

One Family's Diagnosis Journey

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1. Autism - One Family's Diagnosis Journey - Getting a diagnosis

Thanks for listening to me Kim. I was just wondering whether I could ask you in reverse a few questions so I can get some understanding for families from a parent's point of view. Would that be alright? That's fine. Great. How was your journey getting a diagnosis with your daughter? She was really little and there were lots of health issues. She had lots of very low blood sugars. These were unexplained and she was in hospital a lot which was quite hard. She had no speech and still doesn't talk. She was late with all her milestones to sit, crawl and walk. We now know that this was due to a muscle wasting condition called myotonic dystrophy.

And that's quite recent diagnosis? Yes it was. It comes from a parent and I was diagnosed as an adult so these problems that she had we didn't know that she had them because I was diagnosed late and thus. I was quite young when I had Charlotte, only 21 and I didn't know what I was doing with a baby much less a neurodiverse one. It was quite hard. I was put on lots of courses for parenting and someone said to me if you want your child to learn to talk you have to talk to them. And of course you were doing that all the time. About everything as you do with any baby. Yeah. It wasn't helpful to say the least.

No, no. We went through the Ministry of Education's early intervention office. We had an early intervention teacher and a psychologist and we did play observations through a big one way mirror. Alright. With someone playing with her and then me entering the room and see if she was different, how she played with toys which is different to typical developing children. I think that's called an ADOS. Yeah, it is. And then we did something called the CARS test. Yes. And my husband did it, I did it, the psychologist did it and I think the kidney teachers may have as well. And then they put all the results together.

Yeah, and they correlated well so she wasn't reacting differently for different people so it was quite clear that she was on the autistic spectrum. And this was right about the time she was three. Okay. Yep. And so that's good age because I get many referrals. Yes. For children. Yes. From as young as two. Yep. Generally not much younger than two. And it means that it's really good because you can get early intervention, you can get a lot of help before they go to school. For some children when it's not quite so clear, they might be a wee bit older, more like six or seven. Yep. For some who mask a lot and don't show the autism, and masking is obviously trying to make sure that they don't show autism.

Yep. And they're obviously trying to fit in, then sometimes it's as late as 12 or 15, which is really hard. That would be really hard. Yeah. Yeah, it is. So that's awesome. Yep. So how was your journey for your son? Was it much different? Yes, it was very different. Obviously, Charlotte's a paediatrician. You're my son from our visits for her because he used to come along. So we had a clinic appointment for him, just sort of some observations and questions. And then you actually came on a school visit first and came to see us at home to give us your observations and how you found that. Then we had another clinic appointment with his paediatrician.

At that appointment, they had enough information to say that autism was probably quite clear. And they said that we didn't need an ADOS. Oh, brilliant. Yeah. So we didn't have to go through that with him because, you know, he's older sister. Yeah, yeah, sure. So we got a diagnosis on the second visit. Because it was very clear that he was on the spectrum. When it came up that someone sort of said that there might be some differences for him, how did you feel? I wasn't shocked because I'd already gone through things with Charlotte. But I was more worried about his speech.

um right he started kindy and he was saying single words which by three most this is at three most kids are saying you know talking quite fluently yeah um within four months he was speaking fluently though um so we kind of think maybe it was a little bit of learned behavior because he saw um his sister getting things without having to use speech gestures and she would bring us things yeah and um maybe he learned from that so he didn't feel the need to use his words but yeah he caught up quickly fair enough and how old was he when he got his diagnosis um nearly seven um cool so that was that's more the age that we often yeah yeah um oh i mean we saw signs a lot earlier but we sort of sort of held off as well because it's hard having two yeah um but it was you know there's family history on um both sides and yeah um we catch up so yeah we knew what we were doing yeah sure

2. Autism - One Family's Diagnosis Journey - Siblings

Yes and I guess to make it clear for other families, we need to ensure that siblings don't get a diagnosis just because their siblings got a diagnosis. We need to make sure that they really are autistic and that they're not displaying traits or learnt behaviour. So we have to do due diligence really and make that assessment. So that's what would have happened. So he didn't try or feel he needed to probably but luckily when he started kindergarten he talked with him in a few months.

3. Autism - One Family's Diagnosis Journey - Labelling - everyone's different

And it's important too that we don't give out labels just for the label's sake because a lot of families will come to us looking for the label of autism because they know it's going to help them. Actually, people dealing with them at school or doctors or wherever you go need to deal with what's in front of them, what they see, what's happening, not the label. Yes, sometimes the label helps in the fact that we now know roughly what autism is. We can get an idea of what we're likely to see from the child. But on the other hand, families don't want the label. So some come looking for the label and others don't want the label because they don't want their child put in a box.

But it can be helpful. Kim, how do you feel about that? I'm OK with them. I have a friend who talks about my two having autism and formal diagnosis and her child displays traits and doesn't. It's quite tricky because I sort of feel a bit like they want me to say yes. But they're all very different. You've met one child with autism, you've met one child with autism. Some are quiet, some are very noisy, some lash out. Some are frustrated or stressed and some withdraw into themselves. They're all so different. People hear autism and think they know how this child will react and how I should work with this child.

But it's often not the case. You have to deal with what's in front of you. Both my children are very different, so I have to parent them differently. Cool. The answer to the question is I don't mind labels. Yeah.

4. Autism - One Family's Diagnosis Journey - An interim diagnosis

Did your son get an interim diagnosis of GDD or global developmental delay? This can sometimes be given for extra support while we make that decision. No, he didn't. Okay. Sometimes we will check with families and we'll look at ADHD if we think that's an issue because then we can deal with the ADHD, see what's left over, and obviously, as you know, if we give some medication or whatever,

then we are left with whatever. And if it's autism, then it's autism. Yeah. My son actually has ADHD as well. Oh, cool. I'd forgotten that. Yeah.

5. Autism - One Family's Diagnosis Journey - Who is involved in getting a diagnosis

Who makes the decisions around that? So there are two different ways that children can get a diagnosis of autism via the public system. One is via paediatrics and to do that you need to go via the GP. So the GP will make a referral. We need to get information on everything or from everywhere. So we need school information, we need information that's history. We also need the GPs or whoever's doing the referral and it's usually the GP to say more than just oh they've got problems with social skills. What are those problems? I mean as you know is it non-verbal? Are they just don't have friends? We need more information.

As much information as we can get is good. They then get triaged at the hospital and then we will if they're going to be seen we will see them. So from that clinic appointment if we feel that we need more information just like with your son I came and I did a school visit and then I did a home visit. So that then gave us that extra information. We still need that information at the referral time which your son's referral we got but we also needed extra. If we can't make that decision then they will come back following up on that. Following those observations and potentially like your son get a diagnosis or they get referred now to an assessment team around autism which was similar to what your daughter went through and they get an ADOS assessment and then they come back following that for feedback.

So yeah so that's and as you know there are always wait lists and the wait lists are long so hopefully we can make that decision within clinic first rather than referring to the hospital. Yeah so that's one way of referring them on. Yeah are there other ways? Oh yes sorry the second way I should have carried on but that's all right I forgot. The second way is through the mental health system or CAF. Usually at that point they're referred for ADHD or anxiety and they will pick them up and they will look and decide whether anxiety or ADHD are relevant. If they are and they've still got that anxiety problem then they're referred to the mental health system.

If they have that leftover information left they can then make a diagnosis of autism if they feel that it's relevant they don't have to be referred back to paediatrics for that individually. They already know the child so they just carry on. And then following that they can refer to me as well. Is there any other way you can get a diagnosis? We were very lucky and it happened reasonably quickly for us. Others aren't that lucky though. No they're not are they. Sometimes it's really hard. We don't like it but there's only so much money that goes around and we struggle so it's really hard. But families can go privately they obviously have to pay but that is another way.

Can they still see you? Yep they can. So I accept diagnosis or the Autism Coordination Service accepts diagnosis from anywhere so long as they're between the ages of 0 and 19 or up to the day they turn 20. So we will accept those diagnosis and a lot of people a lot of private practitioners know about us and send those referrals. We'll also get referrals from GPs or from Lifelinks if they know that they haven't the families haven't seen us.

6. Autism - One Family's Diagnosis Journey - A partners perspective

um kim i want to go back to our discussion about how you felt and ask how did gary feel your husband i think it's important that i ask that because he's the dad and i shouldn't just consider a mum's perspective i think it's good for both parents to be considered we've had a chat about it and um he said it didn't affect him so badly as he was working and i did a lot of the appointments so i told him things and and and that there were obviously three things i would miss and because he wasn't there it doesn't sort of hit you quite so hard yeah um but he does say that you know people talk to me oh must be so hard for you kim he's standing right there he experiences the same things yeah um he's he has three older children from his marriage that's right um typically developing they're all grown now though um and you know he he saw much of their growing up and um he didn't know why he wasn't getting charlotte um he was you know it was confusing for him yeah i've seen this but this is different yeah um and things are adding up he feels that dad sometimes he overlooked in an ordeal yeah oh yeah yeah it's not fair

7. Autism - One Family's Diagnosis Journey - The General Practitioner

So how did you find the GP in this process? Our GP doesn't know very much. I think younger GPs may, because autism is more prevalent now, and it's a term that's bandied around a bit. Older ones, not so much. And is your GP a wee bit older? Yeah, he'll be well into his 50s. He doesn't try to sort of say, oh, you need to do this or you need to do that, but he listens to us and he says, what do you want? And I generally know what I need and what I want, and he'll say, oh, do you need this, this, this? And I'll say, yes, yes, no, and he'll do it. He has made referrals for us, which has been great, but largely he just says, what do you want? So that's good. So, I mean, while he might not know a lot about autism, he actually knows enough and he listens to you, which is fantastic. Yeah, he does, which is good. He doesn't pretend to know, which I think sometimes people try to, and that's not helpful either. No, no, that's good. Awesome. Yep.

8. Autism - One Family's Diagnosis Journey - Support - parent groups, Facebook groups

okay so what did you do for um support when your daughter got a diagnosis um wasn't until i was a mum um and dealing with the things that were happening became quite anxious um so that made things really hard um nowadays there's things like facebook social media sites um which i find really helpful they went around when charlotte was going through it so since my son got his um diagnosis um they've been really helpful and um yeah um there are other groups uh that i've been referred to or have been asked about and parent to parent in autism new zealand um i particularly did not find these very helpful but that's not one size fits all um definitely recommend people trying them because it's not right for everybody but it is really really good for some others it was really hard um and i stopped going to sort of pure groups um because they're talking about um you know daughter learning to go to ballet and you know we should be able to keep time and the son's starting a soccer team and he's worried about performance and things and that wasn't charlotte no i was trying to keep pants on yeah so yeah well it wasn't for me and i stopped going um so that was a bit hard um i know some families will find groups like that really good and helpful and that's great so it's worth checking out because it might be right for them yeah sure so when your son got his diagnosis and social media was more prevalent um what were there any specific um groups or facebook things that you're doing there are two facebook groups that i belong to that i find really helpful um there's autism in new zealand parents and carers and that's really good it's relevant to new zealand which helps yeah um and um it was also helpful to me because i think it was really helpful to me because i think it was really helpful to me because i think it was really helpful to me because i think it was really helpful to me just helps people who are struggling and see people struggling with the same things it's a safe space that there's you know i don't see anything negative or derogatory on there that's good it's really good everyone's on the same page and dealing with the same stuff yeah um and you know if you know if they don't know someone else might yeah um and there's also another one called iphones i-f-u-n-z yeah um which is individualized funding uses in new zealand and people talk about think getting funded for things um you know sensory toys or um so like how to use their carer support yeah or their individualized funding if they have that yeah um and that helps people with a with ideas because you've got to spend this money or they take it from you yes yes um but also um you know ideas of what they can use it for also um realizing oh you know i need one of those too and it'd be really good yeah um is there are there any others that you would look at there are groups and ones that i have um joined in the past but i find a little bit of quite american and there are a lot of um ideas that americans have around autism that aren't really different to us but different to us yeah no that's cool and don't tolerate to correlate to me at all yeah no cool all right cool things

9. Autism - One Family's Diagnosis Journey - Getting help - beating the drum

So is there anything else that you would recommend families do or who they should contact? Lifelinks, we were talking about them earlier. They provide support and help. They can be used in a variety of ways. Learn to connect with you and the autism coordination services. I like the idea that you run your support information as groups so people can come together and do that and maybe meet other families and get support that way. And actually it's been really cool seeing when I do the groups, families connect and go off and do their own little social groups or have lunch together. That's great. So is there anything else you would recommend?

You must keep on and beat the drum for your child. I talk about beating the drum a lot. You've got to be loud and you've got to be long and you've got to keep on doing it. Keep asking for help or advice. But if you need to reword your question, just reword it. Make it more impactful. Do that. Don't ask the same person. They're not listening to you. They are busy and they are stretched. So talk to all the support people because even if that person, like an OT that you're seeing, can't help you with that, they can tell someone who can. And ask more people. Say you're struggling. Talk to lots of different people.

Talk to the SLT, the speech language therapist. They can refer you to an OT. Talk to the OT. They can say, you need to see your GP about that. Tell your GP. He can refer you to somewhere else. Tell everyone. So, you know, you get a... Yeah, yeah. Sure.

10. Autism - One Family's Diagnosis Journey - Advocating for your child

Anything else? What about if professionals sort of try and expect you to do something? What would you say about that? You need to sort of delegate and see who can help you. I'm all about taking advice but sometimes I'm asking them because I don't know what to do. You can't take no for an answer. And I guess you have to also be able to say, actually this isn't what I want and be able to ask for a second opinion. Have you done that? Personally I was feeling quite forced and bullied into getting an ADHD diagnosis for my daughter. She needs Ritalin apparently. This is a few years ago now. I said absolutely not. You can come and administer the drug to her because I can't do it. So don't let... Yeah. Others bully you into a decision and don't... You don't want and you might need to go on to research it yourself and see if that's actually what you want. You know your child best and you need to advocate for them. Don't take it as concrete. Yeah, sure. Ask for a second opinion. Why do you think she needs this? Ask people on Facebook. It's prevalent now. You can get lots of ideas and things like this that you may never have thought of because there are groups for that now and they're helpful. Cool.

11. Autism - One Family's Diagnosis Journey - If I got a diagnosis now

So on reflection, your child's just got a diagnosis. What is the thing that you found, or what was the support, or what was it that you found most useful? It's very isolating, and I felt that quite deeply when my daughter was diagnosed because there wasn't a lot around then. This was a long time ago, talking 15, 16 years. But now, as my son was diagnosed, Facebook is in everybody's lives, and there are lots of networking sites on there. So the networking, not feeling alone. You're not the only one dealing with night waiting. You're not the only one dealing with not eating that particular vegetable. You're not the only one doing any of the things that autistic children find hard. You're on the same journey, even if your children are very different, but if you don't know what to do, someone else might. And also, you can help other people. I find, because I've been doing it for a while, I can say, try this, or go to this person, and need to be in it together. You're never alone, and you don't need to feel isolated. And it's wonderful now that there is such a thing as social media, and especially Facebook. I find it wonderful. Yeah, and it is tough. It can be really tough. So, yeah, support is really key. I agree. Thank you.
