Transcript

Success for children and young people with FASD – July 2014

An Auckland Region Child, Youth and Family resource

**Chapter 1**

Rose: So Morgan, what were the issues for Ryan when you first got involved with him?

Morgan: He was about thirteen when I first got involved; there’d been a longstanding history with Child, Youth and Family from the age of about seven. He’d been diagnosed with Asperger’s there was a suggestion that he might have reactive attachment disorder or oppositional defiant disorder or conduct disorder. Issues with his behaviour at home, with caregivers at school, he was just non-compliant, at times aggressive, violent, would damage property, couldn’t get on with other kids. It had progressed, by the time I was involved with him, that he had started making suicide threats, had started being violent towards his mum, was absconding, started making violent threats towards animals, and there was just no real level of being able to calm him down or kind of work forward. It would go on for like hours!

Rose: So what interventions were involved at that time?

Morgan: There were quite a lot in professionals involved. There’d been two HCN plans already when he was much younger, there’s been several attempts counselling, at different parenting interventions.

This was the thing that was really confounding for heaps of professionals, was some of the best services that we have were involved and it didn’t appear to actually change his behaviour at all. He continued to become more and more unsettled; the violence the threats, the absconding became more and more frequent. It was at that point that the Behaviour Support Psychologist from the Ministry of Education referred for a neuro-psych assessment through Dr Valerie McGinn.

**Chapter 2**

Dr McGinn: When I first met Ryan, he was fourteen, it was at the Child, Youth and Family office and he was really so out of control that they couldn’t manage him anywhere and that was why he was in the office, because he had to be looked after. He was raging around and he was really agitated and unhappy. And I went into a little room with him and sat down on the floor and started playing with toys, because I could see immediately that although he was fourteen, developmentally he was eight or nine. And he calmed down and he started to talk with me. And it was really evident that he had Fetal Alcohol Spectrum Disorder because he has go the face of FASD and also his level of understanding was quite low and he was very immature. And I said to him, gosh you must really be missing your mum and he went immediately from being really angry to just crying and being upset. And it was just sort of immediately evident to me that he was a boy with FASD and he needed to be managed differently.

Morgan: The first day, Dr McGinn gave us some recommendations about how to talk to him differently, what his different functioning levels were – so like he couldn’t take in certain things, you couldn’t be too complicated in the way you talk to him; you had to keep things quite simple. And that made a difference straight away.

Not being able to try to reason through things too much with Ryan. You know making sure that you simplify things enough that you weren’t telling him too many things that might or may happen because he couldn’t manage the ambiguity of that – he needed quite clear ‘yes this is going to happen’ or if we don’t know it’s going to happen ‘we don’t know it’s going to happen but we’re going to find out at this meeting if it’s going to happen.’

Rose: So are you saying that previously people would have naturally have spoken to him like he could have understood things which actually he couldn’t understand?

Morgan: Because he was thirteen at the time and kind of tall and skinny for his age, even though he has an intellectual disability his vocabulary is quite good and so you know; I think everybody does this when a child is taller than their age, you just assume that their reasoning is what they look like. So he looked like a thirteen year old boy, you kind of expect you can reason with him through that is some way, but I think his functioning was about a seven year old. And even the way you talk to a normal seven year old there’s things they might be able to manage like some kind of ‘well we don’t know about that yet’ stuff that even for him, he couldn’t. He really just needed the adults to manage those things for him and what you told him had to be whatever you said it was going to be because he’d just get stuck on that and it had to be that way.

Dr McGinn: I think the thing with children with FASD is they’ve got a brain disability they can’t take all the stress and strain of normal life and so they need to be treated much younger than their chronological age. They need a lot of support and help with things and they need to be well managed across their whole day so that’s at home, at school, during the weekends they need a lot of supervision. If anything goes wrong in any stage of the day, you will have emotional and behavioural problems. Over time when they are well managed they get much more resilient and they can take much more strain, but when I first met Ryan he was really at breaking point – he just couldn’t manage, he couldn’t cope – and it looked like he was being really naughty but he wasn’t being naughty he was just a very stressed child.

**Chapter 3**

Morgan: Next was getting the full assessment from Dr McGinn which really looked at his specific cognitive deficits, his capacities, his functioning level, what he could and could not manage. The next things were the routine, the structure, from the caregiver. So we had a caregiver that was recommended by Dr McGinn who had experience with working with kids who have FASD, kids who had brain injuries, all those kinds of disabilities and that made a massive difference. Just the expect ability of life – he could know what was coming up next so he wasn’t upset about it. We had some on-going support from Dr McGinn both working with the mum, as the plan was return Ryan home to his mum after he was settled, so Dr McGinn worked with her to up skill her – what does it mean having a child who has FASD, how do you manage that. If he can be so settled with his caregiver, how can we pull those things over to a home placement to make that just as stable? She also did some work with school about training the staff and teachers about working with kids with FASD and that made a massive difference in school. She’s made some on-going recommendations about health and other follow up things that have been quite helpful.

Dr McGinn: First of all it’s the process of doing a diagnosis, you can’t just assume – even though I could tell he had FASD – I still had to do a full assessment, I had to get to know him and know what was his needs to be able to advise his social worker, his school and his mum on how to manage him. So that first day I went and saw his mum. She had really tried hard with Ryan and nothing had worked. You get into this situation perhaps where the family blame Child, Youth and Family and Child, Youth and Family blame the family – in fact there’s something else going on that they hadn’t even realised. So I was able to sit with her and talk about the whole development of Ryan from his birth and before his birth and it was then that I asked her whether she had been drinking in the pregnancy and she said that she had. It’s not done in a blaming way. I explain to her what is and how these children present and what sort of problems they have and she says; yes you’re right that’s exactly what’s wrong with my son. So from that moment forward she was engaged, the social worker was engaged and everyone was engaged in trying to move forward in trying to do the best for Ryan. And it wasn’t easy, it took a long time, he remained emotionally volatile and difficult for quite a period of time but as he got realistic expectations, everyone started to talk to him differently and manage him differently he just slowly settled and he’s just blossomed over a couple of years now.

Morgan: Dr McGinn points out that lots of kids who have FASD confabulate – which is a fancy word for they make up story and often they believe in those stories, it’s not really lying because when you lie you know you’re not saying the real thing. And just understanding where the blame lies or doesn’t exist at times. So if he would go to access with his dad which is supervised and then he’d come back and he’d tell his mum ‘oh this happened at access’ normally she would get really angry because it wasn’t okay that this was happening – and so we all just kind of learned that when Ryan says something, rather than getting angry of upset because something happened that shouldn’t have happened, we just check our stories out and talk with the other adults that know what’s happening so it all just manages more smoothly.

**Chapter 4**

Rose: So this was a private service coming to assist, how did that affect you as a site manager and how you could manage the situation?

Roxane: I guess the major thing that affected me as a site manager was talking to Morgan about it and talking at financial clinic, because it was expensive, and talking about the differences that Morgan saw immediately. And also having the rationale for the high cost placement, because the specialised caregiver was high cost and it’s not easy to get approval for high cost placements and we’re all worried about our budgets – but to have the knowledge and the background information to be able to put the rationale for it that made a huge difference. To have her support and to know that my social worker was supported in this different way of thinking and different way of working with this young man.

Also I think because we had tried another HCN plan we had tried to put forward to get another HCN plan and it was like ‘no he’s already had two’ and the professionals who were sitting around the table all seemed to blame mum and I knew it wasn’t mum, there was other stuff going on. So having that extra support and that extra resource really helped to validate that and get a better outcome.

Morgan: Our site funded a lot of things but we also accessed some funding through YSS to help pay for the assessment and on-going work with Dr Val McGinn and some counselling with John Hibbs and other little piece which were a bit pricey to just get the work done that needed to be done but not tax the site too much.

Dr McGinn: The caregiver that Ryan is living with is experienced and I have trained that family in how to look after children with FASD. So they do have a really good routine, they have rules, firm rules but they are flexible depending on how the child is. So it’s a family environment, it’s full of things to do but it doesn’t overstress the child and things are clear and routines are well established. And he did very well in that environment and not his mother has more or less the same environment at home. So now he can go between home and his placement and stay settled and secure and happy in both placements.

Rose: Roxane I understand that he was placed right out of area but you’ve maintained the management of him at this site. You could have transferred this case?

Roxane: Yes, as Morgan said earlier it’s about having that relationship and previous to Morgan coming on board he’d had eight different social workers, nine different caregivers, numerous placements – he’d had quite a bit of uncertainty. And what we’ve learnt over the past two years is that he does need that structure and in order to be able to get his behaviours down they do need to be able to build that trust, trust that the grown up is going to figure it out for him. So as much as it would have been great to transfer because neither is he living in our areas, nor is his mother in our area which is the long term placement we’re moving to and it’s going really well. He knew Morgan, he started to trust Morgan, we put him at the centre, even though it was a time and a financial cost but it’s about him.

**Chapter 5**

Rose: Were there any other key that made a difference?

Morgan: Coordinating all the adults. Keeping everybody on the same page so that as things change we all know what’s happing, what the plan is, so all the adults keep in contact and never passing messages through Ryan, ever.

When you build the environment around what he can manage then he’s not stressed and he’s not anxious and actually he’s a settled person.

Rose: Can you say more about building that environment around him?

Morgan: I think we know a lot about autism and that they need really structured environments and they don’t like change. There’s some similarities with FASD, so he does need routine, he doesn’t manage well with not knowing what to expect so if it’s routine enough and he knows this is how it works and when there’s a problem, this is who I talk to and there’s a level of security and a level of safety – in that someone’s going to sort out whatever problem he might have, then that just removes that level of worry for him.

Rose: But he’s a teenager – shouldn’t he have more freedom?

Morgan: Well he can have freedom when it’s structured in a way he can manage it, and I think that’s what actually makes it work. Freedom that means that he can’t cope and he’s not able to manage stress and he gets upset isn’t really helpful for him or for anyone else and so it’s about managing his life in a way which makes it better.

**Chapter 6**

Rose: So after all of this, he’s going back to mum

Morgan: That’s the plan and it seems to be progressing quite well. He’s like a completely different person, from the child I met at thirteen when I took on this case, to the young person who’s about to turn sixteen now – like a different person. He’s completely calm, he’s super settled, he’s really chirpy and happy, he’s not moody, he’s attending school – asking to go more days because he was only attending four days now he wants to go the fifth day so he is. He’s got plans going forward, he’s been informed about his diagnosis with the help of Dr Valerie McGinn and he’s been able to take that on board and he understands that that’s going to mean some limitations for him, some different plans as an adult but he’s just able to go with that and he’s able to manage some much more than he could before.

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