



russell family fetal alcohol disorders association

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

National Aboriginal and Torres Strait Islander Suicide Prevention Strategy

BACKGROUND

On 1 June 2012 the Department of Health and Ageing appointed the Menzies School of Health Research to conduct a national consultation process to inform the development of a National Aboriginal and Torres Strait Islander Suicide Prevention Strategy.

Menzies is working in partnership with the National Aboriginal Community Controlled Health Organisation (NACCHO) to conduct a series of community forums at selected locations in all states and territories.

Public input is invited from organisations, communities and individuals with an interest in Indigenous health and wellbeing. Details of how to lodge public input is available on this website. Following the consultations, a national workshop will be held in early October, and a draft report provided to the government later in 2012

rffada SUBMISSION

INTRODUCTION TO THE RFFADA

The **Russell Family Fetal Alcohol Disorders Association** (rffada) is a not-for-profit health promotion charity dedicated to ensuring that individuals affected prenatally by alcohol have access to diagnostic services, support and multidisciplinary management planning in Australia and that carers and parents are supported with a “no blame no shame” ethos.

The rffada has proposed a set of five goals for the future of FASD prevention and management in Australia:

1. Diagnostic clinics in every capital city
2. A national media awareness campaign for the prevention of Fetal Alcohol Spectrum Disorder (FASD)
3. Alcohol and pregnancy education in all high schools
4. Training implemented for the employees of all services likely to be visited by a person with FASD;
5. Early intervention funding

In 2007 the 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 Neurodevelopmental 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.

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.

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 accessed on the 02/08/2012

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.

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

<i>small eye openings</i>	<i>flat midface</i>	<i>Flat philtrum</i>	<i>thin upper lip</i>	<i>low birth weight</i>
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Central Nervous System abnormalities, of at least one of the following:

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

During a study entitled **Suicide Attempts among Adults with Foetal Alcohol Spectrum Disorders: Clinical Considerations**, researchers analysed the clinical profiles of 11 adults with FASD. They discovered that those suffering from the condition experienced some form of psychological or mental health-related problem at every developmental stage, according to BNET

http://www.samaritans.org/media_centre/emotional_health_news/foetal-alcohol-spectrum-036.aspx accessed on the 4th September 2012

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)
- 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
Willing and helpful
Athletic
Determined
Wants to please

Bright in some areas
Musical
Generous
Friendly, outgoing
Persistent

Artistic
Mechanical
Good with younger children

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:

Fatigue
Fear, anxiety
Trouble at home
Problems in the community
Lying
Drug and alcohol abuse

Tantrums
Avoidance, withdrawal
Trouble at school
Frustration
Running away

Irritability
Shut down
Mental health problems
Anger and aggression
Legal trouble

SUICIDE AND FETAL ALCOHOL SPECTRUM DISORDER

The rffada is concerned with the number of people with FASD who commit suicide.

¹People diagnosed with fetal alcohol spectrum disorders (FASD) have neuropsychological deficits that may contribute to increased risk for suicide. People with FASD who attempt suicide were more likely to have mental health disorders, substance abuse disorders, a history of trauma or abuse, financial stress, and unstable social support compared to non-attempters.

The organic brain damage that results in neurodevelopmental deficits, including impaired judgment, insight, impulse control, mood regulation, and executive functioning skills which are all critical for problem-solving and decision-making. The confluence of these deficits may contribute to psychosocial and mental health problems at every developmental stage. Suicide attempts are among the most serious of these potential problems. Some individuals with the developmental disability of FASD have IQs below 70 and thus have a concurrent intellectual disability. Suicidality (threats, statements of suicide, or suicidal attempts/gestures) can occur among people of all ages with an intellectual disability. (30) In an outpatient psychiatry clinic sample, 6% of adults with an intellectual disability reported suicidality.

²A US study found that 60% of adults with FASD will at some point enter the criminal justice system, while 23% will attempt to take their own life on at least one occasion, compared to the US national average of 4.6%. During a study entitled Suicide Attempts among Adults with Foetal Alcohol Spectrum Disorders: Clinical Considerations, researchers analysed the clinical profiles of 11 adults with FASD. They discovered that those suffering from the condition experienced some form of psychological or mental health-related problem at every developmental stage.

¹ <http://www.highbeam.com/doc/1G1-179133647.html>

² http://www.samaritans.org/media_centre/emotional_health_news/foetal-alcohol-spectrum-036.aspx

The study also found that 6 of the 11 people assessed had attempted suicide at some point in their lives. Those who had previously attempted to take their own lives were found to have experienced a number of conditions connected to their FASD, including substance abuse and mental health disorders. Those who had attempted suicide were also more likely to have experienced some form of trauma or abuse, and were more likely to find themselves unable to cope with financial problems and without a social support network.

There is a high level of FASD in places where there are high levels of alcohol. While FASD is a problem across all levels of society, it is anecdotally high in Indigenous communities. Anecdotally, from a medical professional who has worked in Cape York for the last two decades, Cape York has the highest rate of FASD in the world.

Even though diagnosis of FASD in Australia is still in its infancy, it's not hard to identify the typical barriers associated with FASD in residents of almost every remote Indigenous community in Australia.

At the last International Conference on FASD in Vancouver BC, a prevalence rate of 10% was cited by one of the keynote speakers. Canada and the United States drink less alcohol per capita than Australia. Even at a rate of 1% which is more commonly cited, we could have a minimum of 220,000 individuals prenatally affected by alcohol. Many of these people will have attempted or completed suicide.

The Final Report from Research on Secondary Disabilities by Ann Streissguth, presented to the FAS Conference in Seattle in September of 1996 revealed that 23% of the adults FAS in her study had attempted suicide, and 43% had threatened to commit suicide.

Regardless of studies available specifically on suicide and FASD, the risk factors for suicide are:

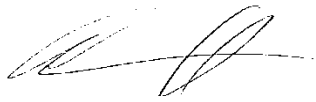
- Previous suicide attempt
- Major physical illnesses
- Central nervous system disorders
- Mental disorders particularly mood disorders, substance use disorders, personality disorders
- Impulsive and/or aggressive tendencies
- History or trauma or abuse
- Family history of suicide
- Chaotic family history
- Lack of social support and increasing isolation
- Local clusters of suicide that have a contagious influence
- Contact with the law
- Barriers to accessing relevant care

All of the points above can be related directly back to FASD.

RECOMMENDATIONS

The rffada recommends that the final report and recommendations for the National Aboriginal and Torres Strait Islander Suicide Prevention Strategy incorporate FASD as a predictor for suicidal behaviour and contain the following recommendations:

- a. FASD Diagnostic centres or teams to be established in each capital city
- b. A national media awareness campaign for the prevention of FASD
- c. Alcohol and pregnancy education in high schools located in remote communities
- d. ³Services to be trained in the identification and management of people with FASD using appropriate strategies and interventions
- e. Funding to be made available for FASD-specific organisations to support people with FASD in community
- f. At risk women need to be supported to remain sober throughout pregnancies
- g. Those families who have family members with FASD to be supported to utilise appropriate strategies and interventions
- h. Education on alcohol and pregnancy to be delivered to the residents of all remote Indigenous communities in Australia
- i. Schools in Indigenous communities to be trained in the identification and appropriate strategies for children with FASD



Russell Family Fetal Alcohol Disorders Association (rffada)

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³ Inappropriate strategies and interventions can cause secondary disabilities of which suicide is one