierarchy, and I'm no Disabilities Studies scholar, but while doing some of my research back in undergrad, I found that it's basically certain disabilities are seen as more preferable or palatable to the public compared to others, and there's different debates on who definitely gets tolerated a little bit more than the others...and I'm not saying one group has it worse than the other.

**Anne:** Right.

**Gaby:** I'm just saying that certain groups are merely tolerated and others are basically hidden out of sight.

**Anne:** Yeah.

**Gaby:** And the one re-occurring theme I did see going was that neurodevelopmental, neurodivergency, and mental health issues were definitely near close to the bottom.

**Anne:** Mm-hmm.

**Gaby:** Even disabled people have been known to get into, like judging each other. Like every time I hear someone go, 'Yeah, I need to use a wheelchair, yeah, my- I need to use a cane, but at least I'm fine- at least my brain's fine.'

[19:58]

**Anne:** Yeah, yeah.

**Gaby:** Basically, the undertone is well, 'at least I'm not *those* people.'

**Anne:** Right.

**Gaby:** And it's pretty sad, cause for me personally, we're *all* facing ableism. There's nothing to be gained from throwing your fellow disabled people under the bus.

**Anne:** ...And then there was *a bus* organized by a group that's a disability advocacy group. and it was a bus to the autism protests that were led by the *parents*--autistic people were not involved with these protests--and it was- it seemed natural for this particular organization- it felt natural for them to join with a parent group where the parents were *speaking for* the disabled people, in this case autistic people, and having to call that out was really uncomfortable but there is sort of this dichotomy.

**Cal Montgomery** talks about it in his essay "Critics of the Dawn." There are the "care" activists and the rights activists--and this does not neatly break down into a binary of parent and just autistic person, cause there a lot of parents who are rights activists--but the "care" activists generally would be parents who say things like 'I am my child's voice. My child can't speak, and so I speak for him.' And then the rights activists are the people usually who actually *are* the children now grown up and saying, 'no, you *aren't* my voice.'

And within disability rights that's where the term "**nothing about us without us**" comes from, but in Ontario, of course right now the "care" activists are dominating and so that's what we see here is the "care" activists.

**Gaby:** Yeah. Right, it's a big hurdle because overall people are reluctant to go against parents, and I definitely feel it's because emotions are running really high. Nobody wants to come across as a 'child hater' or like be associated with the Tories, yeah, but the thing is this is something that needs to be addressed because the "care" activists...I understand they have really good intentions, but they are shutting out the voices of those who need to be there. Those who are telling all of us 'this is not what works, here's what works'. You know what I mean? Yeah.

That's another thing that to me personally has always been foreign in that, yeah, my parents advocated for all of their kids and I did all of my advocating for myself from I was in post-secondary because one: parents really can't help you there, and 2. again, post-secondary, you're on your own, and double if you're dealing with a disability or neurodivergence like I was. So, for me, I mean it's only natural for me that I know myself the best, and I know what I need, and it does feel really weird to me to see people claim to have someone's interest in mind, but aren't actually you know *listening* to that person.

**Anne:** Right. Right, and then it's like sort of normalized and I don't know what other community or disability... I don't think there's another where it's seen as so normal that when we have a government consultation [they don't ask any autistic people to consult]. Luckily our government is including autistics now --but never did before. Imagine a government consultation or a media story that instead of going to the actual disabled people, they go to the parents of the disabled people. I don't know if there's another example where that happens anymore, other than the IDD and autistic community.

[24:41]

**Gaby:** Yeah. Like, it's definitely a strange sight. Yeah, and well I can definitely speak for my own community in that, if any outsider came into my community and basically tried to pull the familiar 'white saviour' narrative over them, they'd be chased and cussed out for it. And I have seen that happen quite a few times myself. So, yeah, like I'm with you there in that.

There's a huge problem right now in Ontario where people are speaking over us and claiming that 'Oh, you're not like my child.' Well, we were those children once. We know what they will face if things continue as they currently are.

**Anne:** The other thing that doesn't get seen, I think outside of social media really, is that there are a lot of really *good* conversations going on between parents and autistic people --especially in social media spaces where people are learning from each other. So, that's something that's happening that's just completely off the [media] radar, and that really is too bad because it's really pretty incredible some of the conversations that are happening and the connections and the learning that's happening there.

**Gaby:** Yeah, I think it's definitely because outrage does seem to get more reactions. Seems to sell more papers.

**Anne:** Well, I wanted to ask, just one more question about *All the Weight of Our Dreams*. Are there any plans to do another book like that book?

**Gaby:** It would involve having enough resources and funds to do another- another project similar to that. So unfortunately I really cannot give a clear answer on that.

**Anne:** If there's a GoFundMe or any kind of a fundraiser, we can put it up and on social media.

**Gaby:** (laughs)

**Anne:** Gaby, thank you so much for coming in. This was such a great interview.

(Theme song – soft piano music)

**Anne:** We were speaking with Gaby, a co-founder of Autistics4Autistics Ontario, and a writer in the anthology *All of Our Dreams*. We spoke in Toronto.

You've been listening to Noncompliant. I'm your host Anne Borden King. Noncompliant was recorded at MCS Recording Studios. Various episodes were engineered by Nathan Gravette and TJ Liebgott. Thanks to our engineers and thanks for listening.