

Podcast Episode 2 Transcript

Alison & James

Hosted by Bronnie Whitelaw, Senior Advisor Teaching & Learning, SERU

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BW Welcome to SERU podcast session two, developed and produced by the Special Education Resource Unit. My name is Bronnie Whitelaw, I'm the Senior Adviser Teaching and Learning at SERU and I'm your host for today. Before we start I would like to acknowledge the traditional custodians of the lands we are recording on today and pay respect to any Aboriginal people listening. We acknowledge and respect the Kurna peoples spiritual relationship with this country and recognise that their cultural and heritage beliefs are still important to the living Kurna people today. I'm thrilled to introduce you to today's guest, Alison Bowden. Alison is a primary school educator who focused on junior primary teaching in the Catholic education system before becoming a Mum. Today we will be discussing her story as a parent of a child with a disability and how she has been supported along this journey. Welcome Alison and thank you for joining me today.

AB Thanks you so much having me Bronnie, it's an honour to be here today.

BW Alison can you please tell us a bit about yourself and your family.

AB My husband and I have 3 beautiful boys, our eldest son James has Down Syndrome and we have our middle son who is 13 months younger than James and we have a three year old, Elijah; so we are a very busy family and I'm happy to be here today to talk about my son.

BW Thank you, so Alison can you talk to us about your son James and share the diagnosis journey and how this impacted you and your husband in those early days and weeks.

AB OK, so our son's diagnosis of Down Syndrome was a complete surprise. So he was diagnosed with Down Syndrome at birth and we were in shock initially and unfortunately the information that we were given about Down Syndrome was quite outdated and we weren't given a lot of you know, congratulations or anything like that, so we were in a bit of kind of like shock mode initially but as soon as James was born we loved him and we are now at a very different place in our lives with thinking about Down Syndrome and it's actually a wonderful thing to be living with a disability today

BW Yeah and I guess that would have been very confronting for you both

AB It was

BW And you would draw some good support out of your relationship with each other to get through the initial phase, like you said, the shock but then learning a bit more about it in that more positive way has reframed the way you feel about the situation that was presented to you.

AB Yes absolutely, that's exactly right.

BW So I'm wondering about what supports you have in place in these early times when you were first learning about your son's diagnosis and the implications for him medically and with his development?

AB That's right, so when, as soon as James was born on day 2 I contacted Down Syndrome SA, so we were very lucky because we had an amazing Early Educator that came into hospital and she was just what we needed it at the time so she was probably one of the first people that said congratulations, James is gorgeous, you're going to have a wonderful life. All the things as a parent first time having a baby, you'd like to hear, so it was really wonderful having her come into the hospital and just having that reassurance that yes, James has Down Syndrome, but he is going to be quite capable as was well, have strengths and have challenges.

BW Yeah

AB He had a major heart defect which wasn't picked up initially

BW Ok how old was he when that was diagnosed?

AB So that was picked up only a few weeks after he was born so we had to be rushed into Women's and Children's and we were in the Rose Ward, which is a very serious place to be in but we were very grateful that we were there. So he was a heart monitor, we had to make sure that he wasn't going into heart failure. So once he was given the heart medication and they taught me how to do nasal gastric feeding and when we were able to do that we were sent home and then when James was five months old, he had to have his heart repaired, which is very common for children with Down Syndrome. A lot of children with Down Syndrome will require heart surgery and it's a pretty standard procedure so we were flown to Melbourne, he had his open heart surgery then basically for the next 12 months we kept him home to make sure that his heart repaired and that his immune system was in check because he was very frail after having that surgery

BW Of course

AB But after that period of time you know we saw light at the end of the tunnel, we got to know him, we fell in love with him instantly so it was after the heart surgery it was a great relief for us.

BW Yeah but it sounds like you had some really positive people coming into your lives

AB We did, we did

BW At the right time to support you through that period, the early stages

AB That's right Down Syndrome SA were particularly good. We also, after James' surgery were contacted by Disability SA and they were wonderful and that's what eventually led us to you through them, yes, which I'll talk about later.

BW OK thank you Alison. So I'm grateful that you were able to connect with us here at SERU and were supported by our staff as a parent borrower

AB Yes that's right

BW Can you tell us a bit about what that support looked like and how that supported you as the parent and supported your son in developing critical early developments skills.

AB Basically when we were told about SERU, I really didn't know what really SERU did, initially apart from

borrowing toys but it actually became a lot more than that so there was a lovely lady that used to work here, a wonderful educator like yourself called Anne and she welcomed James and I, he was only very little when we came in and it was just good to have a chat to her about what I could do to help with James' early stages of development. He was very delayed because of having the heart surgery, but also I wasn't sure what kind of intervention I should do to help support James. So she also liked guided me with what particular things to help him sit up, what mobile toys we could use to help him develop you know some early fine motor skills using music to help him as well with picking up musical toys

BW Unpacking those developmental milestones and then looking at the resources in the collection that you'd be able to utilise to develop those key skills.

AB Exactly, That's right. So it was great to be able to come in and just chat with her and other people here too and say right well James is on his tummy now what toys should I use to motivate him. Posting blocks were a huge for James, that was a massive motivator for him so I did a lot of posting toys and just different blocks and different little toys that were musical and you know, wanted him to play and you know, it was a wonderful experience to come in here and look at the variety that SERU has.

BW Yeah so that sort helped him with his motor planning, with visual-spatial, for his muscle tone as well.

AB And just even chatting to Anne about what else should I do, she also recommended me to go to playgrounds, you know all of those things that you know, at the time I had another baby as well so I didn't have a lot of clarity at the time so she with that guidance as well with other things I can do outside of the home environment, but definitely with educational resources was wonderful.

BW Yeah

AB So yes

BW Well that's very fortunate that you met with the lovely Anne and in her retirement I know that she is very missed by other people so thank you for sharing that. I'm keen to share with our listeners what James' educational journey has been like once he started school what were some of the challenges and successes that you faced and what decisions you made to manage these?

AB Ok so, as a parent of a child with a disability and being a primary school teacher it was very daunting. I knew what exactly what he was going into and I was very worried about how we'd manage, so he actually managed better than I imagined. So what we did, we looked at lots of schools and a little catholic school that appealed to us, James attended that school successfully until 2 o'clock most days up until Year 2.

BW Right

AB James is limited verbally, he uses Proloquo2Go and visual schedules and some Key Signing to communicate. So for the first few years I was very nervous and anxious, he did very well with connecting with others, but by the time he was in year 2, the gap started showing and every child is different with their disability, it affects them differently and for James not being able to talk easily and feeling frustrated with not being able to do some of the tasks that were starting to become a little bit harder for his peer group age.

BW So the academic limitations

AB But at that point we started looking at special schools and we found a wonderful special school at Dulwich and a bit of a drive for us, but James is really enjoying being there and there's options for him to do a lot of gross motor movement which he needs

BW Right, built into the program

AB Built into the program, a program that some of the schools find a bit more challenging. Mainstream schools are wonderful and same with special schools, it's really just knowing how your child is coping and if you feel like they're in the right environment that meets their needs.

BW And that doesn't mean that you have to stay in that environment, if you feel that, for that moment or for that period of time in their educational life that they can't change and move to something that's a better fit for them.

AB That's right

BW Yeah so I think you know is really important to make sure you are looking at what is that right fit for him

AB That's right, the right fit for your child, because you child will tell you and we could see that he wasn't happy where he was and when he wasn't being able to freely communicate and so now he is

BW More able to communicate with his peers

AB Yeah he uses Proloquo2Go everywhere in the school.

BW And with the educators at the school, there's not so many people that you're having to try to communicate with either so and I guess it's part of the curriculum

AB Exactly, yes that's right

BW So it's a bit more proactive in that way for him.

AB That's correct

BW Yeah, so I'm wondering about the use of inclusive technologies, so you said that he's using the AAC and some Key Word Sign

AB Yes that's right

BW How is that really helping in engagement and access at home and at school and have you used technologies and other scaffolds to support his communication more broadly and can you tell us about who helped you to make the decisions about what sort of communication is the most beneficial and effective for him to be able to manage?

AB Well, it has been a massive journey, we from very early stages of his development, we did Key Signing with James and we noticed that when he started school he was dropping that on arrival and we thought is not good

BW He didn't get the communication partner,

AB That's right so not having a communication partner and people not signing back, not deliberately but just not understanding so Novita helped us with assessing that he really needed a communication device for his voice and finding a voice so he can actually tell us how he's feeling, what his wants and needs are. So we were shown Proloquo2Go like we were saying earlier and that has opened up his communication pathways. So he will go to school and have his Proloquo2Go with him on his shoulder and he's little carrier that he can go around and anything that he wants to say to his teachers they use Proloquo2Go. He also has visual schedules of the day as well at home on our wall which match Proloquo2Go so we try and make sure everything matches Proloquo2Go because that is universal and it's consistent

BW Absolutely, makes everything easier for him to transfer from one thing to the other

AB That's right

BW And also it's so important like you mentioned it's about having it with him all day so that he has a voice and an opportunity to use his voice all day every day in every environment.

AB So the good thing about his Proloquo2Go is that already the educators use it in their classroom or they have their own classroom Proloquo2Go, every child is different but for James, he has that as well, they also have a timetable so they go through that and James really loves the visuals. We have screenshots at home or home pages from Proloquo2Go so if he's tired or not feeling like he wants to get his iPad out, when he's having a challenging day or not feeling well he can just point to what he's saying.

BW So he's still using the same format

AB Exactly, the same thing but not having to access. We've also done this other thing where we've got a hard copy of Proloquo2Go with all the screen shots of about five pages so then when we have days where we are in the car and we've forgotten accidentally Proloquo2Go we've got something

BW Because technology doesn't always work

AB I know that's been a challenge in my life

BW It's got these limitation

AB Exactly

BW Some times its as you've said you forgot to charge it up to there might be a glitch or something needs to be updated in the program, it just allows him to have an alternative so that he is not dependent on that one thing, that's super important.

AB And the good thing too about once we got to know Proloquo2Go and James started accessing things on there saying what he wanted to eat for example, we did what he wanted so that was what the Speech Therapist from Novita said, as soon as he says something initially on Proloquo2Go and actually says he really wants something, do it. So one of the first things he said was he wanted McDonalds

BW Of course

AB And we drove past McDonalds and he pointed to McDonalds on his Proloquo2Go and told us that he wanted fries and soda and so I actually turned the car around and ever since we really started doing that, he's like right well Mum is actually you know hearing what I'm saying

BW I've got a want and need I've presented it to you and you're actually listening and following up with that

AB That's right and the same goes in the help icon and if there's something wrong, he'll go an tell me and it's usually 99% correct. So he has ear infections quite commonly and he'll go straight to ear infections if he has one and we'll go to the doctor with Proloquo2Go and he would tell us what's wrong and the doctor will go yep, you're right James you have an ear infection. So it's really been the best thing for his finding a voice

BW How empowering for him

AB Exactly

BW And that's only going to continue to grow as his skills in using it grow and he's already using it to make full statements

AB 100%

BW How old is he now?

AB He's 10, so he certainly knows what he wants and he very much now knows how navigate the communication device and his brothers have learnt how to do it too so they do have some funny interesting conversations after dinner we have some chat time and some of the things are quite silly with what they say but we all laugh and then we

BW That's what boys do anyway

AB Yeah that's exactly right

BW It's all normal and natural sibling behaviour isn't it

AB Exactly

BW They can engage in that as opposed to being in a reserved role for that

AB That's right, so he, James can say yes and no so that has really helped and he can sign 'finish' and the Proloquo2Go has been for everything else and the other good thing that James has developed over the years, he has a great understanding of body language. So if someone is upset or if someone was really excited like he recognises that and he wants to respect that and be part of that which is really great to see him developing in that area

BW Well it sounds like a wonderful thing that has opened the world up for him in many different ways so he has that voice

AB That's exactly right

BW And as I've said before really empowering . So I'm just wondering as a final kind of conversation piece, what advice would you give other parents who have a child or children with a disability or learning difficulties?

AB So my advice is in the early days I just really wanted to embrace my son to get to know him and enjoy him because he was only a baby for such a small time and I really treasured that time and once I got over the cloud of you know shock and having his surgery and getting to know him. I felt like it was the time for me to start looking at what was around to support James and give him those opportunities to thrive in his learning and development and I feel very lucky that actually we did come to SERU because it gave me a lot of feeling of right, I've got a pathway, there's amazing tools and resources here let's see what we can do you know some toys that you get, you think oh ok that didn't work but then something unexpected worked really well so it's good to have that flexibility and also to be able to speak to educators like yourself and say right, we're going through this stage right now, any ideas, suggestions? it was really wonderful

BW And it can be trial and error and that's ok, we are allowed to play in this space and we know that the resources in our collection are evidence-based and they've been researched before they've been purchased here

AB That's right

BW However, it doesn't mean that everything is going to be the right fit for everybody so to be able to talk about what's worked well and what was a challenge with something and then refine and then try something else that might be another opportunity at any particular skill and so I think that for anybody who's interested we are a free service to parents across all our sectors not only just our government Department for Ed school parents but for Catholic and independent and so we welcome anyone to come along and connect with us.

AB Please come along it's been a great experience for us and the only other thing I would suggest is NDIS has been wonderful so if you feel like you're not sure where to go for your child, you can get help through the NDIS for finding the right supports and therapists as well, so that was a help to us as well having a really good support planner and working out where to go from here to support James to have a fulfilling life

BW Oh beautiful thank you so much

AB That's ok thanks for having me in today

BW OK Alison I really appreciate your time and sharing your beautiful story of the journey of you as a family and the amazing James who is doing so well and as you said he's flourishing.

AB Thank you so much

BW Thanks

AB Bye bye