FAS Day Presentation

Good morning – thanks for inviting me to this workshop in honour of International FASDAY.

FASD is a condition which has long been ignored in Australia so it is an honour for me to be able to be part of it here.

My name is Elizabeth Russell and with regard to FASD I have many hats.

Secretary of the Russell Family Fetal Alcohol Disorders Association…….

The author of three books on FASD……..

The co-developer of the first publicly available training modules on FASD in Australia…….

And last and most importantly the birth mother of my two boys who both have FASD……..

On this day especially I would like to send a challenge to state and federal governments to ensure that all service providers receive training or information on this condition so they may be able to provide the practical help for my son and the other estimated 200,000 people who have been prenatally exposed to alcohol currently living in Australia.

Even though I am one of the people that other people come to for advice on FASD I can't always get the services that my son needs.

As a result I often hear the words that I would give anything NOT to hear.
………….“Just let me go. I can't do this anymore. I just want to die. I try so hard but I always fuck up. Please mum just let me go.”…………..

My 25 year old son who has full FAS said this to me last week and many times before that. As his mother, it is very hard listening to his words and knowing that he has felt distressed, depressed, rejected, anxious and different most of his life and when he asks me to ‘let him go' he wants me to sanction his suicide.

I wish I could believe that Seth is the author of his own misfortune ----- that the pathway he has chosen and continues to choose is the result of an informed decision. I'm not saying that just because it would mean there would be no guilt for me but if it were his choice, then it could also be his choice to turn his life around……….

But choice has very little to do with it.

So even though I have attended many international and national conferences, presented to anyone who asked, and have written three books, I struggle to save my own son. With all my contacts both here and overseas, I still can't convince services that my son needs their support even if he says he doesn't.

I understand that there may be medical professionals or people in the audience who may work in some of the organisations I speak about. I am not disrespecting you or the work you do, I am telling you the reality of having a loved one with FASD in Australia and the difficulties it entails.

Seth's doctor would not prescribe him anti-depressants because, he said, he didn't know enough about FAS. He told us to go to a psychiatrist. The psychiatrist said he wouldn't treat Seth until he had taken some responsibility for his life. After that statement I asked if he needed some information on FAS - he told me he understood the condition.

One of the first things I read when I first began my research into what was ailing Seth was that a person with FAS finds great difficulty showing remorse or taking responsibility ………… its like expecting a blind person to read simply because he has eyes.

'If' and 'only' are two words that don't mean much when they are said apart but said together they can represent an unbearable situation. If only Seth had both a psychiatrist and a social worker who really understood FASD ------------------ he, his wife and sons would have the chance of a better life than the one that is stumbled through at the moment – but there is no such psychiatrist in the city where Seth lives and his IQ is too high to be eligible for a social worker from Disability Services Queensland.

If only I hadn't used alcohol while I was pregnant. If only someone had mentioned something! If only my eldest son had been diagnosed with Alcohol Related Neuro-developmental Disorder when his paediatrician told me he thought Mick was 'retarded', Seth would be a normal kid with an interest in his family, the ability to support his wife Hayley rather than as he does, often create more problems for her.

IQ is not an accurate indicator of disability. People with FASD have problems with executive functioning which affects the higher functioning and decision making ability of the individual. They can have a normal IQ but not be able to use it because of the damage to the rest of the brain. However the eligibility of many of the services which would be suitable for people with FASD is based on IQ. So services that would be good for my son can't accept him.

Each service that we **have** managed to access has been only because of my advocacy and because a doctor from the United States Dr Sterling Clarren took time out from being a world-wide expert on the condition to make a diagnosis and help us. In actual fact it's only through the good graces of Dr Clarren that I was able to get any support at all.

Some of the problems in daily living that adults face include having problems with employment, problems with money, problems fitting in with peers, problems with relationships, problems parenting appropriately, problems with addictions and problems with the police. So typically they have no job, no home, no friends and no money ------------------- the two things they do have are regular brushes with the police and a predisposition to addiction.

What a life!

Seth knows money just slips through his fingers. He knows that his behaviour is hurting the people he loves. He thinks he is a burden on his family. More than anything he wants to be liked by people, he wants to have friends and live a normal life but everything he does makes his dream harder and harder to achieve. I want his wife to live a happy life with a man who loves her and can help her when she needs it. I also want my grandsons to have the best possible upbringing. All of which is mutually exclusive if that man is Seth.

I feel so useless knowing the level of pain and suffering my son experiences daily. But even harder is that I have started to hope that one day he **will** take the option of suicide because **I** can't cope with his pain. I am very lucky in that my family is supportive and my husband and I have been together for 35 years but in essence we are alone with this condition.

Whenever I try to access services, things fall apart – so we try and work alone with only the support of others in the same situation as us …………but it's really not enough.

I am not the only mother in Australia who is watching her child die but I am the only one presenting today and very selfishly I beg you to help us by training existing services, changing the eligibility criteria providing us with FASD specific services and clinics, or all of the above as a matter of urgency. At least now there is training available whereas 12 months ago – each organisation who wanted to learn more, had to do their own research.

A parent's or carer's perspective fleshes out the condition where medical information and statistics cannot. Indeed, there is no way that any medical or allied health professional can truly understand the enormous impact of this condition on the affected person and his or her family without recognising and accepting this perspective.

This condition isn't just an Indigenous issue; it's a problem wherever alcohol is used. In fact our Indigenous friends have more services and supports in place and understand FASD better than in mainstream Australia.

It's frightening just how all-encompassing the affects of prenatal alcohol exposure are. As I have said earlier, it can implicate the social, emotional, physical and financial life of the individual and family. FASD is a truly hidden disability and our estimated 200,000 affected individuals, instead of learning appropriate and functional skills in services where they can reach their full potential, are likely to be found in:

- In Stream 4 of the Job Services Australia employment program
- On the Disability Support Pension (DSP) for the primary disability of low IQ or the secondary disabilities of mental health problems, drug and alcohol addiction, heart and kidney problems, seizure disorders, personality disorders and other related medical conditions or syndromes
- Supported by families and diagnosed with ADD, ADHD, Asperger's Syndrome and autism or other behavioural conditions
- Incarcerated in prison, rehabilitation service or in a mental institution
- Chronic alcohol and drug users living on the streets
- Suffering from chronic mental health issues or other physical disabilities
- Diagnosed with or suspected of having alcohol related brain injury from alcohol consumption post birth
- With partners who tend to 'look after' them, or
- with partners who have similar problems

Recently much has happened in the world of FASD in Australia. We have some positive developments such as the availability of the first and only publicly available training modules in FASD, we also have the Liliwan Project happening in Fitzroy Crossing which will be Australia's first population based prevalence research ---- and then on the other side of the coin, we have reports such as the one recently launched in Melbourne by the Alcohol Education and Rehabilitation Foundation. FASD is hardly mentioned and when it **is** the first line goes like this: "The incidence of Fetal Alcohol Syndrome is relatively rare in Australia overall, although higher in Indigenous populations." And the recent research by the Telethon Institute – usually a leader in FASD matters, which finds that "light to moderate alcohol consumption during pregnancy does not cause behavioural problems in children".

Every presentation I have delivered has resulted in someone coming up to me afterward saying that one of their clients, patients, relatives or friends has symptoms such as the ones I describe. FASD is NOT rare, it has reached epidemic proportions in Australia.

On the front page of NOFASARD's website there is a news item which reads: Rights of Persons with Disabilities -------The Failure by Australian Governments to address FASD is a breach of human rights - in particular Convention on Rights of Persons with Disabilities Article 25(b).

Would you like to hear what Article 25 (b) states?

It says that all parties should provide those health services needed by persons with disabilities specifically because of their disabilities including early identification and intervention services which are designed to minimise and prevent further disabilities ----- all Australian governments have signed off on this!

Yet we still have no diagnostic services, no specialised clinics, no specialist medical practitioners to which GPs can refer and from a recent survey conducted by the Telethon Institute, there are only 2 per cent of medical people in Western Australia who believe they can handle FASD.

This then results in situations like ours. Parents are likely to be stressed, anxious and depressed; siblings, if they are not affected themselves, have a very difficult time managing the behaviour or their brother or sister; and sometimes even worse is the fact that friends and family don't understand the behaviour of the affected person and either shun the child or question the parenting ability of the parents.

We know that parenting a child with FASD has to be the most difficult disabilities to parent so that the child doesn't acquire any of the secondary disabilities because everything that you learned about tough love and natural justice and consequences is not relevant in the world of FASD. In fact some of these usually 'excellent' parenting techniques can set the child and parents up for failure time after time.

I often wonder how many children and adolescents have died because of this condition with no one ever realising that they have had a brain injury all their lives. How many parents blame themselves? How many friends and family have 'dis-owned' the individual because of his or her behaviour; how many times has a frightened teenager been kicked out of home feeling guilty about things that they have no control over?

As one of many mothers of children with FASD --I know that when our affected child yells at us, he or she needs us to know that it’s just frustration or from being overwhelmed with choices or problems, even though they are choices that are very easily made by you or me.

They will need us to know that when they persist at something it’s because they **cannot** change their mind, not because they choose not to.

They want us to be there for them regardless of how much they annoy us, or how often we have to bail them out of some predicament that they may have unknowingly initiated.

They also need us to advocate on their behalf, if necessary, for medication and other things that will improve their quality of life.

And above all, they need us to keep coming back to them no matter how many times they yell at us to ‘leave them alone’.

But if they exhibit behaviours that are dangerous to themselves or to others then that’s when they need us to be at our strongest and do whatever we can do to ensure the safety of everyone, because occasionally the damage is so severe that there is very little help outside of an institution.

And sometimes, no matter what we do or how many services we access, nothing will stop them from destroying themselves.

What we need to do as a country is ask why Australia is 25 years behind the rest of the ‘civilised’ world in the diagnosis and management of this condition; why is FASD not mentioned in most major policy and discussion documents where it should be receiving priority attention; why does FASD not appear on the government list of registered disabilities; why there is no Medicare number for rebate for diagnosis; why is FASD not listed in the employment services database, and most of all why it is the parents and carers alone who are carrying the financial, social, personal and emotional burden of helping their loved ones be the best they can be.

Thanks

Anne Russell

Elizabeth (Anne) Russell