[00:00:06]

This is Tell Your Story Special Edition, where we address relevant topics for our community. The topic for this special edition is about autism.

Welcome back to the second half of our conversation with Melissa Minaya.

Another question because you mentioned about they gave tools or taught him how to control his own emotions, and behavior, and everything else. Because you were mentioning mostly in school and because the environment and how it affects him sometimes. Does that happens at home? Does he practice that at home? Depends on the situation?

[00:00:59]

No, we practice that at home a lot. I learned to incorporate those tools myself. [LAUGHTER] When he was younger, it was, let's breathe and count to 10. It was how we got him to calm down from his meltdown. It was like, let's take some deep breaths. Let's bring the oxygen back into the body. It's like meditation, and we would physically bring his arms up above his head, take a deep breath and slowly take a deep breath out, bring your arms back down. It was physical reminder of body movement with the breath, counting. We did a lot of, let's count down from 10. Let's count up to 10. Do you feel better now? Are we calm now? As parents, realizing that we couldn't get him or Amauri to do anything when they were at the height of a meltdown. If you are super frustrated and super upset about something, no one can talk to you and get you to do anything even as an adult. Really waiting and giving him space to get to the point of calming down. Also learning to ask him, do you need space right now or it looks like you need space. Space could be, do you want to be in another room, or let's drop this topic for now. Sometimes we would be like, do you want to go and draw? For Andre, drawing has always been a great outlet. He loved writing. Even as a toddler, we would give him a pen and a notebook, and I still have some of these old notebooks, and he would just scribble. I would give it to him in the back of the car, and he would scribble. He would ask me constantly to draw the PJ Masks characters, [LAUGHTER] and he would just color them in over, and over, and over again. Some of this is part of the repetitive behavior of how his autism is expressed, but also, it was really calming for him. If it was calming for him, why would I stop doing it?

[00:03:25]

Exactly.

[00:03:27]

These are some of the things that we then incorporated into ways of, we know he loves drawing, it calms him down, so we would draw. In the car when he would get really anxious and upset about something, I would turn on some of his favorite music. Music also really calms him down.

[00:03:45]

He loves music.

[00:03:46]

The daycare realized that there's one of the songs from the Spider-Man into the Spider-Verse movie with Miles Morales. He loved that song, so I told them, and whenever he would get super agitated, they saw he wasn't coming down. They would just play the song and they would just leave it low. He would realize it was playing, and it would calm him down.

[00:04:15]

Interesting.

[00:04:17]

These are things like, yes, we definitely we use them at home, we would use them out in public. Now, he doesn't need things like the music. Sometimes he still needs a drawing, [LAUGHTER] so he would do that in class. For some teachers, that was a put off of, why are you drawing when you're supposed to be listening. Well, he was still listening, but he also was drawing. [LAUGHTER] Navigating that process of, now what works. Now, what do you need? We could see as the years have gone by where he doesn't need a physical way of calming himself down mentally or emotionally. We can see it happening in his head. He's like, I'm upset about something, I'm upset about something, and he won't say anything, but you can see his eyes filling up with tears and he's slowly taking a breath, he's calming himself down.

[00:05:22]

Doing himself.

[00:05:23]

He now has learned to do it himself, which is such a fantastic way.

[00:05:29]

It is beautiful to think about it.

[00:05:31]

He helps other kids get there too.

[00:05:33]

He does that.

[00:05:38]

That is one of the signs to me and Bruce that we have really made the best decisions to, let's find all of the resources that he might need. We're not going to be afraid of it, we're not going to say it's stigmatizing him. We could have been like, we don't want him pulled out of class because other kids will think he's different. We were like, pull him out as many times as you need to. [LAUGHTER] Three times a week he was getting pulled out of class. Was he missing things in the classroom? Yeah. But he wasn't going to get any benefit from those things if he didn't first address some of these struggles in the areas that he needed.

[00:06:23]

Because that's the same thing about saying the boxing mentality as well. Yeah, he should stay in class to learn that, but if his mood and his behavior was so intense that he could not focus on that, what would he be learning there?

[00:06:37]

It's no help to anyone. It's no help to the kids around him, it's no help to the teacher, and it's definitely no help to him.

[00:06:46]

One thing that I love about what you're saying is identifying the emotion that's coming up. Saying out loud, I'm feeling this, I'm feeling this. Now that he's self-regulating, he knows how to manage that. He doesn't need to maybe not count loud, but how many of us name what we're feeling. You just have a feeling, I'm angry, but why and what reason. Is it reasonable or not? Sometimes we are frustrating for our own way to think that you have a reason for that, and you can lash out at someone and be rude or whatever it is, instead of identify first and think about that properly and calm yourself down and then trying to catch a level of expressing that without hurting anyone. Hurting anyone else.

[00:07:38]

Because sometimes our feeling of releasing this emotion is by hurting someone I don't know. It's really beautiful, different way to think about things. While you were explaining about how he managed to do something when you're saying he should be listening, why is he drawing. I keep thinking about certain things that happened to me in terms of how I watching TV. If it's not interesting enough, but I still want to watch, sometimes doing something in my hands, if it's a crochet or something, help me to deal with that, process what's happening there, but it's still doing something else. Which makes me feel like, this skill here, this movement or motor thing helps my brain to process that one, intellectually, whatever it was. It is things that we don't know, we don't pay attention much and would be helpful, but usually, if you are in a setting that demands that you focus and pay attention, nothing else you can do otherwise, someone's going to be upset to call your attention.

[00:08:58]

Exactly. You're not paying attention. You're not doing what you're supposed to be doing. Then it makes the other person thinks that it's being done on purpose. No, it's not. I'm not purposefully not paying attention. It's just I need an adjustment before being able to continue.

[00:09:19]

We're all human and we have our own triggers, and I think learning what each of our triggers are is important when we are also dealing with either children or adults who are neurodivergent. I think we now live in a world, thankfully, where like you mentioned earlier, people are being more open about this, and it can only really help us as a society. I know that as parents of an autistic child, we have a level of privilege because Andre is verbal. He yes, has speech and language issues, and he still has trouble processing, and he struggles with reading, and gaining knowledge and information from things he's reading or what people are saying. But he doesn't need an assisted device to communicate. Those are things that I'm conscious of and remind, I think both of the kids that other children learn differently. You learn in this way, but you also struggle in this way. But you excel in this other way. Other kids that you see may struggle in ways that you don't struggle and then need help. But then in things that they're really good at, maybe they could help you in doing some of those. It's one of the things the autistic community is so diverse within that group itself. It's such a spectrum. I realize that my struggles are not another parent's struggle. That other parent's struggles may not be my struggles. But we are all in this together, and if that means that I then have to think about tools and resources that maybe Andre doesn't need, but could benefit someone else, then I keep that in the back of my mind. I don't deal with that, or my family doesn't have to deal with that struggle. But I've read about or I've heard about X, Y, and, Z, and keeping that level of being cognizant about that is really important.

[00:11:52]

No, that's important for everyone. I think we haven't mentioned this before. It's like you are speaking a different language. A language that others that are learning about autism or have an autistic child in any level or any age you understand in one way or the other what you're talking about, instead of having to explain everything. I feel like if you have a community that is more involved with the same topic, it would be much easier to feel included, feel that you belong there instead of still feeling judged. The judgment is not there in the background anymore for you to worry about. You can just be yourself and your child can just be. I think that's important.

[00:12:40]

If they get upset because they're strawberries and not blueberries, then it's okay.

[00:12:44]

They might say, is that moment right now?

[00:12:47]

Or when kids have been invited, Andre had a classroom birthday party a couple of years ago, and friends came over, and some of the friends just wanted to sit and not play, and the parents are like, I'm so sorry. He's not wanting to go out and play with the friends. I'm like, don't worry about it. He doesn't have to. He can just come and eat cake. If he doesn't want to do anything the entire time, he does not have to do that.

[00:13:16]

Exactly.

[00:13:17]

If he wants to go off and play by himself, he can totally do that. There was no forced participation here. I think even Andre himself, at one point, when we were eating pizza, tuned out everybody sitting on the table around him and was just like, watching the TV. Both me and my husband were like, he just needs to focus on one thing right now. He does a lot. I think for me, one thing I really try to do is be really verbal about, your kids doing that. Don't worry about it. Don't worry about if other people are worrying about it either.

[00:13:56]

Yes.

[00:13:56]

You let your child do what they need in the moment and be okay with it because it's okay.

[00:14:07]

I think that's an important thing. What have been the most challenging, rewarding aspects of parenting with autistic child?

[00:14:18]

Wow. I think one of the most rewardings has been getting to experience your child in a new way or a different way that maybe other friends of yours haven't been able to experience. For Andre, being able to see that really empathetic side of him is so special to me because there were points up until a few years ago, he didn't really care about what other kids around him were saying or feeling or doing. To then be able to be like, wow, look, you really want to make sure that that child is not upset about X, Y, or Z. It's not like he's always like that. Sometimes he's like, I still don't care. But knowing that seeing that change in him has been really great. Sometimes Andre will be doing something and is struggling with what the instructions are of how he's supposed to do it. He just finds his own way to figure it out. He's like, well, that's not working the way you people want me to do this.

[00:15:45]

He finds his own way to do it.

[00:15:47]

It's crazy cakes to me. I will think of something else. He does, and he comes out to the same exact conclusion. Seeing his brain develop in that way has been really great. I think one of the challenges for us, particularly when he was younger, and we didn't know yet how to help him was really hard. We took a trip to London when he was three, and Amauri was seven months, and he hated the airport so much. It was just so completely overwhelming and overstimulating to him. We were literally standing at the gate. Bruce was just holding him over his shoulder, and he was screaming.

[00:16:46]

People walking by staring and I'd be like, well, this is just what it is. But those moments where you're like, I don't know how we're going to get through or I don't know how to help him in this moment I think as a parent are like the hardest parts. I think maybe with any child, you go through these waves of things are going really well with them, and then you hit a point where it's like, we're really struggling in this moment. Last spring, I think was one of the moments where he was really struggling in the early spring where it was like, he was struggling at school. We were struggling at home with him. We were like, what's going on? Are your routines changing? Are there different needs that you have? Those moments where you're like, something's changed. The things that usually work are not working. What do we do now? How do we get past this? Those are the hard parts. Now we have to come up with something new all over again. How do we figure that out? How do we get him to express what he needs when he has trouble getting to that point? I think that is one of the hard parts and thinking about the future, thinking about what will puberty look like? The emotions and hormones.

[00:18:13]

Yes.

[00:18:15]

That middle school to early high school and even high school can be a challenge for any child. Then wondering how is it going to manifest here and what changes will we have to make and adjust to.

[00:18:40]

Because you said something before, my question is going to a point where your podiatrist had said, I don't want you use a level here because there are so many factors that involves in behavior that could be, I want this to be an experience that he and his brother can have in a common situation. But have you noticed as it develops in these nine years a change in new challenges or is something that progressively getting under control or if there are something new appearing that you still need to be aware and have new tactics or new approach to control?

[00:19:23]

We've definitely seen I think a progression. I think because Andrea is more high-functioning, he's been able to acquire skills in a new way. I think just general milestones that a kid reaches where they're learning to adjust to their life socially. I think last year in third grade, that social aspect kicks up a notch where it's more boys versus girls, more boys exhibiting different type of behaviors and some become more leaders and some become more followers. We were starting to see those dynamics. It's interesting in the past where he could have cared less about what his friends were doing. Now he was caring more.

[00:20:21]

He's noticing more. Interesting.

[00:20:22]

He's noticing more. But still not really knowing then how to fully deal with what he's noticing. At times, it might be like, girls pay too much attention to what we're doing. All girls are terrible. I'm like, hey, I'm a girl. You have two cousins that are girls, and you get along with them. He's like, but they mind their own business.

[00:20:54]

She's having the zone.

[00:20:55]

Exactly. I'm like, we're not going to generalize here. How do we rein some of this in so it doesn't go to extremes? The behavior can go to extremes. I think as a parent, we're like, we're starting to navigate these school-aged problems that some kids had experienced it early on, and now he's catching up to that.

[00:21:25]

Do you think that this comes from acquired learning? Some other kids are saying this about girls.

[00:21:33]

I think he wants to emulate some of that. He's always modeled some of his behavior off of what people around him are doing. Also, modeling now, things that they're saying. I'm like, well, we are not going to say those type of things here because they might hurt someone's feelings or because they're not bad words, but they're ugly words from how you're using them. Navigating that part of it, probably at a later stage than some other kids, and we see it now. Amauri is going through some of this now. He's in first grade. We're like, let's have all these conversations at the same time with both of them. That's great. We'll get this out of the way now. But I think as parents, I've always been around kids, but I think it's different being around kids and living and having to raise the kids to see all the milestones, the developmental things that they're hitting, and when they're hitting them. Interestingly, with Andrea and Amauri, they're much closer in age in some aspects than just almost three years apart. Even though one's in first and one's in fourth, some of the things that they're learning and navigating to do are going parallel.

[00:22:54]

It's interesting because there is a difference being around kids but living with them 24 hours because when you are just around them and they go but when we have to deal with that and teaching, there is a non-stop there until they go to bed. That's true. Figuring out certain things, which makes a huge difference. What advice would you give to families with a newly diagnosed child?

[00:23:22]

Seek assistance and help. One thing that we didn't do that I think would have been beneficial for us then and would probably be beneficial for us going forward is doing counseling and therapy to be able to get all of those fears and thoughts out. I think as parents, a lot of our focus was like, resources for Andre, which I think were really important. But it's also important for parents to take care of themselves, and to have a safe place where they can be brave about what they're feeling and why they're feeling it and really talk that out, let it out in a space that can also be constructive for that. Definitely getting help, seeking resources. I think as a parent, with a new diagnosis is really important and talking to other parents about it. There's so many things that can that are like a stigma, especially in this world of social media where you see all of the precocious four-year-olds doing all of these great things and reciting dissertations.

[00:24:49]

At four, Andre could barely answer the question, what's your name? I remember he was four-years-old when someone asked him, Oh, what's your name? And he answered Andre. I was so amazed.

[00:25:04]

Wow.

[00:25:05]

We were at a realtor's office and I got back into the car with Andre, and I told I was like, he said his name was Andre and I know most people for a four-year-old, it's like, Well, yeah, he's four. He should know the answer to his own name.

[00:25:19]

Yeah.

[00:25:19]

I'm like, no, but you don't understand.

[00:25:22]

Exactly.

[00:25:23]

Amauri was doing that at two, and so with Amauri, some of the things that he's gone through, we've been like that's maybe closer to the time it should have happened. Being able to, you know, getting back to your original question, talking to people, finding resources that will be most beneficial for your family and not feeling bad about them. Asking if you're at a preschool or a daycare, asking them, you know, what are the steps that are needed to get someone in to be of support with him in the classroom on a one on one basis. Might not have to be the whole day, maybe it's for a few hours each day. Maybe it's just a few days reaching out to your insurance company and being like we have this diagnosis. What do you cover? What resources are out there and really trying to take advantage of it all.

[00:26:29]

Another one, how is it working full time, having two children? Because we had this conversation before with the special edition mothers at work and came from conversations about being a parent and still have a full time. Yeah. But then you are talking about new development that is not the neurotypical way that you see things, and then you have to have a step up. How is it for you? How is it working since diagnose that you can talk about?

[00:27:11]

It's a struggle. There's no really other way to put it and I'm not going to sugarcoat it.

[00:27:17]

Yeah.

[00:27:17]

It is it is definitely a struggle to work full time and have a child who needs additional services beyond just, like, being in a daycare. From times where we hadn't had the diagnosis yet, but he had been screaming in daycare for three hours and I had to leave work to go pick him up because he's in distress. The daycare providers like, I don't know what else to do. They have tried everything tried everything that they could, you know, you know, it's like, it's been several hours now and now we need mom and dad to come back to help with the situation to managing like I said, outside of school before he was in kindergarten, he would do speech once a week and occupational therapy once a week. Those things all happen during work hours and so I was lucky enough to work with people within a department that was flexible. I think as a manager or an employer of working with someone who has special needs, I don't want to say it's like they need special privileges, but you do need a level of flexibility, especially if you have a great employee who is doing their work, who, you know, wants to be in the office doing what their job responsibilities are. They're going to go through a period where they need a level of flexibility. For me at times, that meant me and my husband worked out a schedule where we found the location where he was having speech and OT. We were able to schedule the appointments back to back so they were on Monday mornings. We alternated months., so one month, I would go every Monday with Andre to his appointments, and then the next month, Bruce would do the Mondays with his appointments. We alternated that way. Should be able to manage be able to do that. Also, on those days, then he wouldn't be in his preschool. We then found, like, an outside babysitter to watch him for, like, the remaining half of the day, so that then on those days when it was my month, I would take him to his appointments in the morning, and then I would work remotely in the afternoon. That part was crucial for me because otherwise, it meant spending my day basically in the car, driving in the morning to his appointment, being there for his appointments, driving him to his sitter, then driving into Cambridge for work. Having to go back to pick him up at a sitter by 5:30, it was really weighing on me. Being able to have a manager and a supervisor and our faculty director who by then, like, knew that I would be doing the work because this was happening before the time, like, of COVID and the time where remote work was more available and honestly, also having to use, my PTO time when I needed to and being, you know, open and available to that.

[00:30:59]

Reminds of what PTO is?

[00:31:01]

Paid time off. Okay. Using my personal time or vacation time, also knowing with your organization. So here at Harvard, your child has an appointment, you use sick time, and there are some laws related to being able to use sick time for your child's service appointments of speech or OT, and also using sick time for any school meetings related to their IEP, their instructional education plan for schools so having to learn all of that and what that meant and when it applied to me and when it didn't what also really important.

[00:31:52]

But if you don't have a supportive work environment, I suggest finding one, I think that is. For managers knowing, if you have employees that you really value, think about what needs they might need in finding ways that work for everybody.

[00:32:12]

That's important. I have to ask one question because I want to put it back in the conversation that you, it just caught my attention. When you said that sometimes you are at work and the kid is in daycare and is having a meltdown, is there situations that the professional that works with your child teacher or daycare instructor has a better way to soothe them or in Andre's case, for example, better than you do. There are situations that you are the only one who can soothe him and the difference between you and your husband, our situation, that your husband is the one to be the one to calm the situation down versus yours. Is that he triangle in terms of other people. How does that work?

[00:33:04]

No, definitely. They definitely even at his preschool, who was really great at finding ways to getting him to settle down and calm down. There were times where they were like, Okay, we've done everything in our toolbox. I think now it's time for a parent stepping in. What we're doing has not been helping we need you to tag in tag in. Because our teachers and providers are human also, and they also have a limit to what they can give out and take in.

[00:33:43]

That could be also the kids reaction to a situation. Because it's not they are failing as professionals. It's because maybe I don't know. An attachment to the parents that they miss at that moment. I want mom to take care of you.

[00:33:58]

Right. Like, I don't want you in this moment.

[00:34:02]

Yes exactly. Yes.

[00:34:05]

I think the same with me and my husband, there's definitely ways in which I was more better suited for some of Andre's tantrums and meltdowns, because I have a more patient. Patience when it comes to that, then sometimes my husband does. But there were there are moments where Andre really needs physical energy and input, and Bruce was really that person for that, because I am not the type of person to be playing around and throwing him on the couch and needing that bodily sensory in.

[00:34:46]

Yes.

[00:34:48]

Bruce is that person.

[00:34:50]

Person for that.

[00:34:52]

Then there are ways that we learned. Bruce learned that there were times when he couldn't come a it with his, like macho exterior. He had to really calm his own body down himself down and be like, Okay, what do you need in this moment? How can I help you? I'm noticing that you're getting agitated and learning that. Like I said, I've been around kids a lot, and so I maybe instinctually have had some of that, I think, before Bruce. But there's definitely times where I'm like, Oh, I don't have the patience for this, and I need someone else to come take it.

[00:35:44]

Then also for reading cues. You can read on Bruce when he needs a break from this, and Bruce might need to look at you and say, Okay, my turn now.

[00:35:56]

Exactly.

[00:35:57]

Because you are.

[00:35:57]

I'm going to take over with.

[00:35:59]

This is really interesting. Thank you. This is great information. I think it is phenomenal how I still think looking from the outside, so much that you learn and we can learn from these children. How we can control ourselves. What you can learn from our own emotion? How can you prioritize things that we just pay attention because they need to learn. When you're talking about emotion, when you're talking about behavior, when you talk about self soothing, self controlling, when someone told you, Oh, one of the aspects or the symptoms or the child is not looking at you or not making eye contact.

[00:36:54]

Eye contact.

[00:36:55]

I keep thinking when did I ever thought about my brother, my sister, my mom, whatever that eye contact was part of an important thing?

[00:37:05]

Yes. We don't even think.

[00:37:07]

There are so many things that is out there, but you never really paid attention and certain things that we should be paying more attention to in order to function, or I don't know. There are always a learning moment in situations that we are facing that we could look into it as, Oh, do I need to deal with this, or what am I going to do with this now? I think there is always a right of learning…process.

[00:37:39]

Yeah, and I think. One thing that I've come to really think about is there's so many ways that we individually are different. I was a very shy kid, and maybe now that would be diagnosis something.

[00:37:59]

Yeah.

[00:38:00]

That I would not venture out and talk to people. If I didn't know you, I was not saying a word. I would sit quietly and not talk at all. Then it was like, Oh, she's just quiet and shy. But now would I have been diagnosed with something and then given the tools to be able to interact more freely in a way that made me comfortable? Or for students back when I was in school, who seemed to have, "behavioral issues" who were lashing out or seemingly to Oh, no, they don't pay attention. They don't want to do any work. It's like well, was it that or was it something else?

[00:38:41]

Yes.

[00:38:42]

What need were they trying to express, but had no way to really express that need? One thing that I've learned and you hear on all the parenting blogs is every behaviors communicating something. What is that person, that child trying to communicate through you through their behavior? It's not always an adaptive behavior. But it's a behavior that's trying to tell you something nonetheless.

[00:39:13]

Sometimes in norms, all these when you're talking about behavior, make me think about places where discipline is so controlled. How folks with some different form of behavior that they cannot control, they didn't learn how are punished to kind of you need to stop that from happening. When they themselves could not. I keep thinking about a military institution, religious institution, educational institutions that have their own set of rules and regulations and discipline very strict. Then you cannot get out of that. What some folks have been through in life and to be able to manage that. I don't know, my mind goes everywhere there, and I don't want to be bringing too much until you can keep talking more in other opportunities as well. Melissa, thank you very much.

[00:40:22]

Thank you.

[00:40:22]

Again, I think this is wonderful. We are going to have our panel, and we can talk more about this. I hope we can still compile if you remember, try start making notes. I would like to have resources that you found things that you read, even if it's not apply directly with your child with Andre, but you think that would be beneficial for other folks. I think it would be nice to have a list of resources from all the participants. When we post the episodes and have this specific place there. Would be nice to have. Thank you again.

[00:41:03]

Thank you.

[00:41:04]

Very much for teaching us, for being this amazing person that you were. I really appreciate.

[00:41:10]

Thank you. This has been great.

[00:41:12]

Thank you. For everybody out there, like we say, I'll see you soon. Bye bye. [MUSIC]