

Russell family fetal alcohol disorders association

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Submission from the Russell Family Fetal Alcohol Disorders Association [rffada]

Queensland Child Protection Commission Inquiry

BACKGROUND

This inquiry has been established by the Queensland Government to review progress of outcomes related to the *Commission of Inquiry into Abuse of Children in Queensland Institutions* (the Forde Inquiry) and the Crime and Misconduct Commission Inquiry to chart a new road map for child protection for the next decade.

The terms of reference ask the Commissioner to make full and careful inquiry in an open independent manner of Queensland's child protection system, including in relation to:

- the implementation of recommendations by the Forde Inquiry and the Crime and Misconduct Commission reports into child abuse
- whether the current use of available resources across the child protection system is adequate and whether resources could be used more efficiently
- the current Queensland government response to children and families in the child protection system
- the transition of children through, and exiting the child protection system
- the effectiveness of monitoring, investigation, oversight and complaint mechanisms and ways to improve the oversight of and public confidence in the child protection system, and
- the adequacy of any government response and action taken by government to allegations of child sexual abuse in youth detention centres

The Commissioner has been asked to include recommendations in his report on issues including:

It is estimated that almost 70% of the children in foster care have been prenatally exposed to alcohol.

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Children from substance abusing households are more likely to spend time in foster care than other children

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- any reforms to ensure that Queensland's child protection system achieves the best possible outcomes to protect children and support families
- strategies to reduce the over-representation of Aboriginal and Torres Strait Islander children in the child protection system, and
- legislative reforms

INTRODUCTION

In 2007 the Russell Family Fetal Alcohol Disorders Association (rffada) was founded by Elizabeth (Anne) Russell the birth mother of two children prenatally exposed to alcohol. Both children have been diagnosed. The oldest Mick was diagnosed with Neuro-developmental Disorder – alcohol exposed and the youngest Seth, with full Fetal Alcohol Syndrome. Two books have been written about Mick and Seth – Alcohol and Pregnancy: A Mother's Responsible Disturbance and Alcohol and Pregnancy: No Blame No Shame. These are the first two books written about FASD in Australia.

The rffada has also developed the first publicly available training on FASD in Australia which has been delivered extensively over the past 18 months (<http://rffada.org/training>).

The rffada has been involved in advocating and supporting people living with FASD and lobbying governments for diagnostic facilities and services.

It is clear that children with FASD are over-represented in the following groups: children under Child Protection Orders; foster children and children who are Wards of the State.

Employees of government departments working with foster parents and foster children, child protection workers and other relevant agencies or departments must be trained in FASD to better support those people they have been tasked to help. Many parents and carers in these categories have asked the rffada for support to speak to these workers so that they are better able to understand the stressors and problems associated with caring for a child or adolescent with FASD.

The rffada has three FaceBook groups: a closed group supporting parents and carers; a closed group supporting people with FASD and a general open group for all-purpose information with a total of more than 200 members. The rffada also has a database of over 1500 supporters comprised of individuals and organisations from a wide variety of organisations, industries and departments. Supporters receive monthly newsletters and general information on FASD.

The foster or adoptive parent of a child with FAS assumes a responsibility far beyond that normally associated with parenting. The constellation of physical, intellectual, and behavioral characteristics that typifies patients with FAS can create a very demanding situation for any family. The children often require constant supervision. Parents require an extraordinary amount of energy, love, and most of all, consistency. Therefore, these parents need support in their efforts. This support can often be provided by the social service network to help prevent the burnout that often accompanies high-stress parenting situations.

Adopting.org accessed on the 02/08/2012

WHAT IS FETAL ALCOHOL SPECTRUM DISORDER (FASD)?

The term Fetal Alcohol Syndrome (FAS) is only one aspect of a spectrum of disorders caused by prenatal exposure to alcohol. The whole spectrum is contained under the term Fetal Alcohol Spectrum Disorders or FASD. Including FAS, there are three conditions comprising the spectrum of disorders:

1. **Fetal Alcohol Syndrome (FAS)** - The diagnosis of FAS is based on three features:
 - Pre- and post-natal growth deficiency
 - A distinct pattern of cranio-facial malformations, and
 - Brain and central nervous system (CNS) dysfunction
2. **Partial Fetal Alcohol Syndrome (pFAS)** – this is an unclear term that has been used in many different ways. More commonly it has been used to indicate that an individual has some, but not all, of the characteristic features of FAS.
3. **Alcohol Related Neurodevelopmental Disorder (ARND)** - Other commonly used terms are Fetal Alcohol Effects, Alcohol Related Birth Defects and Neurodevelopmental Disorder – Alcohol Exposed.

ARND is by far the most common and also the most invisible. It is this condition more than any other which the rffada believes is more likely to result in secondary disabilities primarily because it is invisible. When this is combined with other features of FASD such as good verbal ability which seems to indicate competence and a normal IQ (75% of people prenatally exposed to alcohol will have a normal IQ), other people around the individual such as teachers, parents, family and friends all have expectations of the individual which he or she may not be able to fulfil. In this event, his or her mental health begins to be compromised. Behaviour seems to be within the control of the student but it is often a case of 'cannot' rather than 'will not'

The full syndrome (FAS) is usually identified through facial features and because they are relatively recognisable receive support although this is definitely not a given anywhere in Australia. Even in Western Australia where there seems to be more activity with regard to FASD than elsewhere in Australia, parents and carers on the rffada FaceBook parents and carers group have been waiting for years to access diagnostic services.

The other conditions (pFAS and ARND) are more problematic because, as stated earlier, the individual may have average intelligence, will not have the demonstrable facial features of full FAS, and will almost certainly not have been diagnosed, so friends, family and other significant people in their lives will not fully understand the reasons for their behaviours. They may believe it's because of environment, circumstance, abuse, mental illness, genetics, drugs and alcohol, or just immaturity.

Patients with fetal alcohol syndrome typically have multiple handicaps and require special medical, educational, familial and community assistance. Their caretakers need medical information, peer support, financial assistance and respite care. Many children are alcohol exposed in utero but are placed as normal, healthy infants. These children may require lifelong, expensive, intensive care and intervention to reach their potential. Alcohol use and abuse affects us all. Society-at-large and the adoption community in particular must educate themselves to the very special needs of alcohol affected children.

Adopting.org
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In FAS, the pattern of facial anomalies as a result of maternal drinking can include:

small eye flat midface Flat philtrum thin upper low birth openings lip weight

Central Nervous System abnormalities, of at least one of the following:

decreased structural neurological problems (such as head size abnormalities of the impaired motor skills, poor brain coordination, hearing loss, visual problems)

Including behavioural and/or cognitive problems such as:

<i>Intellectual disability</i>	<i>Learning difficulties</i>	<i>Poor impulse control</i>
<i>Problems with social perception</i>	<i>Problems reasoning</i>	<i>Cognitive processing deficits</i>
<i>Deficits in maths and language</i>	<i>Inability to predict outcomes</i>	<i>Problems using judgement</i>
<i>Problems with attention</i>	<i>Problems with memory</i>	
<i>Slow auditory pace</i>	<i>Developmental lags</i>	

Alcohol is a behavioural teratogen. A teratogen is a substance that causes birth defects and a behavioural teratogen is a substance that also causes behavioural problems. Although alcohol exposure obviously presents a physical risk to the fetus, it is in the area of behaviour that alcohol seems to do the most long-term damage.

People with FASD may have trouble setting personal boundaries and observing other people's boundaries. They often have emotional problems, can be impulsive, may not be able to sustain relationships, and often cannot anticipate consequences. They have difficulty paying attention, have poor organisational skills and have trouble completing tasks.

FASD is permanent, irreversible brain damage and the brain injury is the primary disability, however secondary disabilities may occur when the primary disability is not recognised and appropriate strategies and interventions put into place. Although the primary disabling conditions of fetal alcohol exposure last a lifetime, its secondary disabilities can be prevented.

From life history interviews of 415 individuals with FASD using 450 questions, Dr Streissguth from the University of Washington found that:

- 94% of people diagnosed with FASD experienced mental health problems – which was the most prevalent secondary disability
- 43% of people of school age experienced disrupted school experience (suspension, expulsion or drop out)

The incidence of FASD is unusually high among the US foster care population

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- 42% of people and 60% aged 12 and over had been in trouble with the law (involvement with authorities, charged or convicted of crime)
- 60% had been confined (inpatient treatment for mental health, alcohol/drug problems, or incarceration for crime)
- 45% aged 12 and over were reported to have exhibited Inappropriate Sexual Behaviour
- 30% of people over the age of 12 experienced Alcohol and Drug Problems
- Problems with Employment were indicated in 80% of adults with FASD
- Problems Parenting: Of the 100 females of childbearing age, 30 had given birth; 40% drank during pregnancy, more than half no longer had the child in their care - of their children, 30% have been diagnosed with, or were suspected of having, FASD

If it is not possible to halt the secondary disabilities through appropriate interventions, strategies and environmental modifications, then it is vital that they be understood so that relevant management strategies can be developed and implemented.

Secondary Disabilities

Dr Streissguth's research found that secondary disabilities may be prevented if the following occurs however even with a high level of support and the following, the secondary disabilities may still occur:

- Early diagnosis is a universal protective indicator for all secondary disabilities - only 11% of individuals with FASD were diagnosed by age 6
- Eligibility for services from disability agencies (including Disability Support Pension, Disability Employment Agencies and assessments from appropriate allied health professionals) is another strong protective factor - most individuals with FASD need these services, yet most do not qualify
- Living in a stable home with nurturing parents and minimum of changes in the household
- Protection from violence, from witnessing or being victimised by violence

The brain injury results in an information processing deficit, an inability to reason in the way that others do, and an alarming inability to fit in with the rules and behaviours required by society because of the damage to the corpus callosum. Most often, affected individuals are seen as lazy, unmotivated, disorganised, in denial, or dishonest.

Common strengths:

Highly verbal
Affectionate

Bright in some areas
Musical

Artistic
Mechanical

Many children with FASD go unidentified or undiagnosed. Often behaviours caused by a brain injury as a result of prenatal alcohol exposure are thought to be from difficulties in the child's previous home environment

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<i>Willing and helpful</i>	<i>Generous</i>	<i>Good with younger children</i>
<i>Athletic</i>	<i>Friendly, outgoing</i>	
<i>Determined</i>	<i>Persistent</i>	
<i>Wants to please</i>		

Preventable Secondary Characteristics

In the absence of identification, people with FASD often experience chronic frustration. Over time, patterns of defensive behaviours commonly develop, but these characteristics are believed to be preventable with appropriate supports:

<i>Fatigue</i>	<i>Tantrums</i>	<i>Irritability</i>
<i>Fear, anxiety</i>	<i>Avoidance, withdrawal</i>	<i>Shut down</i>
<i>Trouble at home</i>	<i>Trouble at school</i>	<i>Mental health problems</i>
<i>Problems in the community</i>	<i>Frustration</i>	<i>Anger and aggression</i>
<i>Lying</i>	<i>Running away</i>	<i>Legal trouble</i>
<i>Drug and alcohol abuse</i>		

Children and parents dealing with the problems of FAS/FAE need strong advocates. Advocacy must come from both the parents and the professionals involved.

Adopting.org accessed on the 02/08/2012

SUBMISSION

The rffada believes that the following points will better support those tasked with supporting children through the Child Protection process:

Child Safety Officers

All Child Safety Officers (CSO) should be familiar with FASD and the impact it has on the foster family. The rffada speaks to many foster parents from all locations around Australia and the common theme is that their CSO doesn't understand the problems that they are experiencing and there are no training programs which they can undertake to learn to better manage their children.

Recommendation:

- Mandatory training for CSOs on FASD and the impact of FASD on the family unit including training in strategies, interventions and accommodations which they may be able to pass on to their clients
- Parents and carers training in training in strategies, interventions and accommodations (see <http://rffada.org/training>)

It is reported that up to 80% of children with FASD do not stay with their birth family because of the high needs of parents and children

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Foster Carers

Foster Carers supported by the rffada advise that their children are able to access respite at times but not consistently. Some mothers have said that their children are no longer able to attend respite care because of their behaviour.

Foster carers suffer a great deal of stress when their needs and the needs of their children are not understood and met. They are not able to discuss issues with other families because of confidentiality and privacy demands and have been disciplined for accessing advocacy support.

Recommendation:

- Respite carers should be trained to understand the behaviour of children with FASD and the appropriate intervention to reduce and understand this behaviour (the behaviour of children with FASD is not always within their control. It is a method of communication and it is rarely understood by people who believe that their behaviour is willful. Without training to understand this, children will suffer from mental health problems, substance use disorders and other secondary disabilities)
- Foster carers should be advised if there is any indication that the child has been prenatally exposed to alcohol
- Foster carers should be provided with training on the most appropriate strategies, interventions and accommodations to support children with FASD – this will afford a less stressful environment for the family and perhaps more importantly even halt the progression of secondary disabilities - this is a critical issue for parents and carers of children with FASD – without identification and the appropriate interventions, children can grow to be adolescents with a number of additional problems including:
 - Mental health problems
 - Drug and alcohol addictions
 - Early school dropout /expulsion / suspension
 - Contact with the criminal justice system
 - Inappropriate sexual behaviour

Adults with FASD who also have secondary disabilities can similarly experience:

- Inappropriate parenting
- Problems maintaining employment

To knowingly allow this to happen by either not advising foster parents of the possibility that the child has been prenatally exposed to alcohol or by not providing training to parents and CSOs, is an act of negligence and a contravention of their human rights. Even without a diagnosis much can be done to prevent the secondary disabilities from occurring.

Many parents and foster parents of FAS/FAE children could benefit from respite care, yet few receive it and most don't even know about existing programs which might serve them. The daily stress and demands generated by these children can easily trigger parental burnout

Adopting.org accessed on the 02/08/2012

Studies suggest that a rise in alcohol consumption by women has resulted in 60% more children coming into state care since 1986

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CONCLUSION

The rffada concludes that the Queensland government must provide and/or support initiatives that enable the implementation of mandatory training to all CSOs and targeted foster parents for the safe management of FASD disorders to reduce secondary disabilities and allow the child to reach his or her full potential. Along with support and training for CSOs and foster parents, the Queensland government must provide information to the birth mothers and parents of children in care to prevent subsequent affected births.

There is only one not for profit organisation in Queensland which is unfunded and works specifically to support those parents, carers and individuals living with FASD. Funding must be available to develop and deliver services which support people with this condition in much the same way as Autism organisations have done as the prevalence and incidence of FASD has the potential to far outweigh the level of Autism. In fact it is clearly understood in the United States, Canada and Ireland that FASD is often misdiagnosed as Autism and Asperger's.

There needs to be an overarching proactive government funded organisation overseeing a network of similar organisations in each state. The Russell Family Fetal Alcohol Disorders Association has been provided with in-kind corporate support from Training Connections Australia and its sister companies ITEC Employment and Enterprise Management Group and from the Commonwealth Bank of Australia as a result of the founder being a finalist in the Australian of the Year Awards. However funding needs to be available for training and for staffing this organisation as it currently operates with support from volunteers and the work; presentation requests; enquiries (often from people in distress); keeping up with Facebook contacts and comments; submissions; administration and information dissemination is too much for volunteers.

Funding from the government to continue the work that has been started would mean that the rffada, with input from the corporate organisations mentioned above, could very quickly develop support structures Queensland-wide for training and support for families regardless as to whether a diagnosis has been made (interventions appropriate for children with FASD will not harm any child who does not have this condition however by implementing these strategies and training provided to foster carers and CSOs will help the child with FASD reach his or her full potential). The rffada has already been contacted by many foster parents to this end and the rffada founder has been asked to present to Foster Care Queensland in August on FASD.



Elizabeth Russell

Russell Family Fetal Alcohol Disorders Association (rffada)

2nd August 2012

Despite the many problems of patients with FAS/FAE, these individuals have a great capacity for love and contribution to family and community. The challenge of caretakers and service providers alike is to help these children harness their potential and find their place in the world.

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