

How do they do it?

The story of this family is a story of love and commitment not often seen. They have adopted eight children all of whom have FASD. Those of us who have one or two children with the condition find it difficult enough to cope – this family is exceptional.

Both my husband and I have always been involved with children. For a long time we fostered children within the foster care system but then about fourteen years ago one of my first foster families asked me to look after children outside of the system. That meant that we would not get any assistance from the foster care system, only whatever Centrelink* could provide.

This family was desperate and had nowhere to go so I caved in and said 'yes, but only for a few weeks'. A few weeks stretched into a few years and now, fourteen years later, I'm still looking after this little girl who came to me so tiny and ill. Still to this day I don't know how I got her two siblings – a brother and a sister. It could have been the same way: they came to stay for a day or so and never left.

*Centrelink is the gatekeeper for many Federal Government programs and is also the Australian government agency which assesses and distributes income support to the unemployed, parents, people with disabilities and the elderly.

Now I have Vicki 15, Sapphire 12 ½, Linda 8, Tracey 6, Kiao 3, Louise 8, Hannah 4½ and Kim 6. They all have Fetal Alcohol Spectrum Disorder but only some of them have been diagnosed. Sapphire, Linda and Vicki were diagnosed by a paediatrician in South Australia. Hannah's mum didn't even know she was pregnant until she actually had the baby – she thought she just had kidney problems so she didn't stop drinking.

At six months of age Hannah was in and out of hospital with 'failure to thrive', low muscle tone, and the doctors said she appeared retarded, blind and deaf. At about one year old we commenced early intervention visits at the hospital so I could learn how to provide stimulation for her to encourage her toward her milestones. This seemed to help because once she got going she was like a little dynamo, into everything with no idea of danger.

For anyone who knows about how Fetal Alcohol Syndrome affects the behaviour of children, it would seem obvious that our household is not a typical household. Our kind of normality is different to everyone else's normality. We understand the children and that they are trying to behave and we understand that when they take money out of my purse it is not because they are actually stealing someone else's belongings, it's because they don't understand the concept of property.

Children with FAS suffer constantly from stimulus overload so they need a calm environment with fewer people around them in order to be able to cope with life and learn. However, I did take Hannah to playgroups, craft groups with crèches, anything that might help her. She began speech therapy paid for by the government but at that time her speech did not progress.

When she was three years old she started both Kindergarten and a private school for people with intellectual disabilities but because we were five kilometres away she was transported by taxi to and from school for four years until we had a change of teachers. This adjustment to her routine precipitated a huge and dramatic change in her behaviour because the new teacher couldn't effectively cope with the class or with Hannah.

Hannah is able to access care which is covered by Home and Community Care, Family Day Care; and Vacation Care at the school which caters for children with disabilities.

This has all been terribly difficult as you can imagine but what has completely saved me is connecting with other families with the same problems around the world. I don't know what I would have done if I had not been able to hook up with them via email. I was very stressed until then.

Doctors are unwilling to diagnose children because of the guilt to the family. To me having a diagnosis allows you to access services and educate others about the condition.

Tracey is a difficult child and has a tremendous amount of inappropriate behaviours which are very difficult to manage at school. A lot of her behaviours could be attributed to sexual or other abuse, but these behaviours are not because of that – she behaves in this manner because she has FAS. If she's not accurately diagnosed then everyone will always be wondering whether she had been abused.

It's hard because everything gets broken, used, taken away or lost because they fossick into everything. They want everything NOW. Sometimes I'd like to scream because I'm so frustrated with them but then the next minute they say 'I love you' – I have learned to go with the flow. I get through it the best way I can. I have to understand that it's not me that's the problem it's the condition they have – Fetal Alcohol Syndrome.

My husband and I have learned to live very much in the moment and understand that beyond these behaviours, they are very loving kids and we love them all. They are our family and I'm very depressed at the moment thinking that two of my children will be leaving us to go back to their families after Christmas. It's great that their parents are able to have them back but it's very sad for us. Nevertheless we'll always be their Nana and Poppa.

Some people believe that I must get a lot of benefits and services because I have so many children with disabilities but it's not true. There are no services available for kids with FAS. It seems like I've been fighting forever. I do access 'normal' services but there is nothing that is specific for FASD.

Hannah had to eventually have physiotherapy to improve her coordination and muscle tone and she also needed glasses to correct her sight. Her ears proved to be another problem with specialist appointments by the dozen for ear tubes which didn't rectify the problem at all so now she has to wear hearing aids.

Obviously with these multiple disabilities, Hannah will need care for the remainder of her life, such as supported accommodation, supported employment; she will need to be assisted with shopping, cooking and public transport. She will also need to be reminded to shower and attend to personal hygiene like most children with FASD.

Because Tracey didn't fit the criteria (didn't have the facial features) she didn't get any services at school even though she has a great teacher who knows about FAS. The one thing I do have is free tutoring but even that will be cancelled next year. I've had to put one of my kids into a private special school because she was being bullied and was totally out of control. The teacher maintained she didn't have a problem; she just needed behaviour management or more discipline at home. These kids are very trusting and other students can take advantage of them. That was what was happening to Tracey and it kept getting her into trouble.

I use a lot of outside support such as Vacation Care. It helps the children interact with others their own age and also gives them an idea of what things are like outside of home by offering them extra learning situations. I have tried to keep them very protected because they can so easily get into trouble.

Hannah will be going to school next year and it will be a tremendous experience for her. I have provided the

various schools they go to with education on FASD. If I can educate one of the older children's teachers about FAS then he will most likely pick up the next one when he or she moves up in the next year. It's great then because they know what FAS is about and can understand what will be needed for the next child. But without a teacher understanding about FAS, the child, the teacher and the rest of the classroom would be very stressed and frustrated.

Emily is a really bright child but she is always up at the office for little misdemeanours. But at least at that school the teachers have taken the information about FAS on board.

I gave the high school lots of written information about FAS prior to Vicki going to high school but even then when she did actually go I felt I had to discuss the condition with the teacher. I remember saying to her 'Do you realise that with Vicki she will listen to what you are saying and say all the right things to you and answer all your questions but then she will walk out of your office then forget everything when she gets with her friends?' When she said 'Oh you mean like Asperger's Syndrome?' I knew she was aware of what Vicki would be like. But even with this understanding by her teacher I have had to constantly intervene and try and find ways to help her get through each week without getting suspended.

We have had some wonderful times and some very low times with these children but I get to my lowest when I think deeply about their condition and what it means to them in the long term. Then I realise that my kids will never be able to learn some things. Vicki still can't add up change – I mean she's 15 now and still doesn't know how much change to expect when she buys something. However will they cope with life, particularly the children who haven't as yet been diagnosed? I am desperately trying to train them so they can be more independent in the long term but just when I think they've got it – they forget it.

Everyone in the community needs to have information about FASD because only then will they realise the horrible effects that alcohol has on the child. I believe that no one sets out to intentionally harm their children. They either don't have the information or they can only do what they can do. We are all only doing the best we can and I know that's an overused cliché but I believe it's entirely true when we think about the mothers who give birth to children with FAS. Some of my mums have lived dreadful lives, they've been abused, live on the street, were never cared for or looked after by their parents, and many have FAS themselves. How can we make any judgements about them when we haven't had to cope with the abuse or neglect they have?

Because of their struggles with this condition one of the most rewarding things for me is seeing my children achieve – anything. I believe that God has given me these children, for their sake of course, because without us they would be in a very different and difficult situation, but for me as well. I have learned so much about patience, and I've learned not to look at things on the surface and make judgements about people. Other people look at my kids and think they are naughty; I look at them and see how much they are trying.