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This is tell me your story special edition, where we address relevant topics for our community. The topic for this special edition is about autism. Hello, everyone. This is Edgar Kley Filho from the Eagle Opportunity Office. My pronouns are he, him, his. Today, we are talking to Melissa Minaya from the medical school, who will tell us about her story as a parent of an autist child. Thanks for joining us, Melissa. Please tell us a little bit about yourself and the work you do at Harvard.

[00:00:52]

I'm Melissa Maher, my pronouns are she, her, and hers. I work at Harvard Medical School. I'm in the office of Research administration, and I'm an Associate Director of grants and contracts. I manage a team of four people who negotiate grants and other research awards or research agreements for the university. I've been at the medical school for 10 years in the same office.

[00:01:15]

Ten years already. Let's go and jump right in in our conversation. I think my first question would be, how you define autism to someone who has never met a person with autism?

[00:01:31]

Sure. I guess first, I'll start with this thing a lot of people say is that if you've met one person with autism, you've met one person with autism, so it really manifests very differently in different people. But I think the best way I can explain it is just that the brain is wired a little bit differently. An autistic person might think or experience the world a little bit differently from, what you would consider a neurotypical person.

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How does autism manifest in your child?

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Sure. My son, I'm not going to say his name just for privacy reasons, but my son, he's six, and he's in kindergarten. He's level one autism, so it's a spectrum and there's three levels and so one is what people might think of as more high functioning. He's fully verbal and he's very bright and loves to talk and communicate. For him, it manifests in a few different ways. First, is some sensory challenges, like sensitivity to different sensory inputs, whether it be, visual stimuli or loud noises or even just crowds, large crowds of people or smells or textures, things like that. Then also on the flip side, there's also some needing sensory inputs, he likes to cocoon himself, be surrounded by stuffed animals or blankets or things or sometimes he likes to roll or spin as a sensory input. That's one piece of it. Then, the other areas where it affects him is emotional regulation. He struggles a little bit more with that and impulse control, and then just general social challenges like learning, I guess the social. The unspoken social roles and just how to manage all of that. When he gets overstimulated or dysregulated, it doesn't happen as much anymore, but especially when he's younger, sometimes you'll see what you would call an autistic meltdown. It's different from a tantrum because the tantrum is more the child is purposely trying to get something they want. An autistic meltdown is more of like, it's your brain is short circuits, they're just totally overstimulated or dysregulated and they just can't process anything else, and they shut down and it can manifest as yelling or acting out or whatever. You have to help them get to a calm place before they can resume their normal activities I guess.

[00:04:16]

Question for you. For someone looking at it, if they present one of these moments. They could be calling this attention?

[00:04:25]

They they look similar, they can look similar, because they might be yelling or crying or acting out in an aggressive way or something that, or say, throwing things. I think, in a lot of cases, they can look similar but I guess the underlying, what's going on underneath it is very different.

[00:04:49]

What's your action at that moment? When you notice that's happening, that's beginning, what your first step towards your child?

[00:04:59]

Sometimes you can sense it coming on and you can try to head it off a little bit by establishing a calm situation and I guess, taking them away from whatever the stimulus is. That's an issue or bringing them towards what they need. But I think, once they get to that full meltdown state, the most important thing is really just being calm yourself. They call it co regulation. Essentially, if your child is dysregulated, the more regulated that you can stay, the more calm and collected and just not reacting in kind, not getting upset, not not rising to that level of emotion. That can help your child. Essentially, you're their anchor, in the storm. You're showing them calm, you're providing that reassurance for them. And, every kid is going to be different, and even like, so if my son was having a meltdown, one day a strategy would work and then the next day the same strategy would make it worse and a different strategy. It could change from day to day. But sometimes it might be, a hug or just touching his shoulder or something. Other days he wouldn't want touch, then he'd want to be alone, and he would go in his little fort or something that and have some quiet time. Other days, just like a drink of water or doing something active, a walk around the block or something that could help him calm down. Sometimes you could talk and say, hey, what would help you right now, and he'd be able to communicate. But then other times you would just be too overwhelmed to even talk and so you just had to guess. But the most important thing is just staying calm yourself, which can be really difficult because if other people around you are really emotional, it can be hard to then not do that as well. But I found that to be pretty effective. it's definitely much easier to help him find his calm if we're staying calm.

[00:07:13]

Thinking about what you just said, you said that sometimes it's caused by a stimulus from the environment, would it be noise? Would it be too many children running around or movement that's happening, that would cause a reaction to them, right?

[00:07:32]

It could be any of those things, and it could be even just throughout the day, those little things happen, and maybe in that moment, it doesn't overwhelm him, but after an entire day of small stimuli, it can accumulate a bit. Then, that's why I would sometimes seem to come out of nowhere, but it wasn't really. It was just the last straw, that was the thing that, I've had too much today. It might seem a small thing, but it's really the accumulation of all those things throughout the day. But, it could be a lot of different things. One of the things that I've learned because I'm one of those people I have to research everything. When I found out my son, he was diagnosed with autism and also ADHD. I researched both of those, conditions and wanted to learn all about it. One of the things that I've read that I think is true is that, behavior is communication. When a child is having that autistic meltdown or just, otherwise, acting in a way that, I guess adults would consider undesirable, they're upset or they're acting out, they're really trying to communicate a need that's not being met. It's because they don't have the tools or the words or whatever to be able to say, I'm sad about this or I'm mad about that or I'm upset about that. They're communicating the only way that they know how. Just knowing that and then looking for when they are in that situation, looking for what's the root cause of this behavior? Because if you can say, well, something's wrong, and then you look around like, is there a stimulus that might be impacting him or is there a need? Is he hungry? Is he tired? are we missing signs of that? He's been trying to tell us and we just didn't didn't realize something like that.

[00:09:23]

I keep thinking that living in a world that we live in, that sometimes you react to what people's perceptions are and the judgment that's so common in everybody around you. When you see a child in a situation that we think there's a tantrum without knowing the reason behind that, immediately that comes the sense of a judgment, what the parents are doing. Then you say that one of the most important factors to calm your child down, knowing everything that you know would be you have to be the anchor. You need to be calm yourself. How do you deal with looking at your child have a reaction?

[00:10:10]

At the same time that in your mind, I assume from the first time that it happened if it was in public, what about what people are thinking or what should you do? Because sometimes that's what people write? What can I do to quiet him down wear her down the fastest way possible, because people are looking, people are judging, people did that cross your mind in the beginning? Did you have to prepare yourself and get used to it and thinking, my child's more important right now than anybody else around as a mother, how did that work in that process?

[00:10:46]

I mean, for sure, I've definitely thought about it, but I agree with what you said and in those moments, like my thought is that my child is the most important thing here, and other people may judge or may not understand, but, like, I have to do what's right to him. At the end of the day the judgment of some person that I don't know and I'm never going to see again, probably as much as there's a part of us that never likes to be judged and you may feel self conscious. Our first job is to our children and to keep them happy and safe. I mean, I certainly try to just block all of that out and focus on what he needs in that moment, but I will say we also it doesn't necessarily prevent an over stimulus from ever happening. But now that we know that he is autistic and has ADHD and what some of his challenges are, we're pretty thoughtful about what we do with him. Like, we look for activities that are sensory friendly or we'll go to something when we know it's a little bit less crowded and we'll research what's there and what accommodations they might have, and we bring his headphones everywhere. The noise canceling headphones, and we always carry water with us and snacks. Just all these small things that I'm sure a lot of other parents do as well, but just we have to be extra prepared and make sure we have all of these tools so that and we prepare him. We don't always do, like, a formal social story, but we'll often tell him, like this is where we're going, and this is what to expect. This is the things that you might do or how you might be expected to act and we can always go home if you're enjoying yourself and we do. We'll go home, it doesn't really matter. We tend not to do things where it's like we have to spend a lot of money up front. You know what I mean? We'll find cheaper or free activities because that way, it's like, You know what? If you're not having fun, fine. Like, we went to one thing and it was in a big gymnasium. It was, like, a lot of kids, and it was really noisy and after 5 minutes or not even, he was like, I'm done with this. Like, I don't want to be here and we're like, fine, we'll go home and we did and it's not a big deal. It's really just whatever he's comfortable with, but we try to do that preparation and research as well, and that helps.

[00:13:02]

Another thing there was while you were explaining that I was thinking, usually the neurotypical children, we say that, in a time that expressing their feelings and how they feel in general is not the easiest. But then say if child start crying or getting to that point, it could be that because they are hungry, like I mentioned before, it could be because they are tired and they need to sleep, but they don't want to sleep, they react to that feeling of fighting that. Is that something different for an autistic child or would it be an addition to the stimulus that they are reacting as well? You have to identify what is hunger or being tired because it is just nap time is coming or is a combination of both. How does it work?

[00:13:58]

I think it's a little bit. I mean, it can be an addition to some of the other stimuli. I think sometimes with autistic kids in particular, one of the things that he's worked on at school and in therapy it's called interception. It's basically like, I guess, feeling the signals that your body is giving you. Sometimes kids with autism may may struggle a little bit more with just listening to their body, essentially, noticing or feeling when they're hungry or tired or have to use the restroom or whatever. They may essentially ignore those signals or not realize them. They might get to a point where a typical child might be like, I'm hungry. I'm going to eat right now. But he just doesn't even realize until he's like, really, really hungry or really, really tired, so it then exacerbates whatever other challenges he's having.

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When did you first realize that or suspect that your child was autism, how did you get them formally diagnosed?

[00:14:57]

We actually didn't suspect it. The way it happened was he was in a private a daycare situation with other kids, and he had been doing really well, and then a whole bunch of things happened at once. He went into a new class with more kids and a different teacher. Then some of his friends didn't go with him into the same class or they went a in a weird staging system. He wasn't he didn't know all the kids yet, and around the same time this was I guess, toward the tail end of COVID or in the middle of it somewhere. But he got COVID and he had to stay home for 10 days. He wasn't around all the other kids. I think, I don't know, just being home and in that really quiet environment then going back to the very loud, chaotic school environment he had a lot of trouble adjusting back. At first, we really thought it was just like well it was because he had COVID and then it's a new classroom. There's a lot of new stuff, like, he'll adjust. I'll be fine. But it didn't really get better, and he really kept struggling and he was exhibiting some behaviors that were disruptive and just outbursts or aggression or things like that. It was his teachers there that said this really isn't typical of what we'd expect we think you should get him tested. They had recommended getting tested through the public school, which we did, but we also I just felt like, well, if I'm going to do this, I'm going to do it thoroughly because that's just, I guess my style [LAUGHTER]. I went and I found a doctor who does neuropsych evaluations, and I had him do a full neuropsych evaluation. Then that was how we got the diagnosis of the ASD and the ADHD and to be honest, we were surprised. We really didn't think that anything was not typical, but I guess in retrospect and then seeing how things progressed it made sense in retrospect, but at the time, we were actually fairly surprised. But that was how we came about getting the diagnosis.

[00:17:05]

How did you react and how your family react when you told them. How was the [OVERLAPPING]

[00:17:15]

I mean, everyone was super supportive. I mean, I think our initial reaction and also some folks in the family or even outside the family, really were like, but he can't be autistic. Like, he seems so normal or typical I think that's as I've learned more about autism what I've learned is that an autistic child or an adult can present as very what you'd call typical.

[00:17:44]

In a lot of situations, but it doesn't mean that they aren't autistic. It just means that they've found, I guess, maybe in those situations they're comfortable or maybe they're masking, which is working really hard to fit in with what's typical, even though it's very difficult for them. But everyone has been super supportive. We have a wonderful support network of grandparents and in laws, my brother-in-law and cousins and everything like that, and they've all just been, what do we need to know? How can we help him? How can we help you? It's been really wonderful and he's surrounded by a lot of loving, caring families.

[00:18:23]

That's wonderful.

[00:18:24]

Like I said, now that we understand more about autism, we're like, that makes sense and now we can better help him to deal with whatever challenges he might come across.

[00:18:37]

Also, after diagnosis, how did your family life structure changed?

[00:18:46]

I don't know that it changed dramatically. I think, at that time, he was really struggling in that school that he was in and we realized that it just wasn't a good fit. At first, we weren't sure, was it just the school or was it him or what was the problem? We ended up trying a different school that also didn't really work out and then so I ended up taking a leave of absence and just being home with him for a few months. Then so we went through the process and we were offered a spot in the public preschool with an IEP, but it was two hours a day and my husband and I both work, and we're like, well, what's he going to do the rest of the day? We couldn't find anything that would accept him part time, so what we ended up doing was we chose an ABA program, which for those who don't know, that's applied behavior analysis. It's common in the autism world. It is controversial in the sense that in the past, it was, I think, done differently and it has changed a lot, I think, or at least what we did is nothing like what I've heard it was in the past. But we did a lot of very careful research. I was a little bit skeptical about it. But we did careful research and we found a really great place where it was support for our son, but also for us as well. They did home visits and they counseled us and gave us advice and really included us in his care. I guess it changed in the sense that we put him in a different type of program for a couple of years and that I think helped. He had lost some of his confidence I think going through the struggles when he was in school and there were even adults who said some unkind things to him and made him feel bad like he was a bad kid or something, which honestly, no kid is a bad kid. They're all just doing their best. Being in this different program I think helped helped him gain his confidence back and helped us just feel a little bit more supported. It was great because at least the program that we went to, they were really just giving him coping skills, giving him the vocabulary and the ability to understand what's going on with his body and to feel when he's getting upset and to learn different ways to manage that and to learn to communicate and advocate for himself and feel good about himself. It was not anything about changing who he is or anything like that. It was just about giving him the skills to manage the challenges that he might experience.

[00:21:35]

Might experience. Do you think, Melissa, that having the diagnosis helps more at school and even for yourself or your family to understand the behavior? Because clearly there is this expectation that people should behave in a certain way. That's what we do. Our bias comes really strong when you think that people should behave this way, talk this way, all that kind of thing. If they see a child behave in a different way, that there's not expectation, they are going to judge first is the parents and that poor kid. The program that you described that give you more instruction and more support in terms of how the parents and even how to understand the environment around you. Correct?

[00:22:29]

No, absolutely. I think once we started learning about autism and connecting it with with him and realizing, that makes sense now. It certainly helps us to communicate better with him and to help him feel just more comfortable and then be in situations that he can feel comfortable in. Then it absolutely opens the door to different services and supports that there are some things out there where you don't necessarily need a diagnosis and you can just self-identify as part of a community. But there are also plenty of resources where you have to have a formal diagnosis. Technically, I'm not sure how it works exactly with the IEP, but it's certainly much easier to get an IEP, the individualized education program at school or plan. It's certainly much easier to get that if you have a formal diagnosis or in this case, more than one and that way you can get all those educational supports to help them through school. Luckily for us, that did open those doors and we actually meeting tomorrow, but he has a pretty robust IEP already and we're just going to finalize it tomorrow after they did an extended evaluation. It certainly helps to just make more, I guess, support and resources available to someone.

[00:23:47]

Also, for you, you're working because there are circumstances, sometimes the difficulty for parents when they are working and there is a call from the school, whether it's a fever, whether it's a flu, whatever it is that's happening, you need to leave and go there if you don't have someone to support. For example, family members or your husband is not available as well, working somewhere else, and you are the person that has to leave work and go. This also helps to be able to tell your work, here's what's happening, how you need to leave and take care of my child because that's what's happening.

[00:24:29]

Absolutely. I'm fortunate that the office I work in is extraordinarily flexible and understanding about the situation, and they're very well aware of my son's diagnoses. But certainly, it can be difficult. Luckily, it doesn't happen now that he's in kindergarten and the staff there has been amazing so far. But when he was in the private daycare situation, we were in a situation where we got phone calls almost every day for a little while. He was just really struggling during that period and it was tough because even if I wasn't the one going to pick him up necessarily, you're thinking about it and you're stressed about it. Your heart breaks when your child is not having a good experience and they're struggling, and so it can be it takes an emotional toll and a mental toll, and it can be really hard then to focus back and say, well, I know someone else is physically taking care of my son, but I still am thinking about it and worrying about him and worrying about how we're going to handle this and make things better for him. It can definitely be hard to detach, I guess, from some of that. For example, with the IEP meeting tomorrow, even though I know the team and they're great and I don't expect it to be contentious or anything like that, it's still I'm taking off the afternoon because I'm going to go to the meeting and then I can't even fathom working after that because it's still emotional and draining and there's so much that goes into it. I'm just like, I'm going, I always do that. I take off the rest of the day after I go to one of those meetings because it's just too much to try to go back and forth into those different mindsets.

[00:26:03]

Very true to exactly what you said, getting in and out of that way of thinking. I think I have said that before in another conversation that we have in different topic, but still related to parenting.

[00:26:20]

I can't remember the name of the article. It's been long time ago, but I never forget how much that made a difference for myself. I don't have children, and this is a story, an article that someone wrote from the time that she was single. She was in a course store. Mother had two children, and one gave a huge tantrum. She was in her own thoughts, so judgmental thing, oh, my God, why bringing these kids here? Why allowing to be so loud? Why don't you correct them? All those things that people usually who do not have children and do not understand how it is to raise a child behave, and how they should. Then she had her child. Then she went to stores, and then her child behaves and had the tantrums and have all that. It is an apology for the Coop's mother that she met at that time and the internal judgment that she had. She didn't verbalize that to the person. But she said, I now understand you and I totally understand how it is. I feel the same way, and reading that article long ago, now and I am in a bus or even in a train or if I am in an airplane thinking about that mother, those parents when the child probably is tired or there is over stimulation if it is a diagnosis of some sort, a neuro divergent child. How those parents feel because there is a whole group of people sitting there for a period of time going through that as well. I have a completely different understanding and more empathy based on that one. I hope that's the meaning of what you are doing here to tell other people, too, if they listen to our story, how important it is for you to have some empathy before you judge too hard, have some right to figure out a little bit, try to understand that there is something that not necessarily what you think, and let the parents take care of that and give them some understanding that would be nice.

[00:28:40]

A 100%. I think parenting my child has definitely made me more of an empathetic person. I think I hopefully was before. But I think we've all been guilty at one time or another of silently judging someone for something. I don't think anyone can say they've never done it. But I think having a child who has these diagnoses and struggles at times, it has definitely opened my eyes to just remember that everyone is struggling with something. When I see other parents out and about in the world and they may have a child who's unhappy or having whether it's tantrum or meltdown, I can't tell. But I don't interfere, but I'll try to give them a smile like I see you and you're good. You've got this. I try to be supportive in a silent and unobtrusive way because I know that it's more difficult than others may realize and they're doing their best. I think it does help us to remember, not that we necessarily want to say that neurodivergence, that it's an excuse for terrible behavior as an adult or something. Obviously, there are limits but I think just remembering that everyone is struggling with something and that we don't know the full story.

[00:30:09]

Exactly. I think that's an important message. Do you have other children or you have just one child?

[00:30:17]

No. We just have the one, so no siblings. Unfortunately, no cousins his age either.

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[OVERLAPPING] That's what would be my follow-up question there. There are no other kids around that your son could be playing with?

[00:30:29]

Not really. Honestly, it's interesting. COVID happened when he was two, and we were living in an apartment building, and we had some neighbors that had kids around his age and we're like, we're going to start doing play dates, and we met some other really nice families and we were starting to do that, and then COVID happened and all of that stuff.

[00:30:48]

Everything went to isolation.

[00:30:50]

He did go to daycare for part of that because we really didn't have another option. He also spent a fair amount of time just with my in laws and other adults in the family who could help out while we were working. Honestly, I'd be really interested. This is a little off topic, but I'd really love to see research at some point about how COVID affected people with autism, specifically, because I feel like he might have had some struggles anyway, of course, but I think that really made it a lot harder because he was at a really critical time when he could have been developing those social skills and interacting with other kids, and then it all just shut down, and all he really had was adults around him. I feel bad that he missed out on a couple of years of that building and being around other kids.

[00:31:42]

Interesting, Melissa. I was going to the opposite. I was thinking that COVID was for me in my ignorance here, I thought that, well, because the isolation maybe was easier because he didn't have too much of stimuli around or that thing. But you bring in a completely different point. The chance to be interacting with other kids and see how that would go, and develop from there. I would think to the other saying, now, if what they always ask is a little bit more quiet time and isolation because too much of this stimulus can be a problem. But then you are talking about a different way of how it would have been which is also interesting, you're right, to find out if there is any research, any data there in case what happened.

[00:32:34]

Because it would have been what I'm thinking of is one on one, small play dates where at that age, you let them figure stuff out, but you're also there to coach them and help them. Then afterwards, you can explain a situation or try to explain why someone might have acted that way. I feel like that's an important part of just learning social skills because it's in a small setting and you can do a little bit of coaching. Then once they're in, say, kindergarten, they're expected to have a certain base level of understanding of unwritten social roles. That's a hard thing for autistic people, anyway, unwritten social rules. Then if you missed out on some of that critical social interaction very young, I would think it probably made it more difficult, but I'd be really curious at some point. I hope someone's doing that research. [LAUGHTER]

[00:33:33]

We should try to figure it out. It would be nice. If you have that information by the time you have a depend, would it be nice to tell them I have that information. Where and how have you found resources to support you and your child?

[00:33:50]

A bunch of different places. I think I started with just reading. I've always been a big reader, and I'm a nerd. I love learning. I'm just like, Let me take out every book in the library and start learning about autism and ADHD. Then I just did some Googling, essentially, and I found there's a local organization. I live on the south shore of Massachusetts so our local organization is Community Autism Resources. I think they're funded by DDS, but you don't have to have DDS to be [OVERLAPPING]

[00:34:26]

What is DDS?

[00:34:27]

DDS is Department of Developmental Services. Children can qualify for certain, I guess, aid. It's like, run by the state, and they fund, different centers across the state that provide support for autism. Our center is car, and they're wonderful. You can just email them and they'll send you a whole bunch of resources, and then they run a monthly parent support group that we've been going to for about a year. They run a retreat once a year that we went on. It was an overnight retreat for parents. They have wonderful resources, and we've met lots of other people. Then there's also tons of Facebook groups out there for my local area, and then there's more national ones. Then I feel like you tap into one resource, and then as you talk to people or learn about that, you find out about some other thing. It's did you hear about this program or this camp or this doctor or whatever? Then each thing you find out it leads to something else, and it's just a lot of things that happen to just hear about because it's just like you go from one thing to another and keep accumulating your knowledge.

[00:35:46]

Now, you say that and I want to ask you, as well. When everybody knows the language runs faster so you can just get there and you can run over steps that would be different if you have to explain to someone that's not familiar with autism. Does that make a difference?

[00:36:05]

Yes, I think it does, and that's not to say, I have plenty of other friends who are even not parents or don't have autistic kids. But I think there is certainly it helps to be in a group where you don't have to explain some of the background of what is autism or how are the different ways it could potentially manifest or what are the different types of challenges that your child may face or you may face. You can just jump right into what your concern is for that day without having to go into a ton of background.

[00:36:37]

Does that also take the weight of judgment?

[00:36:39]

Yeah, it's a very welcoming environment and you feel like you can just be totally honest about what's going on and not have judgment, and the other parents just get it because they've been through maybe not the same thing, but similar enough and it is a shared language, not that other parents couldn't understand.

[00:36:58]

Takes a while. Demands more explanation, you should not need to explain too much. I think that's what you're talking about inclusion. Belonging, feeling that you can be yourself in that place without having to explain too much and people will be accepting.

[00:37:17]

Another thing that I want you to touch is, how is your child in terms of expressing himself? What are the things that attracts more to him that got more excited about and he get invested? What are the typical things that makes him happier and he's more invested?

[00:37:43]

He'll find a couple of specific topics that he really loves, and then he'll just talk. He can talk all day about those topics and in great depth. For a while, it was PAW Patrol. That was his thing, and then, now I think he's outgrown that. Now, he really loves Legos.

[00:38:01]

Oh, he does love Legos?

[00:38:03]

He's really good.

[00:38:04]

Building up things.

[00:38:05]

Building, yeah. Then he loves math. He'll watch on YouTube these math videos and he'll just spout out facts about numbers, which is great. I'm trying to think, so he loves Minecraft. He doesn't play it, but he's seen, how there's videos of other people playing a video game, and he'll watch some of those.

[00:38:28]

My nephews is all over that thing. I keep looking at that in my age. I have no clue, no uncle this is how it goes. I'll be here watching with you, but I have no clue. Go ahead, sorry.

[00:38:40]

No. He's very imaginative, so he comes up with, his own very elaborate games and stuff like that. He'll get fixated on a particular show or topic or something, and then, he'll just love to talk about that and he'll want to I don't know, he'll use it as a springboard to imagine all different scenarios or games and things like that. He's very creative.

[00:39:03]

Emotionally, how is the interaction? He reacts well to the emotion, he express or he's still a little bit, step back in certain ways?

[00:39:14]

It's hard to explain. I feel like there's this common misconception that autistic people, are unemotional or don't understand emotions. I think that's in a lot of cases, not accurate. Actually, what tends to be the case, for a lot of people is that they feel things extremely deeply. That's where the challenge comes from. It's so overwhelming because they feel so deeply and so strongly. I think that is true for my son. I think, his feelings run very deep. Through the ABA program and also, we've gotten him tons of books about, emotions and all these things, he has honestly, he's very self aware, and he has incredible, emotional vocabulary. He'll talk about, I'm frustrated about this, and I'm angry about this, and he'll tell you exactly why and he'll explain his thought process, and he's very comfortable talking about emotions. Sometimes you don't feel like you're succeeding as a parent, but at least in that regard, I feel really, proud of him and I feel we did something good there because he really can talk about what he's feeling in a way that other people can understand, and other adults have commented, wow, he's really self aware and he can really express himself. I think all kids really should have lessons that focus on that because it's such an important life skill. I feel like it goes so quickly into the academics now. But actually, I think he's really ahead of the game in that sense.

[00:40:45]

Yeah. Melissa do you know while we're talking about that in terms of emotions, another data that I would like to know more, maybe should research just before we have our panel. Culturally, how different would be autistic children in US versus Europe, Latin America? Because emotions for Latinos are, in our skin. We can talk about feelings, it's much easier. I wonder how it is for autistic children in different cultures when the emotions are more understood because I don't know if I'm expressing myself, right again, for example, you need to learn more from his deep feelings on emotions that your child has so you can understand why that way. I'm judging. Probably we're not raised the same way to have it all out there. You feel them, but hey, you don't need to be right. I'm curious to see if there is already studies, if there is research already to see how that part is much understandable or taken easier than would be here in the process of a parent and everybody learning how to deal with their emotion or not.

[00:42:12]

No, that's a really fascinating question, actually, and yeah, I hadn't thought of that, but that's really interesting because what I said before about masking, that's in a similar way, someone who's autistic almost hiding and may be conscious or unconscious, but hiding some of their more autistic qualities to fit in with neurotypical society. But now that you say that, I wonder if they don't have to mask as much perhaps in other cultures or if they're masking different things depending on what the social mores and customs are of a different culture. Because here I think there's these ideas of, professionalism and there's these ideas of what's appropriate and and all of that. I think it's not just autistic people. I think that affects a lot of marginalized groups, but, I think autistic people would be certainly included in that. As a parent, maybe it's not quite relevant yet, but I do think a lot about, like, how do I teach my son that he is wonderful the way he is and that he shouldn't have to change and that, he's just a wonderful, great person and, to be who he is and be authentic. But here's what society expects and if you don't meet those expectations, it may limit your opportunities. You sometimes have to make choices. Well, do I want to be myself or do I want to, fit myself into this box, to achieve this or that or reach this or that goal and that's tough. I guess I can just give him the information, and hopefully he can make those decisions for himself. I don't know, but it's frustrating that [inaudible 00:44:03] has to be a conversation. The world, I wish it could just be more inclusive so that it would be more open to different types of people without it without needing those kind of accommodations because it's just more flexible to begin with.

[00:44:20]

If you can talk a little bit, what have been the most challenging and rewarding aspects of a parenting a child with autism?

[00:44:29]

Sure.

[00:44:31]

I think the most challenging in the beginning, I guess, before we had the diagnosis was just seeing him struggle and not knowing how to help. Because I think we mentioned this before, but it's always difficult to watch your child struggle. Obviously, you can't fix every single problem for them. But when they're younger of course, you're going to be more hands on and you just hate to see them struggling in a situation where you just assume they're just going to go to daycare, and it's going to be fine, and it's not going to be a big deal. Then he just was so unhappy and like I said, his self-esteem was struck, he was having difficulty with that. I think that was before the diagnosis. Then since the diagnosis, I think just talking about the co-regulation piece having to maintain your own calm in a situation where maybe there's heightened emotions and that can be in the moment you're just doing it. But then afterwards, you feel so drained because you're really marshaling all of your emotional resources, because your body is designed for that fight or flight. If there's an escalation or heightened emotions, your natural response is to meet that and to want to engage with it or get more emotionally yourself, and so you're really fighting your body's natural response to be like, nope, I am going to stay calm. Sometimes it may take five minutes and sometimes it may take half an hour if it was just a really difficult situation to help your child calm down. I think those situations and just that's been challenging and just trying to navigate all of the different services and supports and the IEP. There's just a lot of extra stuff that comes with it and things feeling like, I have to do this research and I have to make sure I know everything that I can possibly know and find every resource that could possibly help because as a parent I think there's this natural feeling of guilt that every parent has and you want to do the best for your child. But when they have this additional diagnosis, I think you worry more like, what if I'm missing something that really would have helped him or what if I'm missing this opportunity or I think there's just more opportunity for worrying that you're not doing enough or that you're not making the right choices for your kid or something like that. I guess that's a little bit heightened. But in terms of the rewarding aspect, I think just seeing the progress he's made. He's, like I said, with his emotional intelligence. Yes, there's some areas still struggling with socializing and things like that. But that'll come and just the fact that he can talk about his emotions. He's just so self-aware and so smart and the fact that he knows that he has, because we've told him about his diagnosis and he knows that he has these diagnoses, and he as much as a six-year-old can, he understands what they mean. He's very open about them, and he's worked really hard to try to learn different coping skills. We're so proud of how hard he's worked and how much he's learned and how much progress he's made and just seeing your kid now that he's in kindergarten, and he's doing great. He's been really happy, and the supports there are really helping him and just seeing him be happy and seeing him be successful in the more mainstream environment. He does have a special ed classroom, but he's spending most of his time in the mainstream classroom. Just seeing him have that confidence in himself, and now he's like, "I'm a big boy, so I can do these things independently at home, too." I'm sure that's probably rewarding for every parent, but I think just when you see I guess you see certain milestones or things that other kids, I guess, it comes more easily to them, or they take it for granted. Of course, the kid's going to hit this milestone. It's like every kid does that. But actually, it's maybe not every kid does or maybe it's not as easy for every kid. Seeing him hit those milestones or achieve those things that were twice as hard for him or three times as hard because of his struggles, and seeing him be proud of himself is wonderful.

[00:49:31]

He enjoys going to school?

[00:49:32]

He does.

[00:49:34]

That's nice. Because that's a good reaction as well. My next question relate to that. I'm going to change a little bit one that we have here that's also based on that part because you said how much he has learned and everything else. What have you learned with your child that changed you?

[00:49:57]

I think the empathy piece that we talked about that was certainly has helped me grow as a person. I'm trying to think.

[00:50:08]

What about emotions? Because when you say that is easier for him to say, I'm frustrated right now. I am identifying what's happening. This is not common for us. We should be more aware of that. We retain too much and sometimes don't name it.

[00:50:32]

That's true.

[00:50:33]

Get frustrated with everything else around and everybody pays a price for that, whether it's co-worker or husband, wives, children, other children, whatever, whoever it is, or someone in the store, someone is going to. While they identify and say, I'm feeling this right now, and I need to have this time to process this. I feel like we should learn more of this thing. That's why I mean in terms of emotions.

[00:51:03]

No, that's true. I think I have tried to do more of that, partly as trying to model it for him, but also partly because, like you said, it's a useful thing to do instead of just stewing or being grumpy and people are like, "Why are you so grumpy?" or whatever the case may be. Now just naming it and saying, I'm really stressed by this situation right now, and I'm struggling to get control of it, but don't take it personally or I'm here with you. Half of my brain is just on this thing. I've done it with my son. I've said, I'm really sad today because such and such happened or I had a really hard day at work, but if I seem a little off or tired, it's not you. It's just I had a hard day, but I'm working to put it aside and let's do something fun together or whatever. I think it is good to be conscious of that.

[00:51:54]

That's nice. What do you want people to know about autism?

[00:52:03]

You're a child.

[00:52:05]

Yeah. I think a few things. One thing is just, I think, remembering that piece about how behavior is communication. I think that's really true for every child, but especially for autistic kids. There's, I think it's, I want to say it's Ross Greene and there's this author who's written a lot about children in general. He says that children do well if they can. If they're struggling, it's because they don't have the tools or the resources or whatever, and they're just trying to get their needs met. I think that can help us have compassion for all kids. But I think also one thing that I found when my son, in particular, was struggling before his diagnosis is, some adults, and I get it, they have a job to do and whatever, but some adults would only see the challenges and they wouldn't see the full person, and he has so many just wonderful qualities. I want to, I guess, remind people that, even if a child or an adult, anyone, has an autism diagnosis or ADHD or whatever the case may be, that's not everything about them. That's not the only thing that defines them and nor should it. They're a whole person, and they have a lot of other things going on, and other qualities, and other interests, and just remembering to look even if someone has struggles, you don't have to define them that way. Yes, my son had moments of acting out or challenging behavior, but he also is the funniest kid I've ever met. He's so creative, and curious, and silly, and smart, and just so many wonderful things. One of the things that I loved when we went to the ABA program is that they immediately saw his good qualities, too, and they were looking at him as a whole child and not just this particular small set of challenges or something. They really saw who he was and were trying to nurture him to bring out those good qualities.

[00:54:21]

Perfect. An advice you would give to a family who is with a newly diagnosed child?

[00:54:33]

Everyone, I think, processes things differently. Even my husband and myself, we both went about it a little bit differently, but for me, it was like, I wanted to read everything I could about autism and ADHD to feel educated. Because I have a background as a lawyer, I was all into the IEP educational regulations and what kids are entitled to and all of that stuff because that's a comfort zone for me, I guess. But I think just seek out information in whatever way is comfortable for you. There are resources out there and don't be afraid. I think the biggest thing is don't be afraid to ask for help. There was just this surgeon general's report about how parents are struggling and there needs to be more support. All parents are struggling, but I think then if you add the extra needs, the autism or something else on top of that, no one can do it alone, and there's absolutely no shame in asking for help, so seek out. There's organizations that provide help, there's grants that can provide different funding, there's Facebook groups, there's probably other support groups, there's books, there's podcasts like this, there's YouTube channels, whatever the case may be. It's not necessarily all centralized, but there are a ton of resources.

[00:56:00]

That are available.

[00:56:01]

Just find what meets your needs and feels comfortable for you, and don't be afraid to take advantage of those.

[00:56:08]

Great. I also know that you start a group at Harvard University.

[00:56:14]

Yes, I did. I started a group at Harvard. I think I called it the Harvard Parents of Children With Special Needs. It's essentially just a group where people can come together. It's for anyone who's an employee across all of Harvard. We have members from the medical school, the law school, the Kennedy School, Graduate School of Education, just all over Harvard. People can come and just talk and share their stories, and share resources, and have some support if they're parenting a child with special needs. That can include autism. Really, if you feel like you fit the definition, then you fit the definition. It's meant to be very inclusive. Anyone who feels like they could benefit from the group, we're happy to have them. I basically started it because I assumed a group like that would exist already, and I started looking for one because I found it difficult just juggling the demands of work and parenthood. I think Harvard is a place where, it attracts people who are high achievers, and I've always been someone who I take pride in my work and I want to do my best and bring 100% every day, but I was struggling with that. I was like, well, maybe there's other parents who work at Harvard who are struggling with something similar and it would be great just to feel like I'm not alone in that and get some support there. I realized that there wasn't a group already, so I started asking some questions and reached out to, I'm trying to think it was maybe the Office of Work Life, or CWD, or a few different places, the disability office. I confirmed this group doesn't exist, but I went through the appropriate channels and said, can I start a group? Is that okay? How do I do? After a while, I got the go ahead and started a group. Pretty quickly, I think we're up to 40 members.

[00:58:20]

Already?

[00:58:20]

Yeah.

[00:58:21]

Wow. Nice.

[00:58:23]

I think we started roughly a year ago, maybe a little less. That's been great. We just meet over Zoom every few months. I usually book an hour, and there's no set agenda, really. People can just talk about whatever is on their mind with their kids, whether it's school issues, or things at home, or they can talk about challenges or wins, things that have gone well that they're proud of, whatever they want to talk about. We share resources with one another every meeting I end up with this. Obviously, the specific stories and things stay confidential, but very often in the meetings, we'll share resources like, here's a doctor who's really great with autistic kids, or here's a summer camp for autistic kids or something like that. I keep a running list. In our files, we have a Microsoft Teams group where we can all communicate between meetings if we want to just ask questions or connect. We have a whole bunch of files with all the resources that we've shared, and people can refer back to that. We've had guest speakers. We had Harvard's EAP provider come and talk about different resources that might be available through the EAP, that would maybe be specially applicable to or relevant to parents of children with special needs. It's been amazing. I'm really glad that I started the group, and I'm glad that it's had such a great response. It definitely has made me feel less alone, and I hope it's done that for other folks who are participating as well. Like I said, it's really open to anyone who feels like they meet that definition of a parent working at Harvard, who has a child with special needs of some kind. Pretty much, you can reach out to me, shoot me an email, and I can add you to the group.

[01:00:15]

That's great. Thank you, Melissa. I think you are getting to the end of our conversation. Thank you very much for accepting to come and participate. I know that you are going to have our panel on April 2nd to talk about with other folks in our HLS community. I wish you well. Thank you for everything that you are doing. Thanks for the group that you created because I think it's very important. I know that you may having a group of people that you can also talk about things that matters to you and feel less lonely in that segment is really important, too, is a part of what we talk about inclusion as well. Thank you very much for coming all the way from medical school to see us to see us. But it's interesting that a lawyer come from medical school to law school to talk to us.

[01:01:09]

It is funny.

[01:01:12]

You see that we end up we're going to find our lawyers anywhere they are.

[01:01:15]

Full circle.

[01:01:17]

Thank you very much for participating. I really appreciate that.

[01:01:21]

Well, thank you so much for having me. It was a pleasure to be here.

[01:01:24]

Thank you. For everybody out there, until our next time. Bye bye.