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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 Klay Filho from the Equal Opportunity Office. My pronouns are he, him, his. Today, we are talking to Allison Patenaud from CEEB who will tell us about her story as a parent of an autistic child. Thank you for joining us, Allison. Please tell us a little bit about yourself and the work you do at Harvard.

[00:00:51]

Thank you, Edgar, for having me today.

[00:00:54]

What do you do at Harvard?

[00:00:57]

I am the director of Community Engagement, Equity and Belonging at Harvard Law School. What that means is I work primarily with student organizations, student journals, and then I also help with mentorship programs. But I do actually kind of oversee a lot of the different aspects of SIB and our portfolio. I work with future leaders in law in the summer and help Dean Monroe on any initiatives that she is working on. I try to just kind of be available for anything that's going on in CEEB.

[00:01:33]

In your office, you have all the organizations and journals?

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We do. Yes. It is. We have around over 100 student organizations and journals right now at HLS.

[00:01:45]

Wow.

[00:01:46]

I work a lot with students, which I love. It's a real blessing to work with students every day.

[00:01:51]

Yeah, I remember that feeling. I work with them, too. I was part of the office in the past, so I know exactly what you're talking about. It is a great feeling. Okay, let's jump right on our topic here. How would you define autism to someone who has never met a person with autism?

[00:02:08]

Sure. Autism is a neurodivergence in people and I think it's hard to define autism because there's so many different characteristics as it's on a spectrum. Yeah. But I think some people classify it as a learning disability, some people classify it as neurodivergence, and I just classify it as a part of our life every day.

[00:02:33]

Yeah. When did you first realize or suspect that your child was autistic and how did you get them formally diagnosed?

[00:02:42]

Sure. My son, Nathan, is 12-years-old right now. He started off as a typically developing child. He was walking early. He started saying a few words. When he was about 18 months old, I started to notice some regression. He stopped waving at us. He stopped saying mama and dada, and he wouldn't respond to his name when we would say his name. He wouldn't turn around anymore. Initially we thought that he had a hearing problem. Like he had hearing loss. We took him to the pediatrician, and my pediatrician said, no, it's just it's just boys develop later than girls. I should also mention I was about eight or nine months pregnant when this started with my second child second child. I just kept thinking, as a mother sometimes does, like, there is something going on here. I told my pediatrician, I really think that we should at least have a consult with early intervention and so early intervention came in two days before I gave birth to my second child and said, Yes, there's some serious red flags for autism and so that was really difficult because we were in such a transitional point in our family about to welcome my daughter. We started with early intervention very soon after I gave birth and he would go once a week to an early intervention center. And then we also went on a waiting list for both Mass General Lurie Center, which is their Autism Center and Children's Hospital, waiting. There's sometimes year to year and a half waiting list to get an official diagnosis. We waited about six months, and then we got a call from Children's Hospital. This was about December and Nathan had just turned two and we went to children's hospital and had the full workup, and they very, like, clearly said, yes, he's autistic.

[00:05:03]

Then they already gave you the diagnosis in the spectrum.

[00:05:08]

They didn't. Initially, like 12 years ago, they didn't have the spectrum, they just identified that it was autism.

[00:05:16]

One thing, I'm sorry to cut you, but one thing that I'm curious is so and I'm saying this also because I'm surprised because I don't know at all anything about this. But also for folks listening, until 18 months, you felt like it was neurotypical child like any other.

[00:05:38]

Yeah.

[00:05:38]

Was already expressing some words, acting and then there was a progression in a different direction that you said.

[00:05:45]

Correct. Like a regression.

[00:05:47]

Really?

[00:05:47]

Yes. A lot of people actually think and this was debunked very early on in research with autism, but think that vaccinations have something to do with it because a lot of kids on the spectrum start to regress around that time. That's been that's certainly been debunked. Just so everyone that's listening that vaccinations do not cause autism. But that is something that people think because around 18 months is when you kind of finish up your series of shots. You know, that is when the regression started, but it has nothing to do with vaccines.

[00:06:26]

For the amount of people who have been vaccinated in the past, for the same vaccines that became apparent for everybody to take, we would have much more if they thought going through that direction, thinking that the vaccine has anything to do with it.

[00:06:40]

Correct.

[00:06:41]

Because you have, I think, a growing number of autism around the world recently, that they still don't know.

[00:06:50]

There's definitely research being done. There's only one tie currently that people like scientifically know. If you have what's called fragile X syndrome, you most likely will have autism. But I got tested for fragile X early on in this process, and I don't I'm not a carrier of fragile X, and the mother passes fragile X down to the child and so Nathan doesn't have fragile X either, so that's not a correlation.

[00:07:21]

Correlation that explanation that they gave. How did your family members react to the when you had the diagnose? That's a great question. For I'm saying your immediate family, you, your husband. And you said that you were just having this second child.

[00:07:40]

Yeah.

[00:07:40]

Then, of course.

[00:07:41]

Our extended family.

[00:07:42]

Your extended family.

[00:07:43]

Yeah. My husband and I, luckily, have a really solid marriage. We've been married for 16 years now. But, you know, this was shocking because I think with autism, it's not like you can plan. Like, this is going to happen. We're going to have a child with different needs, and we are going to need to plan for that. This just got dropped on us really very shortly after I had my second before I had my second child.

[00:08:15]

Yeah.

[00:08:17]

It was shocking. We weren't sad for ourselves. We were sad for our child just because we don't want him to struggle. As we know, the world can be really harsh.

[00:08:31]

Yeah.

[00:08:33]

We were very frightened for what was going to happen. But we didn't know how it was going to manifest. We didn't know how it was going to progress in his body or how he would progress in school. But we started immediately getting him as many therapies as possible.

[00:08:54]

Trying to find all the resources that would have [OVERLAPPING]

[00:08:56]

Yeah, we really dug in with research. My husband's also an educator. He's a teacher, so he does have autistic children that come through his school as well. He's a fifth-grade teacher. We really try to support each other as much as possible. My daughter doesn't know any differently because she was so little. By the time Nathan was officially diagnosed, she was about five months old, so this has always been a part of her life. It was one of those things where some of our family members were so supportive and there immediately. My parents, for instance, who are older and didn't really know anything about autism were just like, whatever you need, we will provide you or help you with, and whatever we can do. I have older siblings that have children, and they were all really supportive, as well. Some of my aunts and uncles were so supportive and just like, anything we can help you with, and it was great. Some of our other family members were scared and didn't have the words or the understanding of what was going on and made it about themselves; so how do you think I feel now that I have a grandchild with autism or a nephew with autism or niece with it?

[00:10:25]

Yes.

[00:10:28]

That was tough. Most of our family members have come around and are so supportive now but in the early days, we felt very isolated. Some of our family was so supportive and others were just [OVERLAPPING] not at all or just kept us at a distance because they didn't know how to act around Nathan and they didn't know what he was going to do. I think it was ignorance.

[00:10:59]

Yeah, I believe it is.

[00:11:04]

Those relationships had to be rebuilt in a different way, which was complicated and at times, very sad, but I feel like we're in a much better place as a family unit today than we were back then.

[00:11:20]

That already goes into what my next following-up question would be in terms of how your family life structure changes because when you have something new that you need to deal with, and there is a lot in terms of a behavior, and people judge in different ways based on what should be acceptable for a child to behave in certain place publicly and even in your family. Starting in your family in gatherings, in birthday parties, whatever that you have. If one child is a little bit wilder than the others, of course, there would be, "Oh, you are not raising your child properly".

[00:12:01]

Correct.

[00:12:03]

Then if it's in the public space, then you have other lenses because other people, oh, my God, how you let your child to behave this way. Then you have a child with a diagnosis that has nothing to do about how it's being raised is how the brain works. How all these stimulus around is going to affect that child that moment; the noise, the visual, too many people touching, everything else, and we still need to face judgment. At the same time, like you just said, ignorance. I can see some people being scared how to approach, how to behave, what to say, can't touch or cannot touch, can say something loud or cannot say. We can give the benefit of the doubt for those who feel that they don't know what to do, but everyone could have a chance to say, how should I act, or tell me what I should be doing that would make your life easier. Or how can I interact with your child in a way that can be acceptable to you? I think that would be the easiest for everyone.

[00:13:10]

I think everybody has their own stuff going on, so we weren't thinking that our families and friends were going to stop and just help us immediately.

[00:13:18]

But interaction or being there if you need, it would be an easier way. Like we're friends.

[00:13:32]

Right. We're here if you need us. We will support you and Nathan as much as we can is what we needed. We didn't get that. We actually lost a lot of friends, and then we made a lot of new amazing friends from the community. But we lost a lot of friends initially just because they didn't want to deal. They didn't want our kid running around their house and jumping on their furniture, and even it doesn't matter how many times I tell him to stop, he's not going to stop, and that's not his fault. Nathan also has several other diagnoses besides just autism. He also has attention hyperactive deficit disorder.

[00:14:16]

The ADHD.

[00:14:16]

ADHD. Then recently in the last two years, he was diagnosed with a seizure disorder, so he is also epileptic. He's had some massive seizures that we have been dealing with as a family. There's several different things going on with Nathan. But back when autism was the only thing that we knew. I think we're an open book. Anytime anybody wants to ask me, I'm never someone to say, no, I don't want to talk about that. I'm happy to answer questions. I'm happy to talk about resources with other people if they need help with resources because we didn't have a lot of that. We were just flying by the seat of our pants, and we were really lucky that we were able to get the help that we did. Right after Nathan was diagnosed and we started early intervention, we started, you can get ABA therapy in-house until the child's three years old, and then they'll go into public school. We started interviewing with different ABA centers around Massachusetts, and we were so fortunate that we got an interview with The New England Center for Children, which is the Number 1 and one of the oldest autism schools in the country. They had fantastic therapist that would come to our house 30 hours a week and work with Nathan.

[00:15:45]

Wow.

[00:15:46]

It was so fantastic. Some of these people we're still friendly with. We went to their weddings. We've seen their children grow up because we needed that community. We needed someone to understand what we were going through. We have some great friends that we kept after he was diagnosed and came in and helped us, but they didn't have kids with autism, so they didn't understand.

[00:16:10]

Wow. But they were there with you?

[00:16:13]

Yeah, definitely. We had friends that were like, we'll babysit, we'll do whatever you need to do to help you all, but we don't know what you're going through. When you finally find a community that knows what you're going through, and I think the best thing that ever happened to us was we had an early intervention. They had a parents' group every Thursday. I would go to the parents' group, and then the therapist would take the kids in the other room, and all the parents would sit with the therapist and talk about the struggles of the week.

[00:16:45]

Wow.

[00:16:47]

Those people became a second family to me. Early intervention age ends the day the child turns three years old. That's it, and then early intervention's over.

[00:17:02]

Wow.

[00:17:03]

We ended up all connecting and staying together. We still meet once a month, almost all of us, all these families at each other's homes, and just the parents. We call it play group.

[00:17:19]

We still talk about struggles that we have and things that our kids are going through, and our kids are on the spectrum for different types of autism. I know that sounds weird, but it's a spectrum. They are on the whole range of the spectrum. But you can see the different struggles that the children have and then us as parents have. It's been so fantastic to continue to have these people in our lives.

[00:17:51]

I have so many questions based on just what you said because it sounds like an amazing group of folks getting together. It's I think what I have asked before for other members is like when you speak the same language.

[00:18:05]

Exactly.

[00:18:05]

You don't have to explain too much. You don't have to justify too much. Everybody understand if the child is behaving or starting having a moment that you don't need to be feeling uncomfortable to, I'm sorry about this. You are going to take care of that, or they are going to understand what's going on there. Can you imagine communities or places that don't have the community that you have to start with, but also the support, medical support that you had from the beginning. How that would be or how challenging?

[00:18:40]

Yeah, it would be so challenging. Some parents have a different thought on ABA therapy, but it's really worked so well for Nathan. It's Applied Behavioral Analysis is what ABA stands for. Essentially the child does trials throughout the day of different tasks that they need to accomplish. The therapist takes data on that to see how they can adjust.

[00:19:07]

That's going to be my question as well. Your group, for example, this group of folks have different levels in the spectrum and they are keeping data, getting information from the children.

[00:19:19]

Well, so that group, not necessarily because we all went to different schools. Our kids aren't all on the same school system.

[00:19:28]

Yours?

[00:19:29]

Yeah, my child. I probably am skipping several questions on this list.

[00:19:34]

No, that's good. All good.

[00:19:34]

My son, we had to get Nathan out of the public school system just because he is and I think we talked about this. Autism has three different levels which they diagnose currently. One through three, one being the least severe, three being the most severe. Nathan is a definite three. Nathan's completely nonverbal. He doesn't speak at all. He needs a lot of care. He wears a diaper still at night. He can't brush his teeth. He cannot bathe himself. He can feed himself somewhat, but tends to over stuff his mouth and then can choke. We have to monitor how he eats. It's a lot of work. But so the pandemic happened, and he was going into second grade or third grade. Second grade. We couldn't get him out of the school system. We were planning on getting him out of because he was in public school. We had a good special education program at the school that we were at for public school, but it wasn't enough for Nathan. It could have been enough for a lot of students, but it wasn't enough for Nathan.

[00:20:51]

Would it be good enough when you say for a lot of the students, but students in respect of autism from let's suppose 1, 2. More or less.

[00:20:59]

Yes.

[00:20:59]

Not for the level 3?

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Correct. Exactly. We we had to get a lawyer, and we had to fight the school system to get Nathan out of public school, and it took two years.

[00:21:13]

Two years for you to win.

[00:21:14]

Two years.

[00:21:15]

You have enough data information that justified that being in a public school would not be beneficial for this child.

[00:21:22]

Correct. We had to prove over a course of two years that he wasn't meeting any of his IEP goals, if he wasn't progressing educationally, and we had to bring in outside consultants. We had to bring in people that observed from different hospitals to say, this is not a good place for him. In last year, we finally got him out of the school system. We were granted access to leave the school system. Then we had to find a school for him to go to. A lot of the schools right now that are autism specific are wait lists of years and years because we have quite a few students now that have been diagnosed with autism. We needed to find a good fit for him, and we needed it to not be on the other side of the state because we don't want him to be on a bus for a really long period of time. We did end up finding a fantastic school, and we were so lucky that it was between the summer of his fourth grade and fifth grade year, so he didn't have to transition back to public school and then leave the public school system. He got to do that over the summer. His school now, it's called Hopeful Journeys and it's in Beverly, Massachusetts. It's a full year school program, so they don't have summers off. They get a few weeks off a year, and they got regular vacations that students get, but they work throughout the school year. It's a fantastic school.

[00:22:58]

They staffed and prepared for the full year program.

[00:23:01]

Correct.

[00:23:02]

Considering that all the staff you need should have their time as well but they have staffed in a way that will be the students will have their support year long without worrying about how the school regular function should be.

[00:23:15]

Exactly.

[00:23:15]

That's wonderful.

[00:23:16]

It's amazing. They don't just do academics. They teach vocational things. They're working on teeth brushing with Nathan, on pottying with Nathan. They're working on making his bed and sorting his clothes. They have a full apartment in the school that they can show students how to help themselves. They have a PHO dentist's office and a doctor's office, so they can practice that before they go to the doctor or dentist. They have a school store that if the students can work in the school store, that they can help with that. It's just an amazing program. I can't say enough about it, and the staff is just fantastic. But it's been such a huge win for us and specifically for Nathan, because I've seen him grow a lot, and he's been doing so much better now that he's in this place, and he gets to stay there till he's 22-years-old.

[00:24:13]

Really?

[00:24:13]

Yeah, which is amazing.

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That's wonderful. You are already ahead of time. Thank you for being so thorough with that, because that was going to be since he started participating in this program with this school in Beverly. Can you see difference in progression?

[00:24:28]

I can.

[00:24:29]

The learning process that we can do.

[00:24:31]

Yes. Because he's in a group of six students, and each student has a para professional that's just for them. Then it's just such a different environment than a public school system. Again, the public school system that he was in was great for what they had but it wasn't great for him. My daughter still in that public school system. I obviously know it's a good public school system. But I think that for Nathan, especially, like, he has a lot of medical issues. His epilepsy is also something.

[00:25:09]

Needs to be monitored.

[00:25:10]

It needs to be monitored closely and this school has the ability to do that because other students in the school have epilepsy as well. It's just a much more safe environment for him. It's just a special place. It's really wonderful.

[00:25:26]

Why you were describing the school before and some better improvement place that you took before this final one, it felt like they need to observe, when you were saying that there is a wait list for certain school for autism, that takes a year, a year and a half to get into. That's not even enough because you need to consider in each level the children are to have the specific place and the training for those staff to take care of that child because that is clearly a completely different way to take care of them when they are level one and two and to the three, again. Because then they all would be in the same environment being taking care and interacting with each other in the same again, using language as a way to express that. But in the same rhythm in the same understanding, connection there or engagement that you say, you mentioned your other child.

[00:26:26]

Yes.

[00:26:27]

Can you say the name?

[00:26:28]

Yep, my daughter's name is Morgan.

[00:26:31]

Morgan goes to a public school?

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She does. She is in fifth.

[00:26:34]

She's a neurotypical child

[00:26:35]

She's a neurotypical child. She's well above her grade level, especially in maturity, I would say, she's very a sassy fifth grader. She loves Taylor Swift.

[00:26:48]

There you go.

[00:26:49]

She loves sparkles and clothes and sports and just very neurotypical. I think she's such a sweet girl, and I think a lot of it has to do with her brother because she has a lot of patience. She has a lot of resilience. It's scary when you see your brother having a seizure on the floor and you don't know what's going on, especially the first time it happened and we had to call the ambulance and the police came and the fire department, and her brother was taken out. We had no idea what was going on. We didn't know if he had a heart attack or a stroke. We had no idea what was going on, because he can't tell us. He can't tell us, Mum, my head hurts or mummy, my tummy hurts. Like, he can't say those things and so when that happened, it rocked all of our worlds, but it rocked her world specifically because she was like seven or eight.

[00:27:54]

That was the first time?

[00:27:55]

That was the first time he had a seizure. Nathan was 10. Morgan was like eight. I was hysterical, and she was hysterical because you don't know what's going on. My husband luckily was a rock and went with him in the ambulance, but it was such a scary time for our family, and I felt awful for her. I felt awful that she had to see that and go through it, but she knows now if Nathan starts to drool or looks up to the left, like, he's going to have a seizure, and she gets him in position and we have the medicine. She's such a responsible kid for a 10-year-old. I would say much more than most 10-year-olds. In some ways, I feel guilty that she has to have that be more of an adult than some other 10-year-olds. But in other ways, I know she's going to be such a better person because of her brother. She's so caring and she cares about others and her other classmates, she's so much more caring about because of her experiences with her brother.

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How is her relationship with Nathan?

[00:29:05]

Sure. She's very protective of him. I think she mothers him a little bit, even though he's the older siblings. But it's hard because he doesn't like to play. Nathan's not someone that plays with things. He's very much into technology, but not so much into games or puzzles or drawing. Those are all things that Morgan's really into. Sometimes she feels, to be honest, and we've had these conversations several times, she feels upset that she has a brother with autism because she feels like, why can't my brother talk to me or why can't my brother play tag with me? Those times hurt her, and that hurts all of us. I know it hurts him too, probably, Nathan. But there's other times where you see them in a pool together splashing around or jumping off a boat or things that they both really enjoy, and it's just magic. It really is magic.

Siblings. It is a learning process. For year to year, as they mature a little bit, and things change, for example, there were things with Nathan that were not happening in the beginning that end up, we say as he got older, other things were added to his diagnosis. For you to identify and say, now you need to deal with this new chapter of his life. At the same time for her, she had also to understand why she's developing. Her development to understand I can only imagine because I have no way to figure out how much work it is. But at the same time, thank God that you are in a place in an area in a region that you can have that support as well. To give you a little bit time to be able to work and your husband, as well, to have your own time.

Once you are telling me that Nathan is non-verbal and doesn't have a full communication tools to deal with. I would change this question, then to Morgan. When did you tell Morgan or when was the time for you that you felt, I need to explain to Morgan about her brother and what's going on that he's autistic?

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Sure. We did that very early on.

[00:31:36]

You did?

[00:31:36]

We did, because she has friends that have siblings that are neurotypical, and they're doing things together or playing together, and she's feeling very much like Nathan doesn't like her. That's how she took it as, like, it was something that I did wrong.

[00:31:51]

Because they play together.

[00:31:53]

She's like, he doesn't like me, and that's not it at all. He loves her. I think that we told probably two or three, and very young when she was really developing language skills and we re-up that notion frequently. When she gets mad about something, when he walks into a room without knocking or something like that, we have to remind him, he's got autism, and that's some social norms and social cues that a lot of people have, he wouldn't know to do that. Those things, we remind her frequently, and she knows what it is, and they talk about it at school, and there's other kids that have autism. Yes, we've talked to her a lot about it. We tell Nathan that he has autism too.

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You do?

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Absolutely. Just because Nathan can't communicate to us, it doesn't mean he can't receptively understand what we're saying to him. That's something I think a lot of people should also be careful with.

[00:33:01]

It's a misconception.

[00:33:02]

Right. It's a misconception, but it's also, just because he can't talk back, if you say something mean, he's going to feel that. His feelings will get hurt. We have really tried. That's something that as parents, we have to learn too is not that I want to say mean things to my children, but if you get upset or whatever you have to practice a lot of patience and a lot of restraint when it comes to thinking. You can't just be like, Nathan, why did you do that? You have to remember what's going on here and try to redirect, and sometimes, I'm human. My husband's human. We can get upset and trying to redirect and be this like, perfect parent doesn't always happen, but we try it the best that we can. We try to also tell Morgan that too, if she gets upset with her brother. Normally, to get upset with your brother, she's 10. He's 12. They get upset with each other. But instead of yelling, maybe try to redirect him into a different option.

[00:34:06]

I'm glad that you are saying that because I feel like we always run into situations and when you are talking about the neurotypical world that you are used to and the social rules and social norms and everything else. You were just said in different situations right now how we interact with each other. Sometimes because of a special moment in life, you have someone that you need to remind yourself. I don't need to behave this way because there is someone in front of me that I might think that they don't understand or they don't feel, but they might be feeling my anger, my frustration, how upset I am, everything else. There is a communication tool that we don't know yet the code and how to interact properly. I'm saying all this because in my conversation with Ellen, she mentioned something now you saying this makes me think of. She said that her child being for the entire time, because her son now is 20-years-old, she said that even when she didn't say anything, she noticed that he picked up on her feeling. Her behavior. The way that she said, the tone of her voice. He would call her out and say, are you okay? Or are you feeling something because they can't communicate in that way? Got exactly what you're saying. The fact that he's non-verbal, it doesn't mean that he doesn't understand or feel the emotion or your behavior or your reaction to certain things and could be hurt by words or by attitude.

[00:35:59]

Or also just not noticing his presence. People, a lot of times, even my family members sometimes ignore him. Because they don't think he can communicate. They'll say, hey, Nate, and then they'll talk about him.

[00:36:11]

Like he's not in the room

[00:36:13]

Like he's not in the room. We keep reminding them, he's right here. You can talk to him. I do want to note too, Nathan has a device. It looks almost like it's an iPad, and it's called PEC, which is picture exchange communication. There's pictures for words. Let's say he wants to watch a television show. He can type, I want to watch and then whatever the television show is on the device, and it talks to us. It's not that he can communicate his needs and wants. He can tell us if he needs to use the bathroom. He can tell us if he's upset or he's angry, and we're working on those things. Some of the things come more naturally. His wants come naturally. I want chips, I want water. I want this. I want to go to bed. He doesn't feelings are something that we're trying to work on now with him. I feel sad or I feel anxious or things like that, it's a hard emotion to try to explain to someone that might not know what anxious feels like. That we're working on. He has a private speech therapist, as well as he has school, and then he also goes to ABA after school programming. He is really surrounded by therapists all day long to try to teach him to communicate more.

Wow, that's fantastic.

[00:37:38]

One of the questions when we started talking about doing this project, someone sent a message saying, what is an AAC device?

[00:37:47]

It's essentially an electronic device. It can be an iPad or Samsung, whatever it is. It can talk for the student. He has a voice that's nice. When you think about it I've never heard my son, I don't want sympathy for this, but I've never heard my son say, I love you or mum or dad, he's never said his sister's name. For him to have this device that can say his sister's name Morgan, I need this, that makes her feel seen in heard, too.

[00:38:21]

So he does now?

[00:38:22]

He does now.

[00:38:23]

That's really [inaudible 00:38:24]

[00:38:25]

Yeah. We have our family members pictures in there, so he can say my sisters, Auntie Cheryl, my nieces, my nephews, his aunt Stacy, Auntie Stacey. We have all those pictures of people so if he wants to say something to them, he can go to that page and get their attention that way.

[00:38:47]

That's phenomenon.

[00:38:50]

It's great.

[00:38:50]

Because the communication sometimes is the tool that we still don't have to talk to each other. In a distant world, that's such a stupid analogy, but the only one that I can think of when you have people from different countries who don't speak the language from each place where they're from, and you are trying to figure out with gestures and something to try to get to know certain things.

[00:39:15]

Even a sign language, same thing. Sometimes kids with autism that are non verbal can use sign language. Nathan has trouble manding, which means he has trouble copying what you're trying to do. If you were saying Nathan touch your nose and showing him to touch your nose, he wouldn't necessarily know to touch his nose. Because of that, the way that his brain works, we had to come up with a different solution ASL was not the solution for us. It definitely could be the solution for other people. But a communication device was definitely more his learning style.

[00:39:55]

That's wonderful. What has been the most challenging and rewarding aspects of parenting a child with autism?

[00:40:05]

The most challenging is, I think, the grief of the person that you thought your child would be. When Nathan was born, I thought I was going to have a little by now, 12-year-old boy that was on sports teams or whatever, however he wanted to identify himself dancing, whatever he wanted to do. But someone could live a very independent lifestyle. I don't think parents talk about this a lot because I don't think they want to be this vulnerable. But it's the grief or the loss of that dream for your child that he will one day live on his own, that he will have a job, that he will have his own family, if that's what he chooses to do, and I would support that anyway. Now it's what's Nathan's life going to look like? What happens if something happens to me? Who's going to take care of Nathan? Those are my biggest fears and the most difficulty that I have as a parent with a child with this level of autism. I think other children with autism can absolutely go on and live a very independent life. That's not going to be the opportunity that Nathan has right now as his 12-year-old self today and the way he has progressed 1-12, I don't think he'll be able to live independently moving forward. That's the most difficult pill to swallow. The rewards are endless. He has taught us resiliency, patience, love. He is quite literally the most happy, loving, affectionate child that you could want. Even though he can't tell us he loves us, he shows us how much he loves us in so many ways, even if he walks up and just gives his sister a kiss on the head. What 12-year-old boy would give their 10-year-old sister a kiss on the head? He's taught me patience and understanding. He really opened our eyes up to the world in terms of, I don't ever judge anyone I meet. My first inclination with anyone I meet now is just openness, because if I see a child having a tantrum in a grocery store, I don't think, Oh, my God, that parent is so awful. We don't know what that child's going through. We don't know the sensory processing that they're doing right now and I've been there. The shame or the embarrassment you feel as a parent when that's happening. If we could all just give each other a little more grace and love, I think would be much better off and that's what Nathan's taught us.

[00:43:01]

We were ahead of the game again because my main question would be what you have changed. Not how your child made you change, but what you have changed, what you have learned about yourself having an autistic child. You mentioned quite a few patience, understanding, loving, understanding people around you, understanding the community around you, observing everything that's going on, and how much you are so caught up in social rules that were built to please the average lifestyle but not necessarily to understand when certain situations happen. You can be so harsh in criticizing judging people based on these built or constructed social rules. Are there to help, but sometimes I feel like if it's there to help when something like this happened or in any other circumstance, why are so harsh to judge and stigmatize someone?

[00:44:04]

That is 100% something he's taught us. It's opened my world up to just be like everybody lives in a silo to a certain extent, and they don't know what they don't know. He's changed not just me and my husband, but our whole entire family, just showing more love and patience and acceptance and understanding for people with different needs or just people in general. I think that's part of it. The other thing he's taught me is advocacy because I was such a people pleaser when I was younger and now I'm his voice in the world. I am the one advocating for him so I have found my own voice through him not having a voice. Maybe I advocate too much. I'm sure some people in this building would probably say that, but I think that that is something that he's taught me that I have actually have a pretty good skill set in now and can advocate. I've been on boards for special education. I've been advocating for the autism community in general and fundraising and trying to fund more research. It's something that my husband and I are really passionate about now is like education and making sure that these kids have opportunities in the world that they might not have had even 10 years ago.

[00:45:37]

That's the perfect segue from my next question then. What you want people to know about autism or your child?

[00:45:46]

I think there's a saying in the autism community if you've met someone with autism, you've met one person with autism. Autism is different and shows up differently in each person. If you think someone is quirky or shy, whatever it is, I think I just want people to understand meet people where they are. Don't pass judgments from first glance. Don't be judgmental in how people act.

[00:46:15]

I just hope people are kind. I think that's the biggest thing. There's a lot of judgment and bullying and meanness in this world right now, and I think we could all really just use just a little bit more kindness every day. That's for everyone, not just for children with autism, but patience and kindness would really go a long way.

[00:46:40]

Another advice that you would give to a family with a newly diagnosed child.

[00:46:47]

I would say get as much help as early on as you can and advocate as much as you can, because you will not get things unless you ask for them.

[00:46:59]

Would it be also good for people, because I think about your experience and based on what you were telling me, coming from until 18 month, having a child that already is speaking or saying few words and in a different level, and then everything that comes after in this stages as Nathan grew up, things that were added to his diagnosis for the first one. People should really focus on the diagnosis but also pay attention closely to how the child grows, progresses, and be attempted for other diagnosis as well, like happened to Nathan.

[00:47:45]

Absolutely. AST is only one diagnosis. There's several other diagnoses that can happen in anyone's life. I think parents know their children. I think if there's changes in behaviors or regressions, they should definitely go see a specialist. Early intervention if someone's newly diagnosed that's younger, I think is a huge benefit. If not the public school system or private school system depending on what you're in, has specialists that can help you get resources and really advocate as much as you can for as many resources as you can get because the more that these children have, the better off that they are.

[00:48:32]

I know you for quite a while, at least for eight years. I'll say more about this after because I want to ask the question first. How is it to work full time while you're having a child in Level 3 autism?

[00:48:50]

In some ways, it's lifesaving, and in other ways, it's exhausting. I hope I help a lot of people in my current position. But if I didn't have this job, I think it would be all consuming in terms of our life. Autism would be in the forefront so much more because my husband and I both have full time. My husband actually has two jobs. I have a very full time job here, and I think it's been lifesaving in a way because it gives us distractions to know that other life is going on besides what's going on with our child. It gives us perspectives. It gives us interactions with other people to help us stay sane a little bit, when you have a high need child, regardless of what the diagnosis is, it takes a lot out of the parents, like, physically, emotionally, mentally. Having a job can sometimes be a blessing to get away from the caregiving aspect of it. But then sometimes it can also be exhausting because we can have high stress actions here, and then I go home to a high stress situation there, so there's not a lot of downtime. But I have a phenomenal team that I work with that are so wonderful and are always understanding. My boss is Dean Monroe is just a Saint, and she is just such a good person to work for and is so caring and understanding of what's going on in my life. It's been wonderful to have the support of colleagues at Harvard, including you. It's been wonderful to have that support, and having people check in on you, colleagues, just be like, hey, how are you doing today? How's it going at home? How's Nathan doing? It definitely helps a lot.

[00:51:00]

[inaudible 00:51:00] I'm asking this question because when we did the panel on mothers at work, we were talking about how difficult already is parents working. Having a child because they receive this maternity leave or paternity leave for a few months.

[00:51:20]

Then you just go back to work.

[00:51:22]

Then you go back to work and feel like, your child defend by themselves, dad don't have to worry about that and everything else. Sometimes I used to get frustrated with certain circumstances when parent was called into school because whatever happens in the school you need to attend and you don't have daycare or if you don't have a babysitter, you have to go. The school needs you there. Sometimes other workers could judge that, in a sense, there you go, earlier or whatever.

[00:51:49]

Totally.

[00:51:50]

Not understanding anything about what the person is going through. You are escalating that to a completely different level. The reason that I'm saying this is I work with you for eight years. I had no clue about what you go through. No clue whatsoever. You are very discreet when you say that you are loud and people should know, well, I work with you closely, and I didn't. You are not that loud. You do your job. You are doing everything that you have to do, and it is an intense job working where we work because it's a graduate school. It's Harvard Law School, and our jobs are not easy, facing things and everything that happens here depends on the movement that students have, and you still have your private life that you are dealing with a lot. When you say we should have more grace, we should have a lot of grace and having more empathy for everybody who work with us. Work doesn't need again, like social rules and everything else, needs to be this prison that you have to come your nine to five with no possibility of having as a human being, things that should be considered because you do your job, you do it well, and people doesn't need to know what time you were leaving early or not or because you were coming late if your job is being done. I'm so grateful that you accept to participate in this and be so vulnerable to talk about things that happen in your life that other people can benefit from this. There is so much to learn. There is so much to explore and to research and bring more information. You gave me so much knowledge already from your experience for your day to day. I'm really grateful for you. I'm really admire your work. You are much more now, I don't know if it's the right thing to say, much more now because I should admire before. But based on your life, based on everything that you are doing. It's a different level of looking at you and thank you for what you do. I'm so happy that Nathan has the mother that he has because demands love and dedication to take care of your child with that kind of love, to have someone special in your life that you care that much. Thank you very much for coming here.

[00:54:26]

Thank you so much and thank you for shedding some light on autism, and moms or dads with kids with autism. I really appreciate that.

[00:54:35]

I appreciate you even more. We are good with this one. Let's prepare for our panel. In April 2nd, that what we'll be talking about and I hope other folks join us, too.

[00:54:46]

Fantastic.

[00:54:47]

For everybody out there, I'll see you around. Bye bye.

[00:54:52]

Thank you. That was wonderful.

[00:54:53]

[MUSIC]