



russell family fetal alcohol disorders association

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www.rffada.org

Russell Family Fetal Alcohol Disorders Association [rffada]

SUBMISSION FOR THE Senate Standing Committees on Community Affairs

Inquiry into the 'Indefinite detention of people with cognitive impairment'

Relevant Terms of Reference

1. The differing needs of individuals with various types of cognitive and psychiatric impairments **such as fetal alcohol syndrome**, intellectual disability or acquired brain injury and mental health disorders;
2. The impact of the introduction and application of the National Disability Insurance Scheme, including the ability of individuals with cognitive and psychiatric impairment to receive support under the National Disability Insurance Scheme while in detention.

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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 experience improved access to diagnostic services, support and multidisciplinary response 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

The rffada is completely unfunded and is staffed by volunteers only.

Fetal Alcohol Spectrum Disorders

FASD is a physical disability with psychiatric and mental health sequelae. It has an amalgamation of factors which when combined, will often lead the individual into the criminal justice system. FASD is a cognitive impairment which can result in an intellectual impairment, therefore it cannot be taken in isolation from other social and medical issues which are often treated without understanding the etiology. FASD cannot be taken in isolation. Domestic violence, youth mental health, juvenile justice, anti-social behaviour, homelessness, unemployment, dysfunctional family situations, substance use disorders, sex offences, sexual, physical and emotional abuse and

education are all intertwined with FASD and cannot be separated. If we do try and work on these social conditions in isolation we will not be successful. Further as a result of alcohol in utero, the individual can suffer from other physical problems including damage to the heart, kidney, skeleton, hearing and vision.

1. Alcohol is a teratogen which risks adverse fetal outcomes when it is consumed during pregnancy
2. The impairments and disabilities may be cognitive, developmental and/or physical
3. Mental illness is perhaps the most debilitating and preventable sequelae of undiagnosed, misdiagnosed and misunderstood FASD
4. The disabilities caused by prenatal alcohol exposure are a human rights issue of monstrous proportions – this condition underpins domestic violence, bullying, inappropriate sexual behaviour, self-harm, mental health issues and suicide
5. It is the right of every Australian child to know success - a child with undiagnosed FASD suffers from misunderstanding, unachievable expectations by parents, teachers, employers, and friends, each of which eliminates a little more self-confidence, self-esteem and happiness from their lives
6. Over 50% of people with FASD will have experienced life in prison
7. By this time it is likely their secondary disabilities are more critical and damaging in a daily life sense than the primary brain injury
8. This condition must be called for what it is. The indefinite detention of people with cognitive and psychiatric impairment is actually “The Indefinite detention of people with the brain injury called FASD”
9. The most common cause of cognitive impairment is FASD.
10. Ninety-six percent of people with FASD will have a psychiatric disorder

FASD is a term used to describe a grave and ubiquitous health problem conservatively affecting between 500,000 and 1,000,000 people in Australia many of whom are adolescents and young adults (May et al 2015). The physical brain injury can mean information processing difficulties, attention and memory problems, difficulties in sensory integration and emotional regulation and poor cause and effect reasoning which in turn compromise learning. Individuals may be diagnosed with a learning disability without understanding the primary brain injury. Many of those who are diagnosed or acknowledged at risk for fetal alcohol exposure do not have an intellectual disability. This adds to the invisibility of their struggle in school and beyond.

As individuals age, secondary conditions emerge including mental health problems, drug and alcohol addiction, and engagement with the criminal justice system. These issues become an expectation and a ‘rite of passage’ for many Aboriginal and Islander adolescents to be experienced as the gap widens between unrealistic expectations and the continued experience of failure as individuals living with FASD struggle to keep up at school and to experience social acceptance particularly by peers. A longitudinal and seminal study of individuals diagnosed with FASDs (Streissguth *et al*; 2003) found that over 90% will experience a mental health problem. This alarming statistic does not account for those without a diagnosis and yet is clear evidence that any program on mental health MUST include brain functioning, particularly as this relates to FASD, in any program which aims to assist young people with mental health risks. Overall, because the brain cannot be seen and behaviour is observable, it is behaviour which labels and defines the scope of an individual’s ability and an individual’s self-perception.

Because of the lack of understanding of this condition by medical and allied health professionals, accurate differential diagnosis does not often occur. Instead, FASD is often mis-diagnosed inter alia as:

1. ADHD | ADD
2. Personality disorder
3. Mental health disorders
4. Autism | Asperger’s
5. Oppositional Defiant Disorder [ODD]
6. Reactive Attachment Disorder [RAD]

We do not yet have any prevalence rates for Australia and can therefore only cite statistics from overseas which show that we conservatively have between 2 and 5 percent of people are affected by this condition. This is more than Autism, Asperger's, Down Syndrome, and Multiple Sclerosis combined. Using conservative figures, the cost to the government has been assessed as being in the vicinity of \$6 billion.

Problems in addition to mental illness include the dot points below however it is important to note that one person is unlikely to have every symptom. There are so many variables with FASD that while there may be core deficits, there are often very distinct differences between affected individuals. The following table identifies some of the key characteristics.¹

Early 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

Childhood Appearance

- Shorter or thinner than peers
- 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

- Talks excessively, and too quickly
- Interrupts
- 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 mistakes
- Has difficulty recognising consequences of actions
- Slow information processing
- May remember one day and forget the next

Behaviour Regulation

- Poor anger management
- Mood swings
- Impulsive
- Compulsive
- Perseverative
- Inattentive
- Unusual activity level [high or low]
- Illogical lying [confabulation]
- Illogical stealing
- Unusual reaction to sound, touch, light
- Rocks or swings rhythmically
- Fidgety, cannot sit still

Abstract Thinking | Judgment

- Poor judgment
- Unable to plan and execute
- Functions poorly without assistance
- Concrete, black or white thinking
- Does not understand idiom or concepts

Planning | Temporal Skills

- Needs help organising daily tasks
- Cannot organise time

Spatial Skills | Spatial Memory

- Gets lost easily
- Difficulty navigating from point A to point B

¹ FASD Experts <http://www.fasdexpts.com/Screening.shtml> accessed on the 24th February 2014

- Misses appointments
- Has difficulty with multi-step instructions

- Poor memory for sequences and dates

Motor Skills

- Poor | delayed motor skills
- Overly active
- Poor balance
- Accident prone
- Can be clumsy

Social Skills | Adaptive Behaviour

- Poor social | adaptive skills
- Overly-friendly
- Attention-seeking
- Behaves notably younger than chronological age which can lead to difficult situations
- Makes friends one day but friends gone the next
- Easily led | manipulated by others
- 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

Comment from a child with FASD about school:
I was always up at the Principal's office but I never had a clue why I was there. Even when they explained to me what I had done wrong I couldn't remember the time I had done that thing. I was clueless and always frightened to go to school in case I did something that got me into trouble. I got depressed because my friends made fun of me even when I tried hard. I wanted to kill myself because I never knew what was going to happen next.
Seth Russell

For a child with even a few of these problems, life can be confusing and difficult. Frustration at trying hard to please and then being admonished or even punished for misunderstanding or misconstruing directions results in depression and anxiety. Anxiety arises from not knowing when and why they will 'get into trouble' and depression is from believing they are 'stupid', 'unworthy' and 'undeserving'.

However, many people who are incarcerated indefinitely are Indigenous people and they remain in prison because family and providers are unable to care for them once they are released. This situation is untenable and many people are imprisoned beyond the terms of their sentence.

Discussion

1. The differing needs of individuals with various types of cognitive and psychiatric impairments **such as fetal alcohol syndrome**, intellectual disability or acquired brain injury and mental health disorders

The desire to see people with cognitive impairment supported outside of the criminal justice system is ideal but currently unsuitable as there are no appropriate knowledgeable support systems, with appropriate security and discipline outside of the criminal justice system.

People with FASD have very different needs to people with other cognitive impairments. If they are experiencing a level of severity which can compromise the health and wellbeing of themselves or others, they are likely to need a structured, security conscious facility specifically for people with FASD who have high aggression, violence, and frustration levels

All people coming into the justice system, should be screened for FASD.

People identified as having FASD should then be diagnosed and appropriate supports negotiated with services available in their own community on release from prison.

The physical interface between the various systems which could support people with FASD as they are released from prison should be tethered to supports which are coordinated so that the individual does not have to move from one service to another. This would be counterproductive for a person with FASD and unlikely to be effected.

It is imperative that staff members of all relevant services should have accredited training on FASD itself and its interventions and strategies otherwise further damage can be done to the individual and his or her family.

- 2. The impact of the introduction and application of the National Disability Insurance Scheme, including the ability of individuals with cognitive and psychiatric impairment to receive support under the National Disability Insurance Scheme while in detention.**

The NDIS should consider the whole spectrum of disorders as eligible for funding through the NDIS. Only allowing Fetal Alcohol Syndrome to have access to services when it is known that the other diagnoses on the spectrum can be equally damaging to an individual is like saying that only people with breast cancer can have access to support; people with malignant melanoma must do it on their own.

Additionally, it would be difficult for a person with FASD who is without support, to access services to help themselves. It is more likely that people with FASD will be diverted to the NDIS through other services or through family or friends.

*A person with FASD requires a Case Manager who is a consistent, reliable and understanding presence in their lives. Unfortunately the current services which **could** meet the needs of people with FASD do not understand this condition sufficiently well to be of assistance according to the many parents and caregivers supported by the rffada.*

Please do not hesitate to contact me should you require further information.

Elizabeth Russell

Anne Russell

CEO, Russell Family Fetal Alcohol Disorders Association [rffada]

19th January 2016