

Adulthood on the Spectrum: Late diagnosis, raising autistic children and ABA

Andrew: Welcome to "Adulthood on the Spectrum". I am Andrew Komarow, an autistic certified financial planner. I co-run Adulthood on the Spectrum," with my host, Eileen Lamb.

Eileen: Hey everyone, I am Eileen Lamb, an author and photographer from France living in Texas. I'm autistic and my two sons are on the spectrum as well. In this podcast, we want to highlight real voices of autistic adults, you know, not just inspirational stories, but we want to hear about everyone on the spectrum. We want to give a voice to people like us. And today, our guest is Fiona O'Leary you want to introduce yourself?

Fiona: So my name is Fiona O'Leary and I'm from Ireland, Cork. And I have five children. Three of them are autistic. And I'm also on the spectrum. And I'm an autism advocate for eight years now, campaigning against dangerous quack treatments for autism and just really talking a lot about women on the spectrum as well. I've got a diploma of autism studies and I have lived a life. Half my family is autistic. And I suppose I want to just talk about a few issues in relation to that. Thank you. Yes, thanks for being here.

Eileen: So we start by asking our guests how they like to identify themselves, because there are so many differences artistic, Person with autism. And also if you could give us your preferred pronouns, that would be great.

Fiona: Well, I don't know if I'm she or her. And I say I'm autistic, but also that I have Asperger's because that is my diagnosis. I don't really get hung up on those things per say, because I think what's so important when autistic people are talking or trying to give their life experience of being on the spectrum that we don't you know word police come all the time and how they express themselves. And I've seen that as a problem in my advocacy work. So if someone says there are Asperger's or autistic or with autism, that doesn't really annoy me as long as they're getting a chance to talk about their lived experience of being on the spectrum.

Andrew: And so one thing that's interesting to right? I think it's only in the United States, right? Do we really have the DSM five otherwise? Is it ICD 10 or 11, whichever one it is, or whatever manual that we're using elsewhere? And it's also what people know, what they were diagnosed with. And at the end of the day, you know, I feel like a person should be able to refer to themselves. However, a person would like to refer to themselves without being shamed for it. So, no thank you.

Fiona: I think that's really important. I think that's becoming a big problem in the community is where people are expressing themselves when they're being berated for using words that maybe other people don't agree with. But like the goal for me is giving people the independence and the platform to express themselves because it's very hard for a lot of autistic people to do that. You know, even for myself, know, I can talk, but I have communication problems, too, which is part of being on the spectrum. So when someone has the, I suppose, the courage to come out and talk about issues, I think we do support them and not start attacking them about how they, you know, express themselves on the spectrum.

Andrew: And actually talking about just communication issues and I got a little sidetracked, which I mean, that will absolutely happen as I really hate voice memo recording and I really hate everything audio. And I will not listen to voicemail messages like if the transcription isn't recorded, but or but I will do my best to try to meet somebody where they are. So assuming I'm in a place where I can listen to the recording like that, Fiona you have sent voice recordings and I will listen to it's not my preference, but you know, I type back. That's probably not your preference. Right? So meeting people where they are and recognizing that nobody is an expert just because you have autism doesn't mean that you're an expert in all things autism. Right? You're just an expert in your autism. Right?

Fiona: It's the most that is key. I mean, that is so key because it is a spectrum and we're all different on the spectrum like this. You I've got three boys on the spectrum. Yes. We have a lot of common traits, but we're very, very different. And, you know, they express themselves differently to me and I to them. And that's great, because if we were all doing the same thing, we'd be like, you know, it's not for me. It's very important that we're allowed to express how we feel comfortably. That's the most important thing.

Eileen: So you say you have Asperger's and that's the diagnosis you got. That's how you were diagnosed. Can you tell us a bit more about your autism journey, like when were you diagnosed? What was it like?

Fiona: I was diagnosed in college, actually, I was studying autism studies at Cork University College, and I mean, I knew Eileen and Andrew that I was on the spectrum all my life, really truthfully. And I tried to get a diagnosis many times, especially when my second son was diagnosed, because I would have gone to my doctor, you know, kind of telling him that I had anxiety issues. I had struggles with, like communication, social skills. And I could see in my boys myself, it was almost like me as a child, really the same. And I was turned away. You know, doctors then were saying this is a male condition, you know, that women don't get diagnosed autistic. And that went on for many years. And then in 2013, I just went and got a diagnosis myself. And I had a bad experience. The first time, actually the person that diagnosed me wasn't qualified, which was really a horrendous experience for me and for other people that had gone through her as well.

It was a woman in Ireland. I'm not naming her. Then I went and I got a diagnosis through the health board here in Ireland, which took longer. But it was a completely different experience from the person I gone to prior, meaning I met with them several times. It was much more thorough, and I was diagnosed autistic. Asperger's was my the term. But like that didn't really you know, I didn't get hung up on the wording. What was important for me was that I realized who I was.

I realized that, you know, I'm just a different operating system. You know, my brain is wired differently because I don't know what it was like for anyone else here. But when you get a diagnosis as an adult, I think you spend a lot of your, you know, youth trying to fit in, trying to feel like you can be someone like everyone else. Masking is a word I will use, which is often used with women especially. So really, the stress around trying to not be me growing up was terrible.

And then when I realized that I am like my boys, it was liberating. I felt almost that I could belong in myself. And it took many years, Eileen and Andrew, for me to kind of accept that as well. So when you get a diagnosis, you've got that that, you know, you're diagnosed and you have to kind of process that. And autistic people, it can take longer, but it's definitely changed my life in a good way. You know, I don't feel the need to put pressure on myself where I did before, and like, if people don't get me, that's fine.

I don't want to change me for other people. So it was a positive thing in my life. And it's helped me understand. I mean, I think that I could bring some to the family being autistic as well, that I understand the boys maybe a little bit deeper than other people because I understand the challenges they have better because I have them, too.

Andrew: And now you have been trying to get a diagnosis for quite a while. And obviously getting a diagnosis is very different, not just in different countries, but depending where you live in a certain country and different socioeconomic status. Although I've had a diagnosis other places, I just happened to be close to Yale that has lots of studies. So they will, of course, you know, test you for free if you go through and be a guinea pig in a study. And so I've had the pleasure of doing that, among other diagnoses, but. You face a lot of uphill battles, but that was many years ago, right? We're getting close to like a decade ago. Do you think if you were to go through that same process today, that you would have faced as many uphill battles or has..

Fiona: No, no, no, I don't think so. I think that we've improved a lot, especially understanding women. And I know that engaging with other women who have had a diagnosis in recent years, there was definitely a bias there. And actually, it's interesting for me because I actually got all my notes through Freedom of Information Act because I had seen psychologists in my teens. I had gone through that. I had an eating disorder in my teens, which, you know, can be very common in autistic females.

There was a lot of, I said, I suppose, red flags there that were overlooked. But when I read my notes, it really upset me because it was so like a classic autism diagnosis, you know, literally what they were writing. But because I was a girl, I couldn't get that diagnosis. And I think that's really important because I think when you don't have those supports, when you're a teenager or when you're growing up, you know, it can be it's a game like if I would have liked to have had that diagnosis, maybe to support me going to college or in my schoolwork because I do, you mentioned other conditions. I have dyspraxia. I have terrible eyesight, which has caused huge problems in my life. And I suppose I was very much of a daydreamer, which is what they noticed me in school. But it wasn't that. It was really to do with me being autistic or not having the support some place like my boys in school. It's like a completely different time. So I kind of grief that a little bit, too. And then you have to try to explain to your family, you know, and then what do they say? You don't look autistic, you know, this kind of thing that comes with that.

So there's so many things that are really wrapped up in a diagnosis. And I'm still processing that diagnosis at the age of forty nine. I mean, I'm only 50. It's something that I think will take time for me to go through because it's like every day waking up, you don't wake up and think I'm autistic, you know. But it's like most of my life I wasn't diagnosed. I'm only diagnosed since 2013. So the rest of my life, you know, I was I suppose, looked on maybe as being a eccentric , you know, as a somebody that was a bit strange as a child.

That's what my mother would have called me. And always going missing, you know, and always asking questions. Very inquisitive child. But like I do think that there's a difference between that. And I suppose that's why I think getting a diagnosis from a professional is really important.

Eileen: You know, I relate to so many of what you just said. I mean, I feel like you describe me as a child, like I was always getting in trouble because I was looking out of the windows. But I was also so curious, you know, amazing grades like then, you know, and I was shy, which I mean, so many things that first personality traits. Oh, well, she's shy. She's a daydreamer. Oh, she's smart. And then you put all the pieces together and it's like, how did they miss this? You know, like my mom would have to prompt me to say hi, like at the bakery in French, like say hi again.

And I would repeat that type of things. And I would just focus on like giving exact change with coins instead of like, you know, interacting like everything was there. And then it took 25 years. And being in the US to get a diagnosis, because in France I mean, even kids who are like more severe are still not getting diagnosed in 2021. So yeah, I stood no chance.

Fiona: I know, I know a lot about France actually and autism in France and how they view autism. I've actually helped a French family. They moved to Ireland actually from France because of the kind of, you know, the situation you're referring to. So it is different from country to country. But what is really, I suppose, the most awful thing about being a woman is there is that kind of element of, you know, you know, maybe just not, you know, you're stressed or something.

I had a lot of that said to me. And I remember when I got my diagnosis that my doctor actually apologized to me. And that was very good for me because I felt almost like, you know, they weren't listening. And it's sad. And actually, when I when I did get my diagnosis, I was on Irish television talking about this women on the spectrum. And I met a woman and she was in her 70s. There was like we did a talk in the college and she came up to me and she thanked me because she had been diagnosed really most of her life, but kind of hidden away.

So that's the other thing is when you get a diagnosis, sometimes people do want to talk about that and I felt compelled to actually be kind of a spokesperson maybe for women in Ireland, and it's OK, we're not going to we're not we're not going to eat you. We're just people to be positive, I suppose, about autism. And I think that's the most important thing. But also to remember, you know, that different autistic people have different needs and challenges. And that's my real concern now as an advocate, is the divide that we're seeing in the community and how people talk about autism from their own experiences being the only experience.

It's not like my son, you know, is very disabled and autism is a disability. And that's fine, too. And I don't have a problem saying I'm disabled, but there seems to be a problem around that word now as well. And so what I want to say is a lot of autistic people need supports. If we say autism is not a disability, they don't get the supports. Like you asked me about Ireland and autism, it's very hard, very hard for parents to get supports here. We have a government that doesn't have any with no autism act.

We have no legislation. So if you got support for your child in school, that can be taken away any time. And that's what I fight for because I know that my boys couldn't go to school, they wouldn't be in school unless they had a special needs assistance with them. And my son actually did very serious exams last year all by himself during the pandemic. And he did brilliantly. He did so well in his grades and he enjoys school. He enjoys school.

But without the supports, he wouldn't be doing that. So if I say autism is not a disability, can you help him? He doesn't get the supports. And I think that's really important. If we keep saying that it's not a disability, you are going to jeopardize supports for autistic people that need them not as a luxury, but as a lifeline, a necessity. And I see that happening more now with advocates who I used to admire that they seem to not be thinking about people like my son, you know.

Eileen: Yeah.

Fiona: And that worries me, it worries me that when I'm the future, that that will be a serious situation where we will see autistic people being institutionalized, which is what happened in Ireland up until 1992. My son was born in 1992. There were people on the spectrum in institutions in Ireland. And what my goal as a mother, not as a campaigner, but as a mother, is to have as much independence.

My children, meaning that they can do things for themselves, but to get there they need the support or the tools. I use words, tools to help them achieve that. It's not something that they're equipped with. And that's what I think is really important. And helping children on the spectrum isn't a bad thing. Helping any child isn't a bad thing. If we don't teach children, they can't learn and they can't become independent. It's kind of just logic to that. And what I see a lot now in the community is like, don't be talking about your child.

Don't be giving them interventions. I mean, I've seen people criticize speech and language therapy. You know, don't help your child communicate. My son couldn't talk when he was four. He couldn't speak. He couldn't stop talking to after the age of four. And he did have speech and language therapy and would have used communication cards, which I now know is linked to ABA, PECS... The system of PECS .

That wasn't a bad thing for him, know, he'd helped him and he loves talking, he never stops talking. So I've had I've had people give out to me about that, which really, really upsets me.

Eileen: Since you're talking about it, about, you know, my oldest son is eight and he has like 20 words, so he's basically nonverbal. Non-speaking uses AAC to communicate. That's what you learn in ABA therapy. ABA is very controversial. And I know we don't agree that I'm you know, I'm in favor of ABA and you're not. And I'm so thankful that we're able to have this discussion in a respectful way, even though we don't agree.

Can you tell us what you don't like about ABA?

Fiona: Well, I'll tell you, Dylan my son. My first son. He's my son that has cancer as well, which I will talk about as well. When he was diagnosed in 1994, they wanted Dylan to go to a school. It was like an ABA school away from me. He would go away from Monday to Friday and I was

like, no, he's not going away. And I suppose at that time and what I want to say about ABA is that there has been abuses of ABA, meaning it's down to the person like the teacher or whoever.

There's been cases of that like, of course, I'm against that. And I think that's what ABA has kind of been pushed out there by a lot of advocates that it's abuse. But like what I read today and I didn't do this today prior to talking to Eileen, is I looked up ABA as of now and what it means and it means positive reinforcement. So it means like you reward a child for doing something good, be it their homework or whatever. And the reality of things like I think that we're doing that any way with our children every day is like, you know, put your socks through dirty clothes in the washing machine, you know, good boy or good girl, whatever.

And so, like even in school here in Ireland, what they do is they do rewards with the children anyway. But with my sons, they might get a star, you know, like a star on their shirt or they'll get a certificate like the best student. And I suppose what I'm seeing now is that's wrong as well. So it's like positive reinforcement I don't have a problem with. And if that's what ABA is and it's carried out if it's carried out in a non-abusive way, I don't have a problem with that.

What I have a problem with ABA is maybe the routine is a bit intense for me with Dylan when he was growing up, it was something that I didn't sign up for. But in his communication, you know, therapy, they were using PECS, they were using communication cards. And that was not abusive to my son. In fact, he enjoyed it. It was it wasn't like he was having grueling hours of being down, like in a work situation that there was therapists that we've come to our home and spent an hour with Dylan maybe a few times a week, and it worked.

And he started talking to me. I mean, he had no words at all. And one day we just went, "Hello, Mummy", I she thought I was in the kitchen. And, you know, we were very young. I had Dylan and I was twenty-one. I was just like thrown into parenthood. But I was in the kitchen washing dishes and I heard this little voice go, "Hello, Mummy". And I thought that it was a ghost. Because he never said anything to me. And we have a recording of him actually when he said that and it was so wonderful and the thing is when he started talking, he really enjoyed talking to a lot of autistic people don't want to do that. But Dylan is a talker and he never stops talking. But I mean, it wasn't abuse what they did with Dylan in the communication with Dylan, but it wasn't known as ABA. I suppose back then, ABA, for me would have been linked to, you know, some of the horrible things we see from the past.

Some documentaries were made. I saw a documentary in England which was kind of distressing, but like it could be the same in school. You could have a teacher that could be abusive to a child. It's down to the person. And if a mother and father or parents are with their children and the child is happy, then, you know, I think that maybe people maybe need to think, rethink what that is. But you have to help the child to learn. Like you, I saw your video as well about children running onto the road. Dylan was like that.

Dylan was like running away all the time. And I used to be like having a hard time, literally. And even our wedding day, there's actually a photo. There was no photos of me and my husband because we were running around after our son because he was always like that. And I was so scared, you know, so looking back, you know, we used techniques to help him, not hurt himself. But that's what parents do. And I think being an autistic parent helps a lot, because I

can see, I suppose, what I what I saw with my kids, especially with Dylan, because he had a lot of problems when he was small, that I was able to read almost things that would trigger him to have a meltdown.

Like he could get very stressed with people that he didn't know or the faces were not familiar. I was able to kind of get down to his level and understand and predict the situation so he had less meltdowns and actually by the age of seven or eight, he wasn't having meltdowns anymore at all. I mean, it was it was like I knew him. I went into his kind of environment, I suppose. But I still did have help.

You know, but Dylan did have help. He had OT, he had speech and language therapy. He went to a special preschool from a very early age for maybe two and a half. You know, I I did that because I wanted Dylan to have the best chance in his life. And I think to an extent by him with what's happened to him recently.

Andrew: And speaking of Dylan, he has recently gone through cancer treatment during a pandemic. What was that like for your family as well as Dylan, if you feel comfortable sharing for him?

Fiona: It was it was so hard, I mean, like we were we knew that Dylan was. You know, waiting for a scan, he had a lump of a lump on his neck and, you know, they did his blood work and we were waiting for the scan and then out of nowhere, it's cancer. So we went from, like, just being kind of concerned and being hit with this diagnosis. And it was at the time when Ireland was having the worst cases of COVID, you know, really high numbers, people locked in their houses. And literally within 24hours, I'm told that Dylan has lymphoma and that he would be starting chemo.

In 24 hours or so, just imagine I had to tell Dylan that he was going to have chemo, Dylan had never been in a hospital. Dylan does not like hospitals at all. I mean, when his granny was sick a couple of years ago, he didn't want to go in. So I was thinking, how am I going to get my autistic son to even have a needle put into his neck? So first they had to do a big biopsy on his neck and then he had to have a PET scan, which involves drinking a sugary liquid, a dye which is radioactive.

So he had to be told all of that. And then we had the huge, huge issue of consent because they knew that Dylan was autistic, that he has a disability. Do we tell Dylan what's happening to his body? Do we advocate for him or does he do it himself? So we had a I had like an hour to make this decision for my son, you know, I did. There was no time to be wasted. He had cancer. And we decided that Dylan should be the person that is told this, because he's 28 years old.

And he was amazing. He sat down with the oncologist. They told Dylan he had cancer. They told them what they were going to do, and he took it with such dignity. And he went through every round of chemo with such...I don't know. I'm amazed by him. I mean, he just did what he was meant to do. He did the treatment plan and he never missed one session of chemo. He never got sick. I mean, he never threw up. You know, everyone was telling me he's going to throw up, that he's not going to eat is food anymore. Dylan had to start loads of medicines as

well. Steroids, antibiotics. He was on like anti-viral medications that AIDS patients take. So get all of this going into his body. He lost his hair, you know, this beautiful red, curly hair.

The only way he coped and I mean this and my husband and I are going to write something about Dylan because it was because he had those tools. He had those tools to be an independent person, to speak for himself and to actually be able to ask questions to his oncologist. You know, I mean, if I hadn't given Dylan those tools or helped him when he was younger, he wouldn't have been able to do this. There's no there's no doubt in my mind, because he wanted, I suppose, in a way to get his goal through all this was to get back to his friends, because Dylan goes to a service provider and he misses his friends.

And when he was called for the first vaccine for COVID, which was during his chemo, he was so happy because he was saying, mom, I'm nearly there. You know, I'm nearly there. One more round. Then we had to wait to see if chemo had worked. So we after his last chemo, it was eight weeks, nine weeks before we knew and we got the news last Thursday that Dylan is in remission, which is the best news in the world. And Dylan went to that appointment himself with his father and he sat with the oncologist and the team.

And to me, my husband, that's his dad, hadn't didn't have to open his mouth, didn't it? All for himself. He let the doctor examine him. He's had problems with his feet. He's lost his toenails because of chemo. And he did it all himself. And I'm so proud of him. But I mean, it's because Dylan had those reports. He had a very good, very good teachers and school as well that helped him as well. So all of those people made Dylan the strong man he is today.

Eileen: It's really amazing to hear that he's in remission, first of all, and that he was able to do all of this by himself. Is there anything that you wish nurses or doctor would have known about autism or about him to make the experience better?

Fiona: I think what I think firstly, like when you get a diagnosis of cancer, like there were organizations that you can call for counseling, but they don't have anyone trained in autism at all. So I could ring up and say I need counselling, which I did. I had to I mean, I was my world was shattered, you know, but there's nothing there for autism, even for me as an autistic woman talking to a psychologist or somebody that's trained to talk to people about cancer. There's nobody trained in that field. Now, the nurses and the doctors are wonderful.

But like there were times when they would not have known because the nurses changed every time to go through chemo as a different nurse. And he would tell me he would come back. I didn't like that nurse. You know, she wasn't like the nurse the last time. And, you know, even when it went for the vaccine, you know, we had the COVID vaccine. It wasn't even in his chart, you know. So I have to say, he's autistic. Don't be stressing him out because he could get he has OCD, Dylan has OCD.

And I know when Dylan starts counting a lot, he counts numbers that he's stressed. And I could see this happening. And she just kept saying things that I had already told her prior not to say that would trigger him. So even when they are informed, it's like they can't keep it, you know, because it's not compulsory, there is no training. So that's really important. And especially for somebody that gets a cancer diagnosis if they're autistic. But it's harder for autistic people because of the sensory issues going into hospital.

Smell, like Dylan has a huge thing with smells. He has a huge thing with hand washing. He's had them all his life. He's very good at washing his hands. But like he you know, I used to go to chemo with his dad. I wasn't allowed to go because of COVID is only one person. And I used to feel his fear in me. I am so connected to Dylan and I could feel it. And, you know, I could only imagine when I remember, like him talking to me, I ring him at the hospital and he would just say to me, "Are you OK, Mum? Peter asked me if I was OK?"

That's what Dylan's like, he's such a good boy, he's somebody that thinks of other people, but like it's only because he's had that great support around him that has made him. And I mean, like, if you knew Dylan at the age of two or three, you know, when you see him now, I mean, it's a very different experience. And I want to be positive about that because we were told such negative things with his diagnosis that he would not do this, but he would not do that.

I'm going to we've proven them wrong. And I suppose it's because. We've just got Dylan, the support that he needed to. Be the beautiful person he is today, you know, and believe in himself, he has so much confidence. I mean, like Dylan and myself, I often say to my husband, if only I had the confidence that Dylan has. But when I'm with Dylan, he makes me feel really good about myself. So he makes me feel confident when I'm just with him. He's just really grounded and strong. Happy. A very happy person.

Andrew: And in your mind, thank you for sharing that. What makes a good autism advocate? How can we do better despite our differences? And what I really appreciate about one of the things you said a little bit earlier was the fact that you really didn't know much about what ABA was beyond your own experience. And you looked it up. And I really don't think many people actually understand what it is.

I mean, I'm not pretending to be an expert either. So I've been called pro ABA or, you know, and I just think because I'm not outwardly against something that I don't understand, I am therefore supportive of something when I think that's probably how more people should be is not just, you know, be mad at something that they don't understand completely

Just on that my understanding is if, you know, if it's if there's an individualized therapy or treatment plan that's designed to help somebody live their best life and be their best autistic self, and it's done right, then I think that's a good thing. I don't care what we call it because, you know, a lot of times it's very complicated, something like, well, insurance might call it ABA. Right. And therefore, it's billed more and it's paid more.

Well, you know, if we. But if it's OT or speech that is billed under ABA, you know, we don't want to shout from the rooftops that, you know, it's insurance fraud or something, right. Or just and I got I'm for this I'm not involved in any of these insurance practices. But now I guess what I would say is it seems to be, you know, confusing about what makes a good advocate, you know, as being a good advocate, shouting really loud and screaming at parents on the Internet when you disagree with them and telling them they're being horrible parents to their children.

Does that change any minds? What can we do better despite our differences?

Fiona: We need to we need to talk to each other firstly in a civil way, and I think that's the problem. I mean, you're not the only one that's experiencing that kind of I don't know, it's terrible, actually, I'm very sad because I think it's got a lot worse over the last few years. And I think that there's a certain group of people that are kind of making that an ongoing issue. Like I'm here today. I've had a lot of nasty comments said about coming on the show today. But I actually want things to move forward because I want something better for my kids growing up. I really, really feel that, you know, if we don't talk about our differences, we can never resolve them.

And maybe it is the wording, like you said. That's a very good point, Andrew. You know, maybe that the word ABA is something that is, I don't know, attached to something really bad for people from the past. And maybe that's what needs to be done. But like what's really important is that the people saying these things, a lot of them don't have children that need support or don't have children that are in need of the tools, like I mentioned earlier, to make them independent. I that for me, if that was anything I would offer for people listening today, is that your children are separate entities to you and they have to learn how to navigate the world.

And helping them navigate the world isn't a bad thing, helping them to go in and ask for an ice cream themselves. I remember when my son did that actually, and I remember I used to work with kids with disabilities years ago, and I was one of the people working there that was saying how on don't be choosing their ice cream, so let them do it themselves. And it took a bit longer because, like, that's how it how it worked. But it was such a great thing to see the children doing that. Then I taught them how to pay for his own ice cream.

You know, it's a process teaching Dylan to walk. I can go walking with my son now, and I'm not worried about him being going into the road in front of a car. But that took years, years and years and years of doing the same thing over and over. And I walk with him. We do a walk together, 7k walk and it's a difficult walk with hills and everything. But watching him, if a car comes along, I don't have to say anything to me anymore. He pulls it into the side of the road and he stops until the car goes passed and I'm watching him do that.

And I'm thinking this is amazing, this is a good thing. But intervention is not about taking away traits of autistic people, and that's really important. You can't take that away. You can't make someone not autistic, but you can help them to enjoy their life and to be independent. And that that is not being a bad parent and it has to stop. Actually, I am actually at the point now where. Even of late, even recently, even yesterday, some of the stuff that I see really concerns me, but like I fight for my kids and I fight for the community because I really care.

But like, if someone doesn't agree with me or we have a different view, you and me or whatever, me and Eileen , that's fine. That's fine. That's your opinion. We don't attack each other. We talk about it. And you know what? If we sat down together and talk to each other, we could probably solve a lot of this problem that we're seeing. But they don't want to open the conversation routes. And I suppose that's why I'm here today, because I want to talk to people. Even if they think that I'm saying something that is something they don't like, that's OK. You know, we have to talk to each other to work together for a better future for the community.

Eileen: I couldn't agree more with you. I mean, this is the biggest issue right now is that there is no communication. I mean, it's all yelling and insults and we don't achieve anything this way. And on that note, I really appreciate you that, you know, you did some research on ABA and even though, you know, you don't love it, but you still went and try to learn more about it, that's how we can advance and about the autistic thing, trying to make someone not autistic. That's one of the biggest criticism about ABA. And I really wish people would realize that, you know, teaching someone to communicate, whether that's verbal or not, teaching someone to not put themselves in danger like they deserve that it's not about them being non autistic. It's about them having skills that everyone deserves. You know, it's it blows my mind that some people think that it would be OK to let someone be like autistic, if that meant that they don't communicate, and that's very frustrating for the person who can communicate if they just put themselves in danger because they don't understand that playing with the litter bugs and eating that is bad.

They run in the streets. I mean, that's we're not doing them any favor if we don't teach them those skills like no one bats on eyes when a kids go to school and learn math or how to use a different language. So why is teaching an autistic child skills that everyone takes for granted seen as making them non-autistic.

It doesn't make sense to me.

Fiona: I think it's basic parenting. I mean, when you are a parent, you have to protect your child. So we're doing that anyway. I mean, this is what I what I suppose the positive reinforcement element of it, which is something that we do. We do it. We do. Without even noticing, you know, as as a mother. Good boy. Good girl. Praise. It's a good thing. And I know that with my kids in school that it works, you know, and I suppose years ago, if you want to go back to schooling in Ireland, when I was growing up, we had corporal punishment. You know, they were hitting kids in school.

So it was it was the norm here, you know, so being positive to a child, we can feel good about themselves for their achievements doesn't mean that you are doing anything wrong. It just encourages them to learn. And like to me, the most important thing for our kids is to learn, to read and write, to have an education for autistic children. They struggle in that. You know, it's not something that you cannot you can't go to school, in my opinion. And you say that an autistic child doesn't need support to school because that is certainly not my experience with my children and my two sons, not Dylan.

My youngest son would be very good academically as well. Like you mentioned, good grades. But it's not about the grades alone. It's about the environment, helping them in the environment because of sensory issues, because of noise, like my son would have problems with noises. And you know that the teachers understand that and they give them movement breaks so that they can leave if it gets too much. So he has access to a room where he can go and it's lovely sensory room and he can come back when he feels a bit better.

So we fought for those supports. They haven't been given to us on a plate. Parents have had to fight for their support. So like I said, because we have no laws in order to protect autistic people, they can be taken away by the government. But if you go out there and say, I mean, I want to say this because this is important of what I see from some advocates that autistic

people don't need support, you know, and make that general statement. If we just leave them be, they will be fine. That is not true for every autistic person is not true.

And in my opinion, what they're doing is actually pseudoscience. It's not factual. And these are the same advocates that would be campaigning, campaigning against pseudoscience or campaigning against so-called abuse of treatments. In my opinion, it is abusive to not help your child to be an independent, an independent person. If you leave your child without support as they grow, it's harder to teach them those basic things that lots of people take for granted. Like you say, not running onto the roads. You know, it's harder to teach an adult to do that than a child. If you teach a child those safety measures, they will learn that's not being abusive.

You know, and again, children have their own rights. They're not you know, they're they're not they're not extensions of us and, you know, teaching your child to read. And right and go out to be independent, it's a good thing. I'm so happy because I can let my kids go out with those skills and they're happy to do that.

They don't want to be stuck at home with mommy all day. You know, who wants to be stuck with your parents all the time? They want to be teenagers. They want to go out and do things. But if they don't have those tools, they can't do that. But that's what I'm being met with, I'm being met with anger if I talk about my children. I'm attacked by some of these people, and it's become kind of a very. Very, very frightening things to me because they discussed my son who has cancer.

They talked about him and it has to stop. But I'm willing to sit at the table with everybody to try to find a way for us to all advocate. Together, civilly. So that we can make a good future for autistic people, for our kids, you know, and maybe have laws in place that will protect them, you know, in employment and education to get children to have jobs when they grow up. In Ireland, we have a very poor statistics for employment for autistic people.

We're one of the worst countries in the world, you know, so things like that really matter. And again, health care. But like, if we're all fighting, what impression do we give to to the world if we're all fighting and there's all this name calling, use our energy and time to be effective, to bring real change for our community, positive change.

Eileen: That's the perfect way to end this. Just we need to have this discussion so we can help autistic people. That's what we all want. We want the best for autistic people. So we should really get together. We're going to ask you some questions. You know, they're called quickfire questions. So you tell us the first answer that goes through your mind, OK?

Fiona: Yes.

Eileen: What is the best piece of advice you've ever been given?

Fiona: Don't be afraid.

Eileen: What do you do to relax?

Fiona: I write songs and I sing, I listen to music.

Eileen: What is your favorite food?

Fiona: Pasta.

Eileen: I love pasta. And what's your favorite film or movie?

Fiona: "Les Amants du Pont-Neuf", French movie. Wonderful.

Eileen: Another one I don't know, since you are autistic and therefore good at math. How many digits of pi, do you know?

Fiona: I am terrible at math. That's another myth.

Eileen: Just a joke question. What is a question you would like to ask our next guest? Who's our next guest? I don't know, actually.

Andrew: So random, you don't know who it'll be?

Yeah, I think we know actually about maybe we're just not going to tell you. So feel free to ask the question.

Fiona: I would like I would like to ask about music and autistic people and how they experience music, especially because of Andrew. Andrew and I have a love of music. And I'd really like to ask about how autistic people process music. And it's a different it's a different for them. It's just something that really interests me.

Andrew: How do you process music? Other than you like good music because we share that in common. How do you how do you process...

Fiona: I just I just feel it for me. And I even like talking to my boys as well, especially Dylan, that it's it's not just about listening to music, it's something else. And that kind of interests me.

Eileen: So about feelings, do you feel the music? Yeah. All right, well, thanks

Fiona: Before I go, actually, we have a band called "Trouble in Love", we have a Facebook page "Trouble in Love". People want to check out our songs. We did an album during lockdown last year. So it's myself, my husband. My daughter plays as well. But "Trouble in Love".

Eileen: Tell us about where people can find you online, so "Trouble in Love," anything else?

Fiona: On YouTube, YouTube, Spotify, Apple, iTunes, we have a little CD, an album, "Trouble in Love", I mean, I'll send it to you. I think I've been annoying Andrew with some of my songs, but yeah, music is a part of my life. So "Trouble in Love." Facebook, Spotify, YouTube and iTunes as well as CD baby. It's for free. You know, it's for the love of music, you know.

Eileen: Thank you so much for talking to us today.

Fiona: Thank you, Eileen. And keep up the good work here. Thank you. Yeah. Take care, guys.

Andrew: Take care. Bye.