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

House Standing Committee on Indigenous Affairs

Inquiry into the harmful use of alcohol in Aboriginal and Torres Strait Islander communities

BACKGROUND

The Committee will inquire into and report on the harmful use of alcohol in Aboriginal and Torres Strait Islander communities, with a particular focus on:

- Patterns of supply of, and demand for alcohol in different Aboriginal and Torres Strait Islander communities, age groups and genders
- The social and economic determinants of harmful alcohol use across Aboriginal and Torres Strait Islander communities
- *Trends and prevalence of alcohol related harm, including alcohol-fuelled violence and impacts on newborns e.g. Foetal Alcohol Syndrome and Foetal Alcohol Spectrum Disorders*
- *The implications of Foetal Alcohol Syndrome and Foetal Alcohol Spectrum Disorders being declared disabilities*
- Best practice treatments and support for minimising alcohol misuse and alcohol-related harm
- Best practice strategies to minimise alcohol misuse and alcohol-related harm
- Best practice identification to include international and domestic comparisons

INTRODUCTION

The **Russell Family Fetal Alcohol Disorders Association** (rffada) is a national 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 provides a range of support resources and information relating to Fetal Alcohol Spectrum Disorder, or FASD. The rffada Strategic Plan is based on four key priorities.

1. Prevention
2. Support
3. Training and Education

4. Research and Projects

SUBMISSION

Trends and prevalence of alcohol related harm, including alcohol-fuelled violence and impacts on newborns e.g. Foetal Alcohol Syndrome and Foetal Alcohol Spectrum Disorders

FASD is a grave and ubiquitous problem affecting hundreds of thousands of families in Australia. Many of these families will not know that their child or loved one has a physical disability; nor will they understand the reason for their behaviour, inability to hold down a job, trouble with the police, mental health problems, addiction and other complications. Believing instead that their child has control over their behaviour creates rifts within families and can eventually lead to homelessness and family breakdown.

In the United States, it has been estimated that each individual with FASD will cost the government \$2.9 million over his or her lifetime¹. The Australian Bureau of Statistics states that there are just over 260,000 births each year in Australia². In the report on The Financial Impact of FASD³, the SAMHSA FASD Center for Excellence stated that the United States has an annual birth rate of just fewer than 4 million⁴, with 40,000 of those births alcohol affected. Extrapolated to Australia's population, this rate suggests that each year, 3,000 babies will be born with symptoms of prenatal alcohol exposure – some of these babies will be from remote Indigenous communities.

The prevalence in Australia is estimated, at a minimum, at 200,000 individuals. It is very likely that any estimates based on 1% will be under ascertained. Nevertheless, using the minimum figures at hand, the cost to the government and the community has been assessed as being in the vicinity of \$6 billion.

You know how you destroy a culture? ...You make sure that kids are born with alcohol foetal syndrome, they won't be able to pass on the dreamtime and the culture — Alastair Hope, Western Australia coroner

Prevention and support strategies can minimise these costs. Australia is lagging far behind other countries in its response to FASD. This may partially be the outcome of the Australian government not recognising FASD as a disability.

Nowhere is FASD more challenging than in remote Indigenous communities. ⁵Foetal Alcohol Syndrome (FAS) or Foetal Alcohol Spectrum Disorder (FASD). FAS (sic) is an affliction across all cultures and not exclusive to Aboriginal people. Alcohol damages the developing child, and its main target is the brain. Children with FAS cannot learn or memorise well, a devastating effect in Aboriginal communities where culture is passed down orally. FAS rates among Aboriginal people are estimated to be between 2.76 and 4.7 per 1,000 births (general population: 0.06 to 0.68).

The problems associated with FASD include:

¹ <http://www.ncbi.nlm.nih.gov/pubmed/15095471> accessed on the 10th February 2014

² <http://www.abs.gov.au/AUSSTATS/abs@.nsf/Latestproducts/04FEBEF9C81FE6BACA25732C002077A2> accessed on the 7th February 2014

³ <http://fasdcenter.samhsa.gov/publications/cost.aspx> accessed on the 7th February 2014

⁴ <http://www.cdc.gov/nchs/fastats/births.htm> accessed on the 7th February 2014

⁵ <http://www.creativespirits.info/aboriginalculture/health/aboriginal-alcohol-consumption#ixzz2uJGZYrbT> accessed on the 25th February 2014

⁶Early Development

- Failure to thrive
- Tremors or jitteriness
- Seizures
- Feeding problems in infancy
- Sleeping problems
- Vision and/or hearing problems
- Difficulty with toilet training, wetting, or soiling
- Problems with personal hygiene
- Difficulty with the onset of puberty
- Problems with sexual functioning

Childhood Appearance

- Shorter or thinner than other children his age
- Eyes may be wide-spaced, smaller than normal, slanted, droopy eyelids
- Lips may be long and/or smooth space between upper lip and nose, thin upper lip

Communication / Speech

- Loud, deep, or unusual sounding voice
- Talks excessively, and too quickly
- Interrupts unremittingly
- Unusual conversational subjects
- Very opinionated
- Speaks indistinctly
- Makes off the wall comments
- Repeats phrases / words frequently

Memory / Learning / Information Processing

- Poor / inconsistent memory
- Slow to learn new skills
- Does not seem to learn from past mistakes
- Has difficulty recognising consequences before acting
- Experiences slow information processing, and poor rates of speed and accuracy

Behaviour Regulation

- Poor anger management
- Fearless in the face of danger
- Mood swings
- Impulsive
- Compulsive
- Perseverative
- Inattentive
- Unusual activity level (high or low)
- Illogical lying
- Illogical stealing
- Unusual reactivity to sound, touch, light
- Rocks or swings rhythmically
- Bangs head, bites or hits self
- Fidgety, cannot sit still

Abstract Thinking / Judgment

⁶ <http://www.fasdexperts.com/Screening.shtml> accessed on the 24th February 2014

- Poor judgment
- Unable to plan and execute
- Functions poorly without assistance
- Concrete, black or white thinking

Planning / Temporal Skills

- Needs help organizing daily tasks
- Cannot organize time
- Misses appointments
- Has difficulty with multi-step instructions

Spatial Skills / Spatial Memory

- Gets lost easily, has difficulty navigating from point A to point B
- Poor memory for sequences and dates

Motor Skills

- Poor / delayed motor skills
- Overly active
- Poor balance
- Accident prone

Social Skills / Adaptive Behaviour

- Poor social/adaptive skills
- Overly-friendly
- Attention-seeking
- Behaves notably younger than chronological age
- Few close friends
- Easily led/manipulated by others
- Laughs inappropriately
- Poor social/sexual boundaries
- Inappropriate social behaviours

Academic / Work Performance

- Gives impression of being more capable than he actually is
- Tries hard and wants to please, but end result is often disappointing
- Has trouble completing tasks
- Has problems with school / job attendance
- School drop-out
- Poor work history

Indigenous communities in Queensland, the Northern Territory, and Western Australia have recognised FASD as a problem but have been unable to identify appropriate and cost-effective programs. The rffada has identified FASD is a problem in Indigenous communities, and has engaged in collaborative partnership with the corporate organisation, My Pathway, to develop a FASD program specific to remote Indigenous communities. The project consists of three stages, has received approval for the FASD program to be rolled out in one community, and another community has requested the program be rolled out under the government's Remote Jobs and Communities Program (RJCP). Stage 2 and 3 are based on ⁷evidence-based programs from Canada.

The project for remote communities in Australia has been outlined in detail if required.

⁷ Fetal Alcohol Spectrum Disorder Ed E Riley, S Clarren, J Weinberg, E Jonsson pp 362, 21.5.3.8

If this program works as expected, it will reduce crime, mental health problems, drug and alcohol problems, improve school dropout and support parenting and employment activities.

The program will be led by the community. Together with support, the FASD 'train the trainer' information will be delivered to a core group identified by community leaders as the most appropriate for this service. All the community will be offered prevention education as well as strategies to manage some of the behaviours they are seeing in the community. The core group will be the 'go to' cohort who will have direct access to our FASD experts.

It is clear that even in 'dry' communities, alcohol and hence FASD is a critical problem that needs to be addressed as soon as possible to help avoid future generations prenatally affected by alcohol.

The implications of Foetal Alcohol Syndrome and Foetal Alcohol Spectrum Disorders being declared disabilities

The rffada, the Foundation for Alcohol Research and Education, the National Organisation for Fetal Alcohol Spectrum Disorder and the Collaboration for Alcohol Related Developmental Disabilities have collaborated to provide Senator Boyce with a petition tabled in the Senate late last year. The petition was to have FASD recognised as a disability by the federal government.

It is critical that the government act quickly to have this condition recognised as a disability.

Elizabeth Russell

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24th February 2014