



RFFADA (Russell Family Fetal Alcohol Disorders Association)

Northern Territory Review of Alcohol Policies and Legislation

THE REVIEW

The Northern Territory (NT) Government is conducting a review of alcohol policies and legislation as part of its undertaking, in the lead up to the 2016 election, to address alcohol harm. The review will report on best practice alcohol policies and legislation that would be applicable to the NT. The overall aim of the review is to develop an integrated alcohol harm reduction framework that is based on the evidence of effective measures to reduce alcohol harm.

RFFADA SUBMISSION

INTRODUCTION TO RFFADA

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

In 2007 RFFADA was founded by Elizabeth (Anne) Russell, the birth mother of two children prenatally exposed to alcohol. Both children have been diagnosed.

Since establishment of the not-for-profit health promotion charity, RFFADA has:

- been involved in advocating and supporting people living with FASD;
- lobbied governments for diagnostic facilities and services;
- developed 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

WHAT IS FETAL ALCOHOL SPECTRUM DISORDER

Fetal Alcohol Spectrum Disorders (FASD) is diagnostic term for a range of disabilities resulting from prenatal alcohol exposure. This can result in a variety of conditions including poor memory, difficulties with speech and language, cognitive deficits, difficulty with judgement, reasoning or understanding consequences of actions, as well as social and emotional delays.

FASD can be prevented by avoiding alcohol during pregnancy. Effective measures to reduce consumption of alcohol include pre-natal screening and brief interventions, increasing the price of alcohol, and introducing culturally safe health promotion initiatives. The NT’s *Select Committee on Action to Prevent Fetal Alcohol*

Spectrum Disorders (FASD) investigated the prevalence of FASD in the NT and the types of actions that could be taken to prevent FASD from occurring and support families affected. The government should act on the recommendations from the Committee's 2015 report and fund services to prevent, diagnose and manage FASD.

NON-GENETIC DISABILITY

Fetal Alcohol Spectrum Disorders (FASD) is the leading preventable cause of non-genetic, permanent developmental disability in Australia (O'Leary, 2002, Foundation for Alcohol Research & Education, 2013). The primary disability of brain damage lasts a lifetime, while secondary disabilities occur when the primary disability is not recognised, and can be prevented through implementation of appropriate strategies and interventions. 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.

The gravity of the impact on the individual affected by exposure to alcohol during the gestational period tragically also affects their family and the community at large. Further complications in the identification of prevalence and incidence of FASD in Australia is limited due to a deficit in specifically trained medical professionals to diagnose FASD, resulting in affected children frequently misdiagnosed with ADD/ADHD or Asperger's Syndrome and inappropriately medicated.

Individuals affected by exposure to alcohol during the perinatal stages tend to suffer from one or more debilitating effects including:

- Low birth weight, shorter than normal, developmental delays, and a failure to thrive leading to height and weight issues across the lifespan;
- Sleep and sucking problems as a baby;
- Relatively recognisable facial anomalies and central nervous system abnormalities include: smaller and narrower eye openings, smaller head circumference, flattened cheekbones, and an indistinct philtrum (an underdeveloped groove or smooth area between the nose and the upper lip), structural abnormalities of the brain;
- Problems with mouth, teeth, hearing, ears, and facial;
- Behavioural issues such as hyperactivity, poor attention span, social withdrawal, stubbornness, impulsiveness, and/or anxiety;
- Weak immune system;
- Epilepsy, cerebral palsy and other muscular problems including abnormal joints and limbs;
- Organ dysfunctions including hormonal disorders, liver damage, and kidney and heart defects;
- Intellectual disability or low IQ;
- Neurological problems including: poor coordination (fine motor skills), reasoning, problem-solving and planning skills, an inability to understand concepts such as time and money and to grasp instructions, and a failure to learn from action-based consequences;
- Mental health problems, and/or reduced levels of short-term memory;
- Deficit in imagination or curiosity, or blending actuality with falsehood;
- Disrupted educational experiences, learning difficulties (particularly maths), speech and language delays, and poor language comprehension;
- Egocentricity, poor socialisation skills including challenges in developing and maintaining friendships and group social interactions, and deficits in appropriate social boundaries such as over-friendliness with strangers and/or sexual behaviour;
- Over-representation with the youth justice system/criminal justice system;
- Alcohol and other substance misuse;
- Challenges caring for themselves and their children;
- Homelessness;

Owing to the state of invisibility, an individual suffering FASD without sentinel facial anomalies is more likely to experience secondary disabilities including mental health problems. In circumstances where an individual demonstrates good verbal ability, which appears to indicate competence and a normal IQ (75% of people prenatally exposed to alcohol will have a normal IQ), other people around the individual including teachers, parents, family and friends will maintain positive expectations of the individual. The individual may not be able to fulfil these expectations, thus leading to anxiety, low self-esteem and the likelihood of the development of addictions.

Without diagnosis, family, friends and other significant people in an individual's life may consider the behavioural actions are related to their environment, personal circumstances, abuse, mental illness, genetics, alcohol and other substance misuse, or simply a state of immaturity.

In describing the effect of alcohol on the unborn child, initially it needs to be understood that alcohol is a behavioural teratogen and a neurotoxin. A teratogen is a substance that causes birth defects, and a behavioural teratogen is a substance that further causes behavioural problems. Alcohol exposure not only presents a physical risk to the fetus, but it is apparent that alcohol causes long-term harm in the area of behavioural characteristics.

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;

Dr Streissguth's research further found secondary disabilities may be prevented if the following actions were implemented. Nonetheless, with implementation of the following actions augmented with high levels of support 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

CLINICAL SUPPORT

Nations, including the United States of America and Canada, have made significant progress in regard to Fetal Alcohol Spectrum Disorders (FASD), with extensive emerging best practice evidence demonstrating moderate use of alcohol (i.e. one to two units of alcohol per day) has no place in pregnancy. The United States of America and Canada lead the global recognition, diagnosis and response to issues relating to Fetal Alcohol Spectrum Disorders (FASD), specifically in the areas of research, gathering accurate, authentic and detailed prenatal drinking behaviours and patterns related information, tangible or projected blood alcohol concentration (BAC) levels, and relative data determining precise times and prevalence of exposure to individual fetuses and children.

Australia is at a vital stage of social change in its national approach to addressing Fetal Alcohol Spectrum Disorders (FASD). For example, in 2009 the National Health and Medical Research Centre (2009) updated the *Australian Guidelines to Reduce Health Risks from Drinking Alcohol* from endorsing the limit of consumption of two units of alcohol per day during pregnancy to recommending that the safest approach for women in the gestational period or planning a pregnancy is to fully abstain from alcohol.

Statistics published by the Foundation for Alcohol Research & Education (2013) highlights that in Australia:

- One in five women continue to consume alcohol while pregnant after knowledge of pregnancy (Callinan and Room, 2012);
- Health professionals continue to be reluctant to ask women about their alcohol consumption during pregnancy (Payne, Elliot, D'Antoine, O'Leary, Mahoney, Haan et al, 2005), despite national guidelines (National Health and Medical Research Council, 2009) which clearly state that it is best to avoid alcohol altogether during pregnancy;
- Few health professionals are familiar with the clinical features of FAS (Telethon Institute for Child Health, 2009) and there is no standardised Australian FASD diagnostic instrument or clinical guidelines for FASD diagnosis;
- Early intervention options for people with FASD are non-existent, resulting in the greater likelihood of poorer life outcomes in education and employment (Streissguth, Bookstein, Barr, Sampson, O'Malley, and Young, 2004);
- Despite the lifelong implications of FASD, getting support is extremely limited and difficult to access;

RECOMMENDATIONS

Take action to prevent Fetal Alcohol Spectrum Disorders' (FASD)

FASD can be prevented by avoiding alcohol during pregnancy. Effective measures to reduce or stop consumption of alcohol include pre-natal screening and brief interventions, increasing the price of alcohol, and introducing culturally safe health promotion initiatives. The NT's *Select Committee on Action to Prevent Fetal Alcohol Spectrum Disorders* (FASD) investigated the prevalence of FASD in the NT and the types of actions that could be taken to prevent FASD from occurring and support families affected. The government should act on the recommendations from the Committee's 2015 report and fund services to prevent, diagnose and manage FASD.

All staff, service providers, health professionals, government organisations and other people who may have contact with people with FASD should have mandatory training on how to recognise children and adults with the condition and how to best support them with appropriate accommodations and interventions.



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