SUBMISSION TO THE SENATE ENQUIRY INTO FASD

BACKGROUND

I was approaching 60 years of age when I was finally approved as a foster carer in South Australia. I had registered with an aboriginal agency to provide respite care for a child one weekend a month and I had specified I did not want a child with a disability. I was almost immediately approached to care for a 3 week old baby boy (R) for 6 weeks while a more permanent placement was found. He was, at that time, living in a hotel with commercial nannies. Of course, I agreed to take him. As I later discovered, his birth mother was barely 16 years of age, was a ward of the State, had no permanent home, was using illicit drugs and alcohol to excess and was in a relationship with a man with a history of violence and a criminal record. R is still in my care and is now aged 11 years.

The events below are pertinent to this submission.

1. At no time was it overtly suggested to me that I raise this child. I was given no information about his background. From the time he was 18 months, it was made clear to me that to relinquish him would cause him emotional damage, due to his strong attachment. By that time, I also loved him. And so we now take this journey together.
2. When R was about 2, I became concerned about his behaviour. I had never had children of my own, so I asked for advice from Child and Adolescent Mental Health Service. They never mentioned the possibility of FASD and led me to believe that all his behavioural problems were a result of my parenting.
3. When R was 5 I requested, via my departmental social worker, another appointment with CAMHS because of his extreme aggression and violence. After no response for over 4 months, in desperation I initiated with my local GP to see a psychologist, who also focused on my parenting. After a few sessions, however, she admitted that she was unable to help and suggested I see a psychiatrist. R started fortnightly sessions with a child psychiatrist which he still attends. She has put him on mood stabilizing drugs, without which he is out of control. While the social worker had indicated Child Protection would pay for this intervention, I had to mount a strong and persistent argument with the Department and was at one time owed $5,000 before I received any reimbursement.
4. Eventually, after the department reluctantly sent R's birth records to the psychiatrist, a diagnosis of FASD was made. In fact, even after the diagnosis was made and confirmed by a department psychiatrist, the departmental and agency workers were in denial about his condition and its implications. I felt great judgment about my parenting and the implication was always present that R's problems were a matter of better parenting skills. Any suggestion that his birth mother was responsible for his condition was dismissed, often with considerable hostility towards me. I was given no information or parenting strategies. I had to find and arrange my own respite care. There was a serious lack of support, information or recognition. In fact, I found myself educating the workers about the condition.
5. R's behavior is typical of a child with FASD. He has trouble concentrating, poor impulse control, an explosive and often violent temper, delayed mental processing, sensory issues, problems in maintaining relationships with his peers, disruptive behavior at school, school refusal, etc.

6. His State school teachers are seriously overworked. His class has 30 students, with 6 children on the autism spectrum and other children with disruptive behaviours. Generally his teachers have no knowledge of FASD or how to manage it other than by punishment and exclusion. This has damaged his self esteem, as he is falling further and further behind. He is constantly in trouble. He finds school exhausting and, as a result, is unsurprisingly refusing to attend.
7. R is now registered with NDIS for this condition. NDIS seems to be focused on physical and intellectual disabilities and I have not been given advice on any programs available to deal with FASD. What is available is totally piecemeal and the NDIS support people are totally ignorant of FASD – denial and ignorance again. The fact that NDIS doesn't cover anything educational is also a problem as most of R's issues centre around his schooling. The few possible programs that exist which may be of help to R are inconvenient and hard to access. The strain of dealing with a child with FASD is exhausting for the whole family, and it is difficult to find the time and energy to go to activities of doubtful benefit.

My story is sadly not an unusual one. The Child Protection department and its political overseers appear not want to admit the extent of this problem. Some estimates are the half the children in care have FASD and that it may be as high as 1 in 20 children across the whole population. This is 3 times the incidence of autism which receives considerably more support and recognition. On average, every class will have one child affected by FASD. The workers have not been educated in the effects of FASD. Teachers are under-resourced and uneducated about the condition. Carers are blamed and left to fend for themselves with these terribly damaged and often violent children.

RECOMMENDATIONS

I have read the recommendations coming out of the *FASD: The Hidden Harm* House of Representatives enquiry, which were handed down in November 2012. In my opinion, the recommended Reference Group was not strong enough. A better resourced and influential organization is needed if any change is to happen. The recommendations are moving in the right direction but overall they are not strong enough. Even with these minimal recommendations, on the ground, I have not seen much evidence of their implementation.

The labeling, which came from Recommendation 11, is farcical and was not, to my knowledge, accompanied by a public awareness campaign. If Recommendation 12 was implemented, it didn't seem to yield any affect on alcohol consumption. I have seen nothing arising from Recommendation 17 ie no materials and training for teachers, foster carers, etc have appeared and I note that Child Protection workers were not even included. Some teachers in R's school have had short FASD awareness training (but not all) but it was not sufficient to skill them for dealing with FASD children in the classroom. I have received nothing.

In my opinion, this time we need strong recommendations which are implemented and properly resourced.

1. *Bring Home Responsibility to the Alcohol Industry*
   The alcohol industry is selling a dangerous product which has serious, life-long effects on innocent children. Just as responsibility for the harmful effects of tobacco and gambling, have had consequences for those industries, so should the alcohol industry bear some responsibilities. In my opinion, all alcohol sold should attract a levy to be applied in total to a specific FASD organization which would, for instance,
   - research the physiology of FASD, its diagnosis and management
   - research the extent and social implications of FASD
   - develop educational materials and approaches to prevent and manage FASD
   - develop guidance for those raising and educating children with FASD
   - develop strategies for the on-going support of children and adults with FASD
   - liaise with international bodies looking at prevention, management, education and social implications of FASD

   Possible immediate preventative responses are:

   - all containers should be labeled with graphic warnings as is done with tobacco products (not the miniscule labeling now used which is really farcical)
   - special classes for adolescents could be run in schools
   - notices could be placed in women's toilets
   - advertising of alcohol and sponsorship of sporting teams, could be banned (as with tobacco)
   - an advertising campaign on TV and social media could be developed to warn and educate about FASD
   - a warning could be a compulsory integral part of all alcohol advertising (as with gambling)
   - resources could be provided to doctors, community centres, child protection services and schools to educate on the causes, diagnosis and consequences of FASD.

2. *Resource Schools*
   A major problem exists in the resourcing of state schools. Teachers need a support person available for every class to aid in the management of behaviours, helping individuals with their work, encouraging and motivating the children. Children with FASD have very special needs and often thrive with one-on-one support. This requires a big increase in school funding. School counselors and teachers need to be better educated on recognizing FASD (as it is often not diagnosed or misdiagnosed) and on the strategies to use to get the best out of FASD students.

3. *Cultural Change in Child Protection Departments and Agencies*
   For children who are in care, the Child Protection agencies need to undergo major cultural change. There have been multiple enquiries into child protection, legislation has been amended, senior staff changed and still the problems persist and the number of people wanting to take on the role of foster carers continues to decline. This is a wider problem than the scope of this enquiry. However, the lack of awareness and understanding of FASD is demonstrative of the culture within these organizations. Children in care are disproportionately represented in the FASD population (some estimate 50% of children in care have FASD). There is a general denial of the condition. For example, my workers visit me every six weeks and nearly every time ask me if he has settled yet, as if his condition were temporary or curable, like a cold. There is an unwillingness to acknowledge the challenges FASD brings to carers. There is a deep disrespect for carers; a readiness to judge and blame carers for the behavioural problems of the children; a refusal to confront birth mothers with the consequences of their actions and to support them; an ignorance of the effects of FASD; a serious lack of respite care; and a lack of understanding of the very difficult task carers are undertaking with these damaged children.

Thank you for the opportunity to tell you my story. FASD is so prevalent and under-diagnosed. It creates such enormous challenges for parents, carers, educators and, of course, for the children themselves. It leaves adults with impaired ability to thrive in society. It creates an enormous social cost. And it is totally unnecessary. It is high time that we took serious action to stem the tide of FASD even at the expense of challenging the alcohol culture of our society. I wish you well in your deliberations and I hope for a strong and effective outcome.

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