

## He was never a 'normal' kid

*Husband and wife medical professionals who would often look after children in trouble found that love and commitment were not enough when the child who is theirs in their heart is not theirs in the eyes of the law.*

We had high hopes for Zeke when we first fostered him, but after a few years it looked less and less likely those hopes would be realised. Our story began when I offered to look after the baby of one of my patients, Lisa, as she was having a very difficult time with a mental illness and drug and alcohol addictions.

She agreed and from the very first we felt involved, very caught up in their situation, and it was impossible for us to turn away from them. My husband and I were both experienced health professionals and did not doubt we could handle an 18-month-old baby for a few months until his mum got back on her feet.

We had fostered children in strife before and we also had a keen interest in disability. My husband was particularly interested in the treatment of delinquent children.

We had all the credentials to look after a child: experience, medical knowledge, commitment and love. After Ezekiel had been with us a few weeks we could see that even at that age he was aggressive and hyperactive but we put that down to the environment during the first 18 months of his life and truly believed his behaviour would improve.

But his strange and unfortunate behaviour continued. He screamed every night all night and nothing I did made any difference. This went on for months until in the end I realised that there was something horribly, horribly wrong with him. The only time he ever slept through the night was when he was heavily medicated.

Lisa would plan to take Zeke away for the week but after a day or so she would be back because he was uncontrollable and she didn't know what to do with him. Eventually she became desperate enough to ask that we become legal custodians of Zeke. By that time my husband Rex and I were so attached to Zeke that there was no question that we would both agree. So we contacted the Family Court and eventually obtained legal guardianship and custody of Zeke.

Zeke saw paediatricians regularly during his childhood and also had EEG biofeedback twice a week for several months. In the hope that it would help him, we accessed the services of a speech therapist and occupational therapist along with psychological counselling. Zeke was also seen by neurologists, a geneticist, psychiatrists and paediatricians, and had assessments and testing performed by each professional. At this time Lisa was living in a Housing Commission house and spending all her money. She never set aside money in case it was needed it through the week. If she had money in her pocket it was gone as soon as she could find something to spend it on which was usually drugs and alcohol and the money would be gone in a day or two.

Rex and I helped her out many times. We gave her money for food and bailed her out of the situations in which she found herself. Once a drug dealer threatened to break her partner's legs if he didn't pay up so we gave her the money to pay the dealer. We bought her cigarettes and eventually I agreed to look after her finances because she admitted that she just couldn't do it. I insisted that we shop for food the first day she got paid so at least she would

have food in the house, but just when things were going well and Lisa got into a good routine, she became paranoid and said we were ripping her off. Then of course the cycle began again with all the money going in the first day or two.

By the time Zeke went to school his behaviour was unbelievable. He became increasingly delinquent and extremely antisocial. After years of being in Special Educational Units, he was enrolled in mainstream schooling but received no additional support in the classroom. This wasn't a pleasant time for him or the other students and teachers. It was also very difficult for me particularly because I had to stop work to look after Zeke because he was only able to remain at school for short periods due to his bizarre behaviour. He was suspended often for throwing faeces and urinating on children. He was initially diagnosed with ADHD but he was not eligible for any services or special teaching staff because he had a normal IQ and did not have any other diagnosis that would allow him access to additional services.

It was only when I read Ann Streissguth's book did I realise that Zeke's behaviour was consistent with Fetal Alcohol Syndrome. I knew Lisa was a drinker and also that Lisa's mum was also a heavy drinker. Lisa was always very impulsive and had poor coping and money management skills which when put together with confirmed maternal drinking meant that Lisa could have FAS too.

When Lisa's next baby was born it was diagnosed with FAS at birth and I know that Ann Streissguth believes that many people who give birth to children with FAS have FAS themselves.

Rex was much older than me and had open heart surgery when Zeke was a young boy. This was a very difficult time for me with Zeke's behaviour and Rex's illness to cope with. No doctor would agree that Zeke had FAS, all they would say was that his behaviour was consistent with FAS. So he didn't have a diagnosis that would allow us to get help for him until one paediatrician diagnosed him with Pervasive Developmental Delay. I have an ethical dilemma in obtaining a diagnosis simply to gain services but it was the only way that Zeke could get the help he needed. When he was diagnosed I was able to advocate for more appropriate services for him from Education Queensland.

However, along with this diagnosis came the unfortunate suggestion that if he engaged in a behaviour modification program it would 'cure' him. Of course, a person with FAS is never going to respond to a behaviour modification program.

After trying everything I could think of at last I agreed to medication and that made an unbelievable difference to him. I was very reluctant to put him on anti-psychotics but I realised that because of my reluctance to use medication I believe that I under-medicated him which resulted in his behaviour not being managed as well as it could have been.

He was on anti-depressants, stimulants for ADHD, and the anti-psychotics. Under this regimen, he was required to go to a paediatrician regularly for reviews of the condition and his medication.

As Rex's particular field of interest was delinquent children, he was exceptionally interested in this medication regimen, and after experiencing Zeke's behaviour he also concluded that prenatal alcohol exposure was clearly a contributing factor to delinquency. However, this was difficult to verify as even alcoholic mothers often deny any alcohol use during pregnancy. Until I researched FAS, I believed that children with this condition were the result of heavily alcohol dependent women; now of course I understand that social drinkers are much more likely to bear a child with FAS.

Lisa denies that Ezekiel has FAS, even though her second child has been formally diagnosed with the condition. Lisa thinks Zeke is a normal child but has been brought up badly by us.

We even took him to the same paediatrician in Brisbane who diagnosed his brother but he would not diagnose the condition in Zeke as he did not want to stigmatise Lisa even though she already had a diagnosed FAS child. It is unbelievable that Zeke's needs are entirely forgotten. He will need services for the rest of his life and for those

services he will need a diagnosis but no one will diagnose him. I agree with Elizabeth that by doing this they are clearly sacrificing the child for the sake of the mother – this is complete and utter medical negligence.

Zeke is now fourteen years old and because of his aggression, lives in \$1000 a month duplex with 24-hour care under the umbrella of Family Services. I still advocate for him vigorously and without my advocacy I am sure Zeke would not have the same quality of care. Zeke has made substantial gains since he has had 24-hour care. This is partly due to his maturity and medication regimen and partly because he has a strict routine and structure in his day. He has two carers, both men, because as he grew older and his aggressiveness intensified, Rex and I found it difficult to restrain him. When he was smaller, we could physically hold him and stop him from hurting us but now, without Rex, I simply don't have the strength.

Even when Rex was alive, we often had to deadlock the house and then lock ourselves in a room so that he wouldn't hurt us. Our life was more or less curtailed before he went into care because I couldn't take him anywhere and no one would come to our house. His behaviour was always socially unacceptable. He can be very offensive and people just thought I was a bad mother. Even my family did not want to be near him and I certainly couldn't allow him to be alone with any little girls as he was hypersexual.

After Rex died I agreed to have Zeke every Sunday and now that he is a little more manageable we both enjoy the time together. Before he was in care I really had no respite, no social life and was often afraid of him. I can't imagine what his life would have been like with Lisa. She surely would not have been able to cope with him. I am certain he would be on the streets or in jail or dead by now.

But now when he comes to visit me things are different. He plays on his Playstation or his computer which I bought for him so that he had something constructive to do when he visited and he also rides his bike. One of the only social contexts in which we are all comfortable is at church. He is accepted and welcome there and when he visits me I make sure that we both attend.

I try not to be judgmental about women who drink while they are pregnant. I know that there are some who just don't know what it can do to their baby and the ones who do know and still drink probably have little control over what they are doing because of their addiction.

So much more education needs to go out to the community. It is a social problem because I know there are people who truly don't believe that alcohol can cause a problem like Zeke's. They seem to prefer to believe that it is caused by bad parenting. This is usually from people whose children have grown up and all is okay or they are comments from parents who don't as yet have children. They also think that if it does cause a problem it is only to the Aboriginal population and it is their disaster to deal with, not something that happens to the white population.

I know that alcohol consumption amongst young women is a huge problem and if they have the attitude that it can't harm an unborn baby or they simply don't know that alcohol can cause problems, what is going to happen in the future and what will happen to their children if they can't cope with them? It does scare me.

But what scares me more is what will happen to Zeke when he turns eighteen because now that he is in care under Family Services, the Family Court order has been extinguished and I have no legal right to offer an opinion. Lisa is now Zeke's legal guardian. This is my greatest grief – at eighteen I truly believe that unless someone can get him a formal diagnosis and put adult services into place for him he will go to jail and jail is not the right place for him. How can anyone put a person with a disability in prison? I am committed to him, I love him, but I can't legally help him. I just don't think I can physically or emotionally bear the thought of Zeke going to jail but what else will there be for a hypersexual, impulsive, aggressive and often violent young man with an invisible disability that no one is skilled enough or courageous enough to diagnose?