

[“It models how to relate, in a way that’s not overwhelming and respects autonomy”](#) Interview with autistic mentor Raya Shields

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Transcribed by Julie Ann Lee

(Theme song - soft piano music)

Anne: Welcome to Noncompliant. I’m your host, Anne Borden King. Raya Shields recently received her Masters Degree from York University’s School of Critical Disability Studies in Toronto. She is autistic, multiply neurodivergent and queer. For the last 12 years she has been mentoring autistic children and youth.

Raya Shields, welcome to the show!

Raya: Thanks for having me!

Anne: You’ve been mentoring autistic kids for some time. Sometimes individually, sometimes in groups. Can you describe how you first got started at it?

Raya: Sure! I first began mentoring when I was in grade 12. I was attending a private school for neurodivergent kids and teens and the school essentially offered a peer mentorship program that I began to participate in, mainly over my lunch hour or in my spares. It started sort of with working one-to-one with some of the younger students, grades 5-8 and I really loved it and developed some really good relationships with the kids through that program. Then it sort of followed from there, I began to work with some of the kids over the weekends or in the summertime throughout the rest of my time in high school.

Anne: Mm-hmm.

Raya: And then following that, I took a gap year between grade 12 and university, and was hired by the school to work in a grade 6-7-8 class, daily as a support assistant which was really fantastic. Then when I started my undergrad in Child and Youth Care at Ryerson, that was just another way I was able to continue the work through internships and I actually ended up returning to my former school to do one of my internships in a grade 7-8 classroom where I basically ran social and arts groups and programs and clubs, and worked one-to-one with kids.

Anne: Wow! That’s a lot of different experiences and areas. Can you describe: what does a mentoring time look like? Or could you give some examples of how that mentoring worked?

Raya: Sure. So obviously it’s different in the school environment in that I sort of followed what teachers would give me to work on with the kids and I would do that. But now, being out of the school environment it really depends on the child or youth that I’m working with, the family and also the stage of life that that person is in. So, my time with the kids that I support is, I like to think, very much interest- and relationship-driven, so it might involve finding ways to explore like, a niche interest in different

kinds of ways. As an example, one of my older teen clients is fascinated with world cuisine right now, so for this individual our time sort of involves ...like he'll choose a cuisine that he wants to try and then we will figure out how we can get there in the city through Google Maps. We'll take the *TTC or walk or whatever, find the place and then we have to negotiate because I have a very restrictive diet and he has a very broad palate. So we kind of have to negotiate to find a place that works for both of us and then we try the food and that's sort of the outing for the week.

But another teen I work with loves dinosaurs, so our time together is often playing board games about dinosaurs or we'll go to the *ROM or something like that. Then yet another teen is learning how to navigate the TTC by himself, so our outings usually are very TTC focussed, and we'll just do outings kind of along the route that he's mastering and then any outing we do is practicing TTC skills like purchasing tickets, reading subway maps, that kind of thing.

And then I also have a couple younger clients and then that time looks really different too because they're in a totally different life space. That might look like, I don't know...two of them are homeschooled so with one it's like recently we did a deep-dive homeschool project about jellyfish. So, we visited the aquarium...another one that I work with, I don't know, we do fun stuff like ride vintage elevators around the city or even just decompressing and just like watching YouTube and chatting. I kind of see it also as a time to just debrief about the week, talk about things that have come up. Maybe they want to work through it or just have someone listen to some of the things that have gone on in their week and I think that can be kind of helpful too having sort of support or someone to listen as you just talk about the things that have gone on for that week.

Anne: Yeah, especially someone who is also autistic who can relate to I'm sure a lot of the things that they're talking about.

Raya: Yeah. Absolutely.

Anne: Do you think, and I ask about the parents...

Raya: Okay.

Anne: Do you think as the parents have observed you, that you've taught the parents something, some social skills for relating with neurodiverse people? What's your feedback been like from them in terms of what they've learned or taken from that?

[5:04]

Raya: Hmm. Ah, that's an interesting question because I'm not actually like 'out' as autistic with all of my clients. So, more recently when I'm taking out new clients, I do share that part of my life because I feel it works better for us. Like, myself as a mentor but also as the family knowing that about me. But some of the clients that I've been working with for like 10 years, they don't know that about me. The kids do, but the parents might not necessarily know.

And so, I guess being out as autistic is ideal for me because then I don't feel the need to hide that huge part of who I am and I am able to stim if I need to. I can ask questions that might seem obvious to other people and let parents know if I am experiencing sensory overload or anything like that. But again, I don't share that currently with all the families I work with. I think it can be helpful for parents to see me

work with their child, whether they know I am autistic or not and sort of see ...I don't know, *hope*- I hope how to relate in a way that's not overwhelming and that respects a child's autonomy. I hope that's how I relate to kids. I don't always get that opportunity, though, especially with older clients because I tend to meet them in the community if they come, or I pick them up from school. So, I don't always get that family piece, but I really appreciate the work done over at Real Social Skills, and I try to incorporate that into my own communication with non-autistic parents.

So, you know I'll get parents who really want to push for a certain skill to be worked on during our sessions, and like the child's not interested, or they're not ready, or it's just not on their radar. So, it's a really fine balance at times trying to contain a parent's anxiety over developing a certain skill or making the time in their mind 'useful time', while also ensuring that the child's readiness level is taken into account, and their interest and like – it's tricky. When I'm in situations like that, I usually try to express my thoughts about the skill that the parent wants addressed for example – Is this a critical life skill? Is this a safety skill? Or is this just an **NT social expectation*?

Anne: Mm-hmm.

Raya: ...And kind of go from there. Yeah.

Anne: That makes sense. I would assume that some parents really understand the deep learning and deep kind of connections and important things that are happening within even just a hang-out session. When someone gets to hang out with someone who is autistic, who's a little bit older, in like a mentor role like you.

Raya: That's my hope.

Anne: Mm-hmm.

Raya: Yeah.

Anne: And if you don't mind, I'm going to switch for a moment, cause I'd like to ask you about your time as an Educational Assistant in the classroom a couple of years ago. What was that like for you?

Raya: To clarify, I don't have any education as an Ed Assistant, but I do have a CYC degree in Child and Youth Care which is often interchangeable in that kind of situation. But to answer your question, it was short and unpleasant and not something I would want to do again.

To describe it basically: I was working with a grade 3 student who I was supporting for half-days in a private school. Super-cool kid. Lots of potential, *utterly failed by the school system*. There was no attempt to modify the classroom or the school environment in a way that would make learning and socializing accessible to him. And I guess like my take-away from it was that when there are difficulties either he was seen as a problem, or I was cast as not being strict enough with him.

I was pushing for him to have access to basic accommodations like eating in a small room instead of the cafeteria which was sensory overload for him. Or working with me one-to-one outside the classroom when it was too overwhelming, or just like something so simple like being able to bring a stim or fidget toy into the classroom. And it was just met with outright hostility like any kind of tiny attempt to make it a little bit more accessible for him. Even something as simple as having reliable access to a breakroom

when he was having a rough time. The school wanted me to let them know a week in advance when he would need it. And (laughs)

Anne: (laughs)

Raya: Any autistic person, myself included who's experienced a meltdown or a shutdown knows we can't predict it a week in advance!

Anne: (whispering) No, oh my G-d!

Raya: So, it was- it was really ridiculous! And I was constantly advocating for just the most basic accommodations. So, for me it was really disheartening. , and like – it was horrible. Just like I was constantly in trouble like being called into the Principal's office because I was just being too soft.

Anne: *You* were being called into the Principal's?

Raya: Yeah, I was!

Anne: Oh my G-d!

[9:53]

Raya: Because I wasn't being strict enough with him, or I was letting him get away with stuff. It was just ridiculous. And there was so much pressure to implement reward charts and token economies which I'm philosophically opposed to in every way. So, I was trying to find ways to get out of that and then they were saying I wasn't doing the job right...anyway, it ended with me just flat out telling the parents 'this is not a good environment for your son,' and that I was not comfortable continuing to work with him in the setting. It was 2 months and a week, I think the job and...

Anne: Wow.

Raya: I mean, it was horrible. I know that there is at least one private school in Toronto that several of my clients attend that's been amazing. So, I know it's possible to include neurodivergent peoples in these settings.

Anne: Yeah.

Raya: I know it is, but it just doesn't happen very often. I wouldn't want to go back and do that all over again. It was horrible.

Anne: What was the reaction of the school when you brought up your concerns, especially at the end maybe when you told them?

Raya: It was interesting because when the mother and myself approached them and said 'this isn't working, we're not going to continue with this,' they were really pushing. They were like, 'No, no, no. It's fine. Just, it's fine if he just keeps coming in.' Like, they wanted the money.

Anne: Of course.

Raya: They were happy that he was suffering and they had no intention of...they weren't going to expel him or anything. *They just were not going to make any accommodations.* So again, it was just presented when we pushed again further and were like 'no, this is not working.' It was either they just suddenly

switched and they were like *I'm* the problem for being 'too lenient and not pushing him enough', or that this 8-year-old child was the problem for failing to adjust to the school environment.

And the staff were so convinced that this kid was purposely acting out to avoid tasks or to get his own way. But as an autistic person – and I'm an adult with hopefully more coping skills than like an 8-year-old little boy – when *I* got home from the job I would often just like me down and cry, because I was just overwhelmed by the sensory environment of the school and managing teacher demands and expectations, and trying to manage social interactions between the kid and the other children in the classroom, and then the parent expectations when we got in the car at the end of the day – when they were like, 'how much work did he do? How much social progress did he make today or this week?'

So I can only imagine the incredibly unrelenting pressure this child was under from all sides – sensory, social, academic, emotional – like I can't even imagine. It was horrible for him!

Anne: Well, he had you. He could bounce that off of you and you were someone who could understand what he was going through... but then in some sense it sounds like you were powerless to make the types of changes.

Raya: Yeah.

Anne: I'm wondering, in that setting as an autistic person, you could probably see some of the things that really needed to change. You mentioned allowing him to get the break room. Are there other things that would have changed that could have made things better in that setting?

Raya: I mean, I think it could be like a whole other podcast because there are so many things that could have changed, but also just like basic things. Like having access to a room he could go to at any point in the day, any time he needs it, no questions asked- just go to the room. That would have been helpful. Like the amount of work that they expect, so much of it is just busywork, it was just like I don't know, 20 spelling words and he already knows how to spell them all, so like why don't you just give him like 4 or something just to demonstrate that he can do it? It was so much wasted time where he wasn't actually ...none of the kids were engaged. It was just stuff to keep them busy and occupied and like when I've worked with homeschool families, the same amount of work gets done in, I don't know, 20 minutes - they would spend like *4 hours* at school to get done. ...The way the curriculum is taught could be modified and then just simple stuff, like allowing him to bring in a comfort object to the class. They were like 'oh, it's distracting.' Well, 'ugh.'

Anne: Oh no!

Raya: You know? Simple, simple things.

Anne: Do you know what he ended up doing? Did he go to the different school?

Raya: Yeah. He ended up switching schools. For me it's one of the saddest stories cause I really wanted to keep working with him...he was homeschooled for a little while, and then unfortunately the family ended up switching to an *ABA centre because they felt that that would be helpful. And now I hear that they've switched back into the public school. So... yeah.

Anne: Well, once you left the school and that environment and continued and expanded your mentorship work outside of that setting, how did that work? And, how did that feel for you?

Raya: It was a big relief. ...I love what I do and the relationships I get to develop and I think people don't realize how essential it is to develop these trust[ing] and secure and unconditional accepting relationships with kids in general but also especially with autistic kids.

Anne: Yeah.

[15:00]

Raya: ...because they experience so much exclusion and pressure to conform to NT social standards by adults who just don't take the time to get to know them and learn about what makes them happy and comfortable and secure. And I think also just autistic ways of being are so pathologized and there's so much pressure to get autistic kids to engage in "typical" activities. Some kids I work with love doing things like playing board games for hours, but other ones are more content like, watching construction and snapping photos of it, another kid likes listening to video game soundtracks and designs crazy elaborate perler bead creations each week. Someone else loves Wonderland and high sensory experiences which I don't share, but you know, we negotiate and we make it work.

So, honestly it really depends on the person but it's great to be able to work outside the confines of a traditional school environment at this point in my work. And I think so much learning happens in the community and at home, so it's awesome to get to explore that.

Anne: Right. It's interesting because they often talk about 'social skills' and 'getting prepared for the real world'. But, *school is nothing like the real world*.

Raya: No, it really isn't.

Anne: And now you're balancing mentorship with also being a graduate student in Critical Disability Studies. What area are you focussing on in your studies?

Raya: I'm almost done the program. I'm currently writing my major research paper which is the last step before I finish my Master of Arts. So, my area of focus is the Judge Rotenberg Center in the USA, and I think that you [interviewed Cal](#) about this a couple weeks ago.

Anne: Yeah, yeah. And how is that in terms of life balance, because it sounds like you're doing a lot. You have studies and a very heavy topic for your research. And then you have your mentorship work with kids all over the city. What's it like balancing that?

Raya: It could be tricky at times, particularly like when my workload with school is really high and I have a lot of deadlines. But in general I find that it works pretty well for me. I think because the topic of my research is so heavy and so difficult to read and write about, I think it's super important for me to be doing the work that I do [with kids] while I'm working on it because it sort of keeps me going, keeps me hopeful, and allows me to see the potential to change the way we currently structure programs for autistic people, so...

Anne: Yeah, yeah. That's great. What do you think is the best part for you about being an autistic mentor? I'll ask you first what the best part is for you.

Raya: For me? This is a tricky one! There's just so many things. Like it's honestly my dream job. I love everything about it. I think one thing that stands out is all the relationships that I get to develop with really amazing kids and teens. And that's probably not something that everybody can say about their job. Like, I love coming to work and I don't really see it as 'work' either. But another aspect that I really value is being able to get to know people over an extended period of time...I generally get to work with the same people over many years. So, I really get to see them grow and change and develop into confident, proud autistic adults which is like totally amazing!

Anne: And what about for the kids? What do you think kids are getting out of mentorship programs like what you do?

Raya: What I hope that kids get out of the mentorship experience is that it gives autistic and neurodivergent kids and teens tools to advocate for themselves and their needs, to find pride in their autistic identity and to be able to have greater access to their communities and feel comfortable with their way of being in the world.

That's my goal as a mentor. Because that's what I want for all autistic people. Not a cure, not a checklist of social skills, mastery of normative skills achieved, but a feeling of security in themselves and greater access to things they want to participate in, in a safe space to work through complex feelings with another person who's experienced that.

(Theme song – soft piano music)

Anne: Wow, what you're doing is absolutely amazing and thanks for taking time to be on the program and I hope to have you back to talk more about autistic mentorship.

Raya: Thanks for having me.

Anne: Thanks.

Raya Shields has been mentoring autistic children and youth for the past 12 years in Toronto. She spoke to us from Toronto.

*

ABA – Applied Behaviour Analysis

NT – Neurotypical

ROM – Royal Ontario Museum

TTC – Toronto Transit Commission (public transportation system in Toronto)