

NEURODIVERSITY > AUTISM > MOTHER AND DAUGHTER'S JOURNEY

Mother and Daughter's Journey

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1. A Mother and Daughter's Journey – introductions

Hi, I'm Alison Schroder and I'm a speech-language therapist and I'm also in a company called Socially Speaking. I've been a speech-language therapist for over 30 years now and I've had a lot of experience in the area of neurodiversity. But I think particularly over the last five years, I've just really learned so much. There's been a lot of advances and a lot of new learning around neurodiversity. And it's probably changed the approach and the way that I have worked with people. But also one of the big learnings I've had is through the families I've worked with. I've had the joy of working with children who've become teenagers and who now are young adults.

So I've gone through the journey with them. And today I'm meeting up with a family that I've worked with for many years. I'm guessing maybe 10, I'm not quite sure. But I'll get them to introduce themselves to you. I'm Laura and When I was eight years old, I received a diagnosis for autism spectrum disorder. How old are you now? I'm 22 now. And I spend two days a week volunteering with SPCA. And as Alison said, I mentioned Socially Speaking. I attend the Young Adult Group and also volunteer with a children's group. Up and down with the kids. Awesome. I'm Gabby, I'm Laura's mum. So Laura is one of twins and she's got two younger brothers as well.

So we're a pretty busy household. Yeah, and I work for the University of Otago. And Laura, you've got a special t-shirt on today. Easily distracted by chickens. That's probably a good segue into kind of some of your hobbies. Do you want to tell us what you enjoy doing? I really enjoy my work at the SPCA, working with the small animals. So rabbits, guinea pigs, poultry, that sort of thing. I am obsessed with anything chickens. Chickens or ducks. And you got me hooked. I do remember, Laura, one time we went for a group trip to Sumner where you bought chicken. I did indeed. And we walked along the beach, which is very cool.

And what about you? And what about, tell us about at your home with all your animals? I'm not going to get into the full list because it'll take too long. But let's just say that we've got quite a few animals at the time. Right, and you enjoy. Okay. What else do you like, Laura? You've got lots of interests. I'm quite keen on cooking. I cook a meal for my family and some family friends every week on a Friday. Is

there a particular meal you cook? Or do you cook a variety of things? I cook a whole variety of things. I tried cooking jackfruit for the first time last week. Oh, nice. What recipe did you put them in?

It was a sort of like a barbecue pulled pork imitation or something. Nice. It actually turned out quite nice. Considering I've never even eaten jackfruit before. They've not cooked it. Right, good. So you're quite adventurous with your cooking then, huh? It can be quite interesting to play around with new ingredients. Yeah, nice. We give Laura a country that she has to cook. Oh. So we had everything from Hawaii to Samoa to whatever, you know, Hungarian, everything. Fantastic. Friday's are good days in our household. Yeah, I bet. Nice. And I've got the delight. I've tried many of your breads before too.

Because I find it really hard to make bread, but you're a bit of a pro aren't you on that? Yeah. And what other hobbies do you like doing? I quite enjoy my cross stitching. And I recently discovered that I really quite enjoy playing board games with some friends of mine. Oh, neat. A particular type of board game? I'm actually really enjoying the slightly more complex ones, the ones where you have to sort of think and there's lots of things going on. Yeah, lots of strategy, which is, yeah, I can see that. Awesome. So.

2. A Mother and Daughter's Journey – diagnosis – what changed

You said that you were diagnosed at eight so you're 22 so that was quite a long time ago and I think probably lots of changes have happened since then but I was just wondering maybe Gaby could you just tell us a little bit about um I don't know for you at eight what happened and kind of a little bit of journey that you've been on?

It's not an easy journey by any stretch of the imagination um so it took us a long time to actually get a diagnosis because we as a family we knew there was something slightly different with Laura it's not that she didn't have the opportunity or the um you know the constant exposure of people around her because you know she's a twin she's got brothers and but we always had an issue with um like issue like at preschool at nursery school you know primary school that that Laura just didn't quite fit in and there were you know it was hard so the the diagnosis in the end was in a way a relief up to that point we were trying to like avoid the you know the stigma of it but at least once you have a diagnosis you know what the actual issue is it's not that she's naughty or that she's difficult or that she's I mean hyperactive or whatever it is we we had more of an idea of what we can now look at and go oh that explains why Laura disappeared up the tree and we got called out to school to get her back down that sort of thing so it's um it was a help it also opened some doors for help from the government and so there was you know minister of education help coming into the school it was very limited but it was something and there was some carer support that was put in place so all of these things I mean it did take ages to actually start rolling out um but it was a start and it was really helpful and so that you could see what the pathway might be that Laura is on i mean at that point autism spectrum disorder was very well described for boys and men the you know the male but for girls it just didn't quite fit it was it just didn't quite ring true that we knew there were some aspects there where we could see yes this is definitely Laura um but not not quite but it definitely helped to get that and then you know you had a bit of a teacher aid at school you had later on in school you had um your room to do exams in so that you can get distracted so these things definitely helped which we wouldn't have had if we didn't have the diagnosis nor do you remember like when you were were you given the diagnosis or do you remember when you knew that you had autism or i don't really remember a particular point in time but i remember mum going through some books and activities and things with me when i was quite young and how do you feel now because um do you feel like some people like to have i suppose they don't like to have a label or some people do how do you feel about um being labeled with autism um i actually don't really mind it that much um i've found that when i've tried to hide it it's just caused more trouble than it's worth right different example um there's been i've had some some issues i studied vet nursing a couple of years ago and there was a problem at one of the vet clinics that i did some placement at where i made the mistake of not mentioning my diagnosis and they were a bit um i guess they just didn't really know why i was acting the way i did yeah and i'm like it's weird and then when we told them what was going on eventually okay why didn't you tell us straight away yeah so then i suppose the more that people know and understand the more able they are to help you and adapt is that how you found it yeah

3. A Mother and Daughter's Journey – education – achievements and challenges

So tell me about a little bit about kind of your experience at school. What were your strengths at school? I always seem to do a little bit better in sciences than pretty much anywhere else. Yeah. Taking after my mum. Yes, I know there's a real science brain in your family, aren't there? And where did you have, what did you achieve at school? What level did you get to? I stayed all the way through to year 13. Yeah. I just, I passed year 13, I didn't get anything special, I just passed it. But you got some excellences in some things too, didn't you? What did you get excellence in? It was mostly like biology papers, the ones that I seemed to do alright at.

Enjoyed those things. And were there any kind of challenges around your schooling that you found hard? A lot of issues with people picking on me and teasing me. Right. And that's hard, isn't it? That's a really, really hard one for a school. How do you feel it was dealt with? Was it something you shared with people or you kept it to yourself? As mum can tell you, I was constantly whinging him out all the

time. Yeah. I think in primary school they were starting to put some, you know, structures in place. Laura, you had like your spot on the floor where you can sit. Yeah. Yeah. Yeah. Where you went too close to your other, you know, classmates because it was hard and that you knew where you were going to go in class.

I remember that. But then in high school, I think we really hit it lucky because Laura was assigned to the deputy principal and he was just great. He was, he didn't sweat the small stuff. He was a guy that everybody had respect for. Yeah. But Laura could go there when she needed some time and space and he had a box of tricks that she could keep busy with. But he could also growl at the big burly boys outside the office. I think he was saving grace at high school. Hey, Laura? Yeah. So it's having that kind of safe person in a safe place is so important for you. Actually, I think I remember many years ago going into your school and they were so understanding.

They really wanted to learn and find out. Yeah. So that was really good, wasn't it? You still had some teachers that just didn't seem to care. Yeah. And it's that understanding. And I suppose it's that, and that's why we kind of wanting to get that knowledge for all of us to learn more so we can support with people. So you said a little bit about you went to do vet nursing. What happened as far as your kind of tertiary training? I mean, the course was very interesting and I learned a lot of interesting stuff, as far as the support systems that they had in place for neurodiversity was practically nothing.

Right. When mum approached them to find out, they're like, we can give you a reader-writer. And do you need a reader-writer? No, not at all. That's not helpful. I don't need that. They were able to give me separate accommodation for the two exams that I had, which was at least something. Yeah. But yeah, as far as other support systems, there was just nothing in place. One of the big challenges there was that because Laura was now an adult, they refused to talk to the parent. The parent was absolutely excluded. And young people like Laura, they still need a little bit of support. And so a lot of the messages were missing.

And then, you know, Laura missed some assignments, et cetera. So I think that was the really hard bit. Actually, the worst. But was that right at the beginning of that course, one of her main lecturers said, nobody like you has ever passed this course. Right. And that, of course, was not good for anybody's self-esteem, especially a young person like Laura. I thought that was terrible. Absolutely. Yeah. And she didn't really specify what she's just like, people like you just don't generally do well in this course. Right. So it's a real lack of understanding. So, I suppose if we could go back in time and wave our magic wand, what do you think places like tertiary places could do to support people's neurodiversity, how could it have been better?

Always struggled with group work, and most of my lecturers there were just not understanding at all about that. Right. So, supporting that. Yeah, because I always struggle with interacting with my classmates. That's always hard for me, because I never really had any new friends there. So, support with group work and maybe support with connection with other people. Yeah, and I never really felt comfortable working with my classmates because I was never able to really interact that much with them. Those sort of interactions were just hard for me. Yeah, absolutely. And I suppose what you're saying too is that understanding.

Yeah. That understanding of neurodiversity from the actual people themselves, and their positive attitude towards it, rather than a blanket. No. No. And I suppose what you're saying, Gabina, maybe it's not just in the, even in a tertiary environment, but it's also even with medical kind of things as well, when young people are 18 or 22, they still may need the support of their parents and parents to be listened to. Yeah. Because they listen to the whole family. Yes. Yeah. They were not very open to that.

4. A Mother and Daughter's Journey – a week's activity

so anyway let's move on to now in your life so you've mentioned a little bit before but how do you fill in your week because one of the reasons why I want to talk to you because I love what you do I think you have a variety of different things um and I think it's lovely to share for other people to see you know what you're doing so talk you through your week with us um so Monday is my day off I just get to stay at home and do whatever um I volunteer at the SPC on Tuesdays and Thursdays I've got my socially speaking adult group on a Tuesday evening and the kids um the socially speaking kids group that volunteer with is on Wednesday afternoon um like today that's where I'll be going afterwards and I've just come from uh Wednesday morning craft group um the Wednesday morning craft group Laura is the youngest by about 50 years that's cool fantastic yeah yeah what kind of craft do you do I'm working with some cross-stitching at the moment actually I wish you'd brought your cross-stitching in it's amazing ah she's you're very very talented in it um and then what do you do tonight that I do with you yeah then Wednesday evenings is yoga yeah just cool with your mum as well yeah you yeah and then Thursday evenings I've got piano lessons um Saturday evenings I go out um playing board games with some friends and first this is also SPCA yeah yeah I mentioned that you've got a variety of different things yeah you do okay that's awesome isn't it so I suppose we're looking into the future you know what kind of goals do you think that you would like um one of the things that I've been looking into is trying to figure out what I'm going to be doing in the future I'm trying to get a job right um so far no luck yeah and how have you been doing that I've been um I've been putting in applications to um for positions that look like they could potentially work for me but yeah but no no luck in that no luck what kind of work are you looking at doing um I'm not sure I always thought I'd like to work with animals yeah um I also am quite good at organizing sort of spaces um one of my little projects at the SPCA is keeping the blanket

shed organized right which is a constant mission yes I'm sure could you come to my house Laura I'd like a lot of organizing to be done there what are your thoughts that gave me around the work yeah I mean I'm obviously been keeping my eyes open as well for a paid job for Laura because I think that would just be good all round yes yes it'll be good for your self-esteem because you are so talented and so useful it'd just be good if somebody else sees their talent and um you know employs you Laura got as far as an interview right yeah that was good once um but that that's quite scary as well so I think it'd be good to get some more interview skills under your belt have you gone to any organizations to do that yeah I think I've been doing a lot of things I've been doing a lot of things I've been doing a lot of things I've been doing a lot of things to support you there no no that might be something yes well that's one thing we are looking also at the group is getting some people in from like places like work bridge and that to come in and support for that extra extra help for you and stuff the other thing we're working on is trying to get Laura a learner's yes but we're working on it and we're working on it too you've driven around the paddock once have you it was terrifying yeah it is scary when you first start to drive but I think you can do that because you live on a kind of um lifestyle block don't you so you can get out in the car and drive around there yep yeah the only problem is this sheep in that paddock I don't want to squash the sheep we might be reporting you to the SBCA um how do you feel about getting your license Laura how do you think that would change your life I mean in some cases being able to drive myself places could be useful um but for the most part I've been walking around um hitching a lift somewhere and then you're taking buses from there yeah um I can see it would would help though wouldn't it as far and sun getting because waiting for a bus sometimes can be a long time it's maybe speeding up time getting to places um well when you're in town once you're in town it's fine because the bus system is pretty good but there's no buses in town when you're in town it's fine because the bus system is pretty good actually but Political Car ça invite enHelp is pretty good as well when you're in town once you're in town it's fine because the bus system is pretty good actually but Well, I've been all the way out and there's no buses near us.

No, no. So mum's your taxi driver. Yeah, nearest bus stop, I looked this up, is an hour 45 minutes walk from our bus. So not only would getting your driver's licence help you, but it probably could significantly help your mum, do you think? So I suppose you were looking at unpaid employment and looking at getting a learner's licence. I suppose thinking about kind of the barriers that might be in the way and maybe support you might need in order to get to those next steps. What do you both think that you might need the extra help in? I'm not sure. I think we were talking about that, maybe getting some help with your CV.

I mean, both your dad and I had a look at it and we think it looks jolly good, actually. But it's obviously not getting quite across the line, so maybe getting some help. Getting some help with interviewing skills so that you're not quite so nervous once we get to that point. I think that would help. Yeah. I mean, the ideal thing, obviously, would be some sort of organisation that knows how to deal with young people like Laura, where you don't have to explain everything, where they just go, oh, yeah, you know. You know, just train you up carefully. Don't immediately expect teamwork and leadership.

And all these things which you normally find in a job ad, you know, you need to have all these things in place. It's like this is a young person who doesn't have that yet and who struggles with teamwork and with, you know, social interaction and, I don't know, customer facing and all these sort of things. It would be lovely to have something that's a little bit protective to start with and then grow from there. And I suppose that's what you've been saying the whole way through, isn't it? The more that people understand and they can, because you're an amazing, lovely young lady and I've had the pleasure of knowing you over all these years and you've got a lot to offer.

And so the more that people can understand and support you, you can blossom to be, you know, into more. So, yeah, that understanding around neurodiversity is just... Because it's a hidden... It is. I hate the word disability, but it is a hidden disability. You come in in a wheelchair, people immediately know what your issue is, but you don't. You know, it's hidden. Yeah. You just go, you're a bit odd. And it is changing, definitely, and the knowledge, as I say, for the years I've worked, and it really is. And people are using and understanding the term neurodiversity. And I use it when I'm going out with my friends and they'll ask me, actually, what is neurodiversity?

And so I'm telling them. So more and more people are knowing. So I think once people understand, they have more empathy and understanding. And as you said, when you did do your course and they understood, they were more helpful. Because most people on the whole are empathetic and understanding.

5. A Mother and Daughter's Journey – self awareness, sensory issues and preferences

Nowadays what I'm finding the bigger issue is not so much me communicating the issue but other people taking the issue seriously. But you're way more self-aware these days and you can articulate it more rather than just having a wee little explosion. So I think you're way more self-aware and you go, I'm feeling anxious now. And you know, you learned how to put yourself away from people when you're starting to feel that way. Don't you think? You're definitely managing those kind of anxious or overwhelming moments much better than you used to and that comes with age too, doesn't it? But yeah. But yeah, I mean you, the kind of sensory overload, you still have a good number of those issues.

Like wrong kind of trousers and don't wear jeans and things like that. Very fussy about food, very fussy about food. So a lot of, you know, things like that stay with you all your life and others you learn to manage. So even though you're fussy with food, you'll cook food from all over the world. Do you eat all the things you cook? Most of them. So it's good, isn't it? Yeah. But there's like serious green stuff in there. But I get on my plate and you pick out. Yeah. The main thing is that I don't like capsicums, I don't like tomatoes and I do not like mushrooms. Right. I have a son who doesn't like mushrooms still and he's the same age and he picks mushrooms out.

So there you go. If something grows in mouldy wood chips, it's not food. So there's still those kind of different things and I suppose we all have ourselves, everyone has kind of sensory preferences. Don't they? I can't get past Brussels sprouts myself. So, but it's how you manage. I'm too bitter for my liking. Yeah. It's how you manage those in everyday life. So you're learning to manage a number of those things, aren't you? What about noise and things? Is that a big thing? Not as much as when I was little. Right. I still find it a bit overwhelming when there's a lot of noises going on, like walking alongside a busy road.

Right. But the main tool I have for combating that or, for instance, if I'm walking on a busy road, I have a little bit of noise. Yeah. Yeah. Yeah. Yeah. Yeah. Yeah. Yeah. Yeah. Yeah. Yeah. And combating that or, for instance, if I'm walking through a shopping mall on my own, is headphones and audiobooks. Absolute lifesaver, audiobooks. Audiobooks and music. Ah. How many audiobooks do you listen to a week? Is it loads or you just...? It depends on the length. Um. Yeah. Yeah. I've seen you walking down the road with your, yeah, headphones on and... Yeah, because otherwise it's having these kind of zooming past like...

Yeah. Yeah. Yeah. Yeah. Oh, yeah. So you're using the same headphones every day? Yeah.

pass like three meters away from you sort of and they were very carefully chosen to be bright white so that they cannot be missed by anybody I was wondering why you got me white once because I was sort of like this is gonna show all my dirty fingerprints on this thing no but you people can see from a mile away that you can't hear them but yeah I mean you still freak out with noises Laura you can't go past the hand dryer yeah I hate the hand dryers and public bathrooms why do they have to be so flippin loud yeah yeah there's still plenty of them around yeah don't go near the things like there's some super high powered ones it just sounds like an airplane taking off it's like uh-uh too loud going through the hospital just now was too noisy as well there's quite a few people a few noises and would people know if they saw you that you're struggling with that if I was just walking past you walking through the hospital probably not if you know me really well like mum I would probably notice that I'm sort of a bit like noises too much noises and what do you find you know like if you have been in that kind of experience what do you find kind of helps you manage those because it's quite a heightened feeling for you as an afterwards are there ways that you can kind of relate yourself afterwards I'm just a bit tired we're working hard and as you say listen to music and those kind of things yeah

6. A Mother and Daughter's Journey – connections and time management

One of the things too I was thinking about was around kind of your whole well-being isn't it really about so managing kind of those sensory things but it's also around you know your movement and exercise because what do you do you you walk a lot don't you would that be your main form of kind of physical movement? For the most part. Yeah how far how far would you think you walk? I suppose it's hard to know but um yeah it is hard to know because all the walking around just walking around at the SPCA. Yeah but there'd be yeah I mean it's physical outside work absolutely and out there. I suppose the indoor work and barn.

Okay barn. Unless you're on poultry duty then you're outside. I was thinking about connection with people do you feel that you have enough connection with people? Not enough or? I feel I do have enough. Yeah so you're kind of filling your bucket on that so you yeah. But way more than ever at school right at school Laura honestly did not have any friends. Right. And then through social speaking she's made a few friends and a friend group now that plays book. Yeah strategy ones if you had me along there I'd be I'd be losing you guys way above my level. Way on me. Yeah yeah yeah which is which is great isn't it so you're getting um that good positive connections and you're getting physical um I suppose one of the things we didn't talk about before but was about time management still a bit of a struggle.

Yeah. Yeah yeah in what way? Um yeah just trying to organize my time utilize it efficiently. So if you've got a structure and a routine can you can you fit to that quite well or is it more? For the most part yeah mornings are a struggle. Hard to get out of bed? Yeah yeah I don't do mornings. Don't do mornings. Laura does not do mornings. I'm a night owl. I'm a night owl so I'm up and about in the middle of the night but I don't do mornings. Right so that's something you do with the job you probably have to manage. Yeah yeah we've been thinking about night shifts but right by and large those are like big burny men doing security rounds so right I can't quite see Laura doing that one.

Ah we have to put our heads together and think about all this don't we.

7. A Mother and Daughter's Journey – siblings and parents

But coming back to what you were saying, getting a window into people, I think for Laura's siblings, seeing how Laura struggled and how she gets on with things and how she reacts to things, I think was a huge help to all of them. I think all three of them have a much better understanding of other people with neurodiversity. Nikki, her twin sister, is going to give a talk at her. She messaged me and I haven't got back to her. Yeah, she's going to give a talk at her company about neurodiversity to try and explain to people in industry what it means, what you look out for, how you can support them.

Because what is she? Science, isn't she? Engineering. Engineering. So there will probably be a number of people neurodiverse there. They'll be on the spectrum. Yeah, and they're understanding. So isn't that cool? So you're actually... So you can see that kind of ripple effect from you, you're actually helping so many other people. Teaching the rest of us. Yeah. Making us better people. That's what I'd like to do, is try and help create an environment where others like me can get the support they need. Yeah. And maybe that's the difference between 10 and 15 years ago, is that you probably didn't know so many people who were adults and neurodiverse.

And now you're older. Yeah. You can talk more about the experiences. And people, particularly me, because I trained and I learnt all about autism, but I've learnt more from working with people with autism and their families than any textbook. So in my training, back in 1989, I remember having three parents come talk to us, three mums, about autism, and not a lot was known then. And they were told that they were fridge mothers, the reason there. And I remember that the reason that children struggled socially was because they were cold. And so it was just so horrible. And I think back to that now, and I can remember the stress on those people.

So Gabby, for you, how have you found as far as kind of what people thought around parenting and your role, I suppose, as a mother? Yeah, I think we've, my husband and I, we've been sent on numerous courses to become better parents. Because... Yeah. I think we've... My husband and I, we've been sent on numerous courses to become better parents. Because... We obviously didn't do a good enough job, and we've got four children, and three of them had no issues whatsoever, but still, yeah, so we're very, very well-trained parents. We've, yeah, again and again, we went, okay, I mean, there's always something that one can learn, you never know, but it was just the absolute belief that, obviously, something wrong with the parenting that causes this sort of behavior.

It's, yeah, it isn't. No, it definitely isn't. Things have changed, I think, over the years, but not that much. And, you know, I know of... Of other people who are going through the same thing still now, where the first finger is getting pointed at the parents, as opposed to maybe there's no more support needed around this family. The whole family needs support. The child or the young person as well as the parents. Absolutely.

8. A Mother and Daughter's Journey – key messages

I want, I've got two last things. I wanted, I kind of thought this, I want mum to say what she's most proud about you. And then I suppose a takeaway from today, kind of a main idea that maybe other people might find useful. I am particularly proud of a very kind, selfless young lady who will go out of her way to produce the most amazing handmade gifts for the family, who goes out and spends hours and hours every week grafting at the SPCA, just as a volunteer or helping out elsewhere. I think you're just lovely, Laura. Just very, very proud of you. And you have a massive brain to go with it. We have like, I don't know, you ask the obscure question about some film star or some TV game or something.

And Laura has the answer like that. How do you know that? I've heard it somewhere, at some stage. I've read it somewhere, I don't know. I like that, but I liked it somewhere. Yeah, yeah. Awesome. This is lovely. That's pretty cool, isn't it, Laura? Okay, so I suppose from both of you, what's a takeaway that maybe for, I don't know, for families around your experiences that maybe you want to share? I don't know. Do you want mum to go first? Mum. I think I'd take her message. If I think back to the very, very early days when Laura was little and wouldn't go to sleep, I think as a parent, you know your child best.

And if you think there's something that needs further investigation, go for it. And don't take the first, second or third answer if it doesn't really agree with what you can see, what you know in your heart. Because. A correct label is always better than having a naughty child or a difficult child. And that is not an instant cure. It's not an instant help. But it's the first tiny little step of getting help and getting the support that you as a whole family need. Because the effect on the whole family is not insignificant, but specifically help the person to grow into. Such a lovely young lady as we have sitting here.

If you've got an idea now, Laura? I guess what I could say is for those people who are working with people with neurodiversity, taking the time to support them, be patient and understanding rather than just brushing them off. And be prepared for getting asked a lot of questions. Well thank you so much I've really enjoyed this and thanks for all your help over the years it's been lovely