



Legislative Assembly Standing Committee on Education and Health Inquiry – Western Australia

Foetal Alcohol Syndrome: prevalence, prevention, identification, funding and treatment to improve education, social and economic outcomes

INTRODUCTION – Russell Family Fetal Alcohol Disorders Association (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.

We are very grateful to our two Patrons for their willingness to be part of the rffada and to support the rffada in its activities around Australia. Our National Patron is The Honourable Dr Sharman Stone MP Co-chair ‘Parliamentarians for the Prevention of FASD’ and our International Patron is Diane V Malbin MSW Fascets Inc, FASD Expert and International Speaker from the United States.

The Russell Family Fetal Alcohol Disorders Association (rffada) has proposed a set of five goals for the future of FASD prevention and management in Australia:

1. A national media awareness campaign for the prevention of FASD;
2. Alcohol and pregnancy education in all high schools;
3. Training implemented for the employees of all services likely to be visited by a person with FASD;
4. Early intervention funding similar in nature to the Better Start Initiative; and
5. Ongoing government funding for the rffada strategic projects

The aims and objectives of the rffada are:

1. To establish diagnostic centres in major locations across Australia
2. To educate and train key individuals and organisations
3. To support, educate and care for birth, foster and adoptive parents using a “no blame no shame” ethos
4. To assist the rffada partners to achieve their aims and objectives in the prevention, education and support of people living with FASD

Vision

Our vision is to have FASD-specific services available for all those who require them and to support raising awareness of the consequences of alcohol consumption during pregnancy.

Mission

The mission of the rffada is to provide information, training and education to increase the capacity of communities, organisations and individuals to support those people living with FASD to live to their full potential.

Values

Education – Awareness – Support

INTRODUCTION – 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.

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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.

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

- small eye openings
- flat midface (cheekbones)
- flattened groove between nose and upper lip
- thin upper lip
- low birth weight

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

- decreased head size
- structural abnormalities of the brain
- neurological problems (such as impaired motor skills, poor coordination, hearing loss, visual problems)
- behavioural and/or cognitive problems such as:
 - intellectual disability
 - learning difficulties
 - poor impulse control
 - problems in social perception

- problems in memory, attention, reasoning and judgment
- deficits in some mathematical and language skills

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.

The corpus callosum is the part of the brain that links the right-brain and the left-brain. The right-brain handles creativity, intuition and impulse and the left-brain handles the rules, logic, order and thoughts. When the two cannot link properly because of prenatal exposure to alcohol or a brain injury of some sort, then the person cannot always predict the outcome of his actions, even though he knows and can repeat the “rules”.

Typical primary characteristics in children, adolescents, and adults include:

- Memory problems
- Difficulty storing and retrieving information
- Inconsistent performance (“on” and “off” days)
- Impulsivity, distractibility, disorganisation
- Ability to repeat instructions, but inability to put them into action
- Difficulty with abstractions, such as maths, money management, time concepts
- Cognitive processing deficits (may think more slowly)
- Slow auditory pace (may only understand every third word of normally paced conversation)
- Developmental lags (may act younger than chronological age)
- Inability to predict outcomes, or understand consequences

Common strengths:

- Highly verbal
- Bright in some areas
- Artistic, musical, mechanical
- Athletic
- Friendly, outgoing and affectionate
- Determined, persistent
- Willing and helpful
- Generous
- 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, tantrums
- Irritability, frustration, anger and aggression
- Fear, anxiety, avoidance and withdrawal
- Shut down, lying, running away
- Trouble at home, school and community
- Legal trouble
- Drug / Alcohol abuse
- mental health problems (depression, self-injury, suicidal tendencies)

SUBMISSION

Education is a critical phase in any child’s life however with an invisible brain injury which results in behaviours out of sync with the world around them, it can be the most degrading and humiliating experience of their lives.

The typical environment of a classroom is the opposite of what would suit a student with FASD. They require:

- no distractions such as open windows; posters on the walls, mobiles on the ceilings etc
- a place to go which is quiet where they can ‘regroup’ such as an area in the corner of the room (not a punishment)
- teachers who understand the condition

- students who have been diagnosed or at least identified (identification of children will allow appropriate strategies and accommodations to be put into place - this will not harm children who do not have FASD if the identification is incorrect but will make a great deal of difference to a student if they do have FASD - in fact NOT putting these appropriate strategies into place will create a great deal of damage to the child
- the same teacher
- the same room
- a routine which is the same day to day
- alerting the child to a transition ie from one task to another

Providing this type of environment will not only save the child but will also save money.

RECOMMENDATIONS

1. Identify children who may have this condition (they will be found in any classroom as well as in Special Ed)
2. Provide a classroom which is NOT identified as 'special' with a teacher who has had accredited training on FASD OR set up all classrooms in this way (it is inexpensive and any strategies or accommodations suitable for a child with FASD will NOT harm a child without FASD but the opposite will do so much damage it may result in suicide)
4. Ensure that ALL teachers are provided with national accredited training on FASD as part of their induction into the school
5. Provide all children with training on prevention from Year 10