

## **Presentation for the House Standing Committee on Social Policy and Legal Affairs 31<sup>st</sup> January**

My name is Anne Russell and I am the birth mother of two children with FASD. My oldest son has **neurodevelopmental disorder – alcohol exposed** and my youngest son has **full Fetal Alcohol Syndrome**.

The Inquiry into FASD in Australia by the House Standing Committee is very exciting to me and my family as well as to the many people who request support from the Russell Family Fetal Alcohol Disorders Association. As the secretary of this organisation, I represent over 700 individuals and organisations supporting the rffada and those people living with FASD.

There are a few points that I would like to make about FASD before I go on to the main part of my presentation.....I have sources for all these points if you need to include them.

- **The incidence of FAS is greater than the incidence of either Down Syndrome or Spina Bifida. The incidence of the whole syndrome is 5 to 10 times higher than the incidence of FAS.<sup>1</sup>**
- **<sup>2</sup>One FASD birth carries lifetime health costs of between \$860,000 and \$4.2 million**
- **Even so called expensive FASD prevention may be cost effective given these figures: up to \$850,000 per child**
- **The typical issues facing an individual with FASD are Mental health; attention deficits; depression; autism criminal justice involvement, depression, suicide, heart and kidney problems, anxiety, drug and alcohol problems, low educational achievement particularly in maths**

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<sup>1</sup> <http://www.hc-sc.gc.ca/fniah-spnia/famil/preg-gros/intro-eng.php>

<sup>2</sup> <http://fasdcenter.samhsa.gov/documents/RickHarwoodPresentation.pdf>

and English; difficulty parenting and problems maintaining employment.

My son Seth is 26 years of age. He has experienced in his short life time – drug and alcohol addiction; terrible problems at school including not being able to learn the way he was taught; suicide attempts; self-harm, depression, anxiety, psychosis, bullying; he is medicated for schizophrenia, was rejected by a number of services which didn't see him as requiring support; was told by a psychiatrist that he had to start taking responsibility for his life and has been ridiculed by friends and mocked by family. Yet even after all that, he has now stopped using drugs and cigarettes; is a good father and a husband; is holding down a part time job; and generally speaking is an asset to the community. But FASD is a condition that is always up and down and while today is good, tomorrow we could be back to the beginning again. The difficulty for me is that when he is good I am always wondering when the next suicide attempt will occur and when he is going through a rough time, I wonder how we will manage to support him through it. We have supported him financially to keep him out of prison, alive and without impediments to his future to the tune of many tens of thousands of dollars and consequently (in part) no longer have a family home. And what's worse ---- we are alone in these problems.

However I think that the time I have to talk to you today will be better spent if I don't talk about my own experience with FASD but if I talk about the problems that two people on the rffada Facebook Support Group have recently expressed.

These two examples from a pool of 451,000 children that the ANCD reported live in families where drug and alcohol problems are problematic.

The first one is from Debbie (not her real name)

Am very upset today - the Dept of Child Safety have told me that my kids no longer qualify for High Support needs (a small extra fortnightly payment). Apparently they say that from the 1st of January the qualifying requirements changed and it's no longer about extra time, emotional support, behaviours etc. it's about how much MONEY you have to spend extra each week... but they don't want to know about the amount of money I have to spend repairing my rental house etc they are only interested in the big things. So suddenly I'm down \$300 a fortnight but the children still destroy just as much as they did on the 31st of December. I asked them – 'what if I had a child in a wheel chair and I was receiving the payment... for them last year.. I bought a new wheelchair for them last year and modified my home last year... do I lose the payment this year because I don't have any big outlays coming up???' They of course don't have the answer to that. I hate this hidden disability stuff.. really really upset about it all right now. I also asked how much is my family worth... my parents no longer speak to me very much, we aren't welcome in their home, they whinge constantly about my 'naughty kids' who just need a good whack and why aren't they toilet trained etc.. when they come to my house. So these children living with me have destroyed that relationship! Never mind really because I can't abide their small mindedness about my children.

Just my rant for the day.

And this one is from Joanne (also not her real name)

Anne i was wondering if anyone can help me. I live in NSW and i have been trying to get services for my 12 yr old foster boy. He hasn't been diagnosed

with anything. I have had doctors and psychologists and pediatricians and counsellors tell me he has anxiety and depression as well as PTSD and maybe autism. The Growth Clinic and everyone says he probably has FASD as his older sister has FAS and his younger sister has FAS and i have 5 kids diagnosed with FASD in different degrees and i am fighting to get him services because he is not diagnosed. No one will see him, no one will medicate him. If he doesn't get meds our agency is going to remove him. A psych even told us he is a paranoid schizophrenic but no one has medicated him. They tell him that if he doesn't want help he doesn't have to, OMG i was crying today at Headspace. When i ...started crying the lady there said how stressed i was about losing him. She told me to go get some counselling for myself but how is that going to help my son when he hears voices talk about killing himself. He wants to die; he is depressed; he hits himself. I was told to commit him if does that. I was so angry when she said to him – 'if u don't want to see anyone u don't have to - we won't make you'. Since when is mental health a choice when it involves self-harm and suicide ideation? He has done pot and was taking from us for 3 weeks. We know he loves us and he talks to us. No one listened 5 yrs ago when we said there was something wrong. He has no empathy and no social skills. We just want help for him. He is going to see our pediatrician and he is going to assess him but not till April. He is not coping with school; he tells everyone he loves school; but he tried to hurt his teacher and got suspended. Luckily the police were not called on that one. The whole family has mental health issues all his cousins and mum and aunties so we know that something is very wrong we just can't get anyone to listen and he shuts down when people try to talk to him. He has major mood swings really happy, really depressed. I am just venting - we just don't want him to be taken away.

How can anyone listen to the problems that these families willingly take on without being moved to help?

I'm trying but I still come across gatekeeping by some services. Personal empowerment and enabling clients to make their own decisions and judgements about whether they need certain services may be appropriate for people who have a fully functioning brain but for those prenatally exposed to alcohol ----- they are not. Several of the symptoms of FASD are poor judgement and poor decision making, lack of insight and inability to link cause and consequence. Most people would understand these symptoms to contraindicate a rational decision about their needs.

So many families in Australia are in the same position as these two troubled families. The ANCD found that over 451,000 children are living in families where drug and alcohol use is problematic.

Please help the people who are suffering in Australia with this condition, alone, misunderstood, lonely, distressed, homeless and isolated not knowing that they have a problem – all the while believing they ARE the problem.

I can't bear to imagine how much pain my son has experienced in his short life, if I were ever to let down my guard and think of that emotionally, I would require hospitalisation.

This Inquiry is our hope for more recognition of FASD.

We need the following:

1. All relevant services trained in FASD – homelessness, drug and alcohol services, mental health, disability services, advocacy services, community health, midwives, nurses, allied health, frontline welfare and social services, employment services, Centrelink staff, fostering and adoption services, child protection, housing and child health, doctors, teachers, criminal justice personnel,

- 2, Diagnostic clinics in all state capitals at least and diagnostic teams trained specifically in FASD
3. A national media awareness campaign for the prevention of FASD using a description of the symptoms of FASD for those people wondering what is wrong with their children, friends, nieces and nephews
4. Alcohol and pregnancy education in all high schools;
5. Early intervention funding similar in nature to the Better Start Initiative;
6. Ongoing government funding for the rffada strategic projects

And .....

I say this now as a mother not as the secretary of the rffada -----  
----- I know there are conscientious, thorough medical professionals in Australia ----- but I spoke to 5 medical professionals to try and get help for my son when he was suicidal and all of them gave me ridiculous suggestions for a person with FASD. All of them either told me verbally or tacitly that they knew FASD. They also let us go home with no support, no referrals and no medication. Each day I came home from work steeling myself to look in every room before I could take a breath. Each time I opened a door, I expected to see my son lying dead from an overdose – every day for months, considering sectioning him under the mental health act but knowing that the police wouldn't understand if he became aggressive which he would, and then he would be up for assaulting a police officer as well as drug related offences. We were lucky, he didn't kill himself but others do, we see it in the statistics – impulsivity, plus mental illness, plus lack of understanding of consequences plus suicide ideation equals hell for a child and his family. FASD and suicide go together like alcohol and violence.

Thank you for inviting me to present at this forum. I know that this Inquiry will see that preventing one affected birth will save everyone money, time and personal turmoil as will effectively supporting those people currently affected - ----- because at the moment, people with FASD are dying needlessly and their families may never know that it could have been avoided – education, training and knowledge are the keys.

Thank you.