ENQUIRY INTO FOETAL ALCOHOL SPECTRUM DISORDER

Response to request for additional information by Senator Griff

I am responding your enquiry about information I received about FASD both as part of my assessment/ pre-service training (which was negligible) and after my foster son R was diagnosed with FASD. I received absolutely no information about FASD from any government agencies. I have had dealings with 4 areas:

a. Child and Adolescent Mental Health Services (CAMHS).
b. Aboriginal Family Support Services (AFSS) - the placement agency
c. Families SA (now Child Protection Department)
d. The Families SA Aboriginal Consultant.

a. CAMHS - I contacted Families SA when my son, R, was 2 years old about his excessively violent and non-compliant behaviour. They had access to his birth records which would have shown his mother's severe alcohol and drug use and the fact that he was born 4 weeks early. They did not refer to FASD at all and gave no indication that he could be affected. I was lectured on parenting and setting boundaries. When he was 4, I put an urgent and desperate request via my social worker for help from CAMHS due to his behaviour. After 4 months, I had heard nothing. At a school planning meeting about 6 months later, the CAMHS rep said they were busy. They would have responded if they had realised he is indigenous but they misallocated him. I secured a private psychologist who also lectured me on parenting. She saw him melt down in the road one day and said "I can't help you. You need a psychiatrist." We found a psychiatrist and R started sessions fortnightly and has ended up on mood stabilising medication. He has recently been diagnosed with related epilepsy and the epilepsy medication seems to be helping him. It took Families SA 9 months to reimburse us for the $5,000 cost of these initial interventions.

b. AFSS - this is the aboriginal specific placement agency. At no point did they advise us of the likelihood R had FASD, what it is or strategies for managing R's behaviour. They were supposed to provide respite of 2 days per month but I ended up arranging it myself via friends due to the inadequacy of what was on offer. In my case, I need a person to mind R in the home rather than sending him away. He is very resistant to going anywhere and there is no doubt that the best for him would be to have in-home respite care, so that he can stay in his familiar surroundings. This type of respite seems to be totally unavailable, so I have very limited time away from him to recharge my batteries. The issue of adequate respite is a key problem for me. I have only had a break of more than one night once in the last 18 months and that was for only 2 nights. I have been asking for an aboriginal male mentor for R for 7 years and have now given up. He has a strong relationship with his birth family, initiated and driven by me. The agency has never openly acknowledged his FASD nor the part his birth mother played in this. There is a great reluctance to put a label on the behaviour or to acknowledge FASD's existence. This denial means that not only do I not get support, I am undermined and blamed. An example of the disrespect I feel was when I expressed my despair and frustration, the answer was to try to remove him, without any discussion with me. They have no understanding of the importance of stability for a FASD child. The threat of removal caused me to conceal from them the behaviours I am dealing with.

c. Families SA – Since I started caring for R when he was 3 weeks old, I have been allocated 3 different offices and 7 different social workers, so it is not easy to develop a relationship. I have moved house once in that time. The social workers made no reference to FASD. In fact, when R's psychiatrist sought his birth records as part of her diagnosis, the social worker refused to send it on, despite his supervisor agreeing to send it. I had to phone every week for 9 months before the records were provided. Immediately on receiving them, the psychiatrist had no hesitation in diagnosing FASD. This diagnosis was a great sorrow and a tremendous relief. I have received good support from my current social worker over the past year. However, she only works part time, so everything takes a long time and her support is limited. Prior to this, I felt disbelieved, blamed and threatened. I am currently waiting for reimbursement for repairs done to my house amounting to over $2,000 and have been waiting for several months, which is putting a great strain on my resources. The lack of understanding of FASD among social workers is appalling. I also note that R's birth mother, who was 15 when she became pregnant, was herself a ward of the state, so this is a cross-generational issue. Who was looking after her?

d. Aboriginal Consultant - part of FSA. I have had a few interactions and they have always been unsatisfactory. She is clearly resentful that I am raising this child, as I am not aboriginal. This is despite his identification with culture and his strong family connection. She totally denies FASD and its consequences. Any hint of criticism of his birth mother is met with anger and denial.

In short, I have received almost no support until very recently from any of the government agencies involved. I have been given no information. I have been blamed and threatened. In fact, I have done my best to educate and inform them but their attitude of denial blocks any understanding. It is only my love for R and my fear of what will happen to him if we don't hang in, that keeps me going. The organisation NOFASD has been a tremendous resource and has been the only light in the storm.

Insofar as Carer Payment is concerned, I am on the Age Pension. There is, I believe, no benefit to me seek the Carer Payment so I have not explored this avenue.

Thank you for your interest and for listening to my story.

Yours faithfully

Nikki Mortier