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6 December 2019

Dear Ms Radcliffe

Submission to the inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

Thank you for this opportunity to provide a submission to the inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder. I am writing this submission in my role as a FASD Consultant, having provided FASD education, support, training and case consultation to families and agencies for the past 10 years. I am a qualified social worker with over 20 years experience in the child protection and out of home care sectors in Victoria and the Northern Territory.

In 2008, while Manager of Out of Home Care services in Alice Springs, I was awarded a Churchill Fellowship and travelled to the US and Canada to explore models of care for children with FASD in the Out of Home Care system. Since that time I have providing training and consulting services in Victoria to agencies including DHHS, Youth Justice, Berry Street, VACCA, Rumbalara Aboriginal Co-operative, the Commission for Children and Young People, and have presented at conferences and workshops. In the Northern Territory I have provided training to Territory Families, Youth Justice, Corrections, NT Police and the Northern Australian Aboriginal Justice Agency.

This submission draws on my research and work experience as well as my experiences talking about FASD in the sector over the past 11 years and I hope to draw attention to some of the gaps which I feel create contribute to significant risks for children, young people, adults and their families if not addressed systematically. I appreciate this opportunity and would be happy to answer any further queries.

Yours sincerely

Prue Walker
FASD Consultant

Introduction

FASD is a neurodevelopmental condition which affects an estimated 1% of the population in Australia. Yet it is poorly understood and recognised, even in service systems in which individuals with FASD are over-represented.

In 2012 I prepared a detailed submission to the House of Representatives Inquiry into Foetal Alcohol Spectrum Disorder titled: *Fetal Alcohol Spectrum Disorder in the Child Protection System: Opportunities for Prevention and Intervention*. In this submission I outlined a range of issues and referenced data in relation to the over-representation of children with FASD in the child protection system and the need for this to be identified and addressed within this system. I have attached a copy of this previous submission as much of it is still relevant.

The report of the Inquiry *FASD: The Hidden Harm*¹ made many relevant recommendations including recognition of FASD as a disability, improving access to diagnosis, and training for professionals. Some of these recommendations have been progressed, such as the development of a diagnostic guide and establishment of some FASD clinics, while others such as training for foster carers and youth workers have been limited in their implementation.

In this submission I am focussing on two key issues: Children in the child protection and youth justice systems, and the need to address the stigma of FASD.

1. Children and Young People in the Child Protection and Youth Justice Systems

Many years ago I ran a FASD workshop for a group of social workers, youth workers and residential carers. During the workshop one participant, I will call him Jim, was struggling with some of my comments. I was somewhat less experienced then, and a tricky participant could throw the workshop as I often found myself focussing on the dissenting voice and trying to win them over with my convincing arguments. Jim wouldn't be convinced. "How can you say someone can't learn cause and effect? How can you say someone can't live independently?" he repeated throughout the day. He wasn't buying my attempts to describe the permanent nature of FASD – he believed everyone was capable of growth and change, and most importantly his knowledge of trauma meant he believed in the power of brain plasticity and recovery. The workshop became a little fraught but I tried to keep it positive and not feel rattled. Jim had a scowl on his face and I could see him mutter to the person next to him. At the end of what felt like a very long day, I asked the group to each describe something they had got out of the day.

Jim's turn came. "I'm angry" he said. Here we go, I thought. But he continued. "I'm angry that if FASD is such a big issue, why has no-one told us about it before now?" The next time I saw Jim he was speaking about FASD at an agency forum.

¹ http://www.aphref.aph.gov.au_house_committee_spla_fasd_report_front.pdf

There are a number of reasons why FASD needs to be better understood and systematically addressed with the child protection and youth justice systems.

1. Parental alcohol misuse is a risk factor for children entering care

Parental alcohol and drug use as a factor in child protection reports and children entering care is well documented in research.

Miller, Fisher, Fetrow and Jordan (2006) in the US found that a wide range of research suggested that parental substance abuse is a predominant cause of children entering (and re-entering) out-of-home care. Estimates from US studies of the prevalence of chemical dependence among families in the child welfare system has been found to be between approximately 50% (Curtis & McCullough, 1993; Murphy, Jellinek, Quinn, Smith, Poitras & Goshko, 1991) up to 80% (Barth, 1994).²

In Victoria, Taskforce 1000 in Victoria identified parental substance misuse as a factor in 87% of Aboriginal children entering care. Western Australian research linking data from births of children between 1983-2007 and subsequent child protection involvement found maternal alcohol use disorder during pregnancy is a risk factor for both FASD and for child neglect:

- 17.6% of children who were prenatally exposed to alcohol were the subject of a substantiated report to child protection compared to 4% of controls.
- Indigenous children were more than twice as likely to be subject of substantiated report/entry to OOH as non-Indigenous children
- Greatest risk of entry into child protection was for children of mothers where alcohol diagnosis was made during pregnancy.³

2. Children with FASD are also over-represented in the care system

A range of international studies have indicated that children with FASD are more likely to be placed in care. Susan Astley and colleagues conducted a study which screened all children entering foster care in Washington State and identified the rate of FAS as 10-15 per 1000, approximately 10 to 15 times greater than the estimated population rate of 1:1000. This study was conducted with high reliability.⁴

Other studies identifying over-representation of children with FASD among the in-care population include:

- A Washington state study of 415 individuals with FAS or Fetal Alcohol Effects (FAE) identified that only 20% had been raised by their biological mothers.⁵
- A Manitoba study found that 11% of all children in care had a FASD diagnosis, representing one-third of all children in care with disabilities.⁶

² Walsh, P., McHugh, M., Blunden, H. and Katz, I. (2018). *Literature Review: Factors Influencing the Outcomes of Children and Young People in Out-of-Home Care*. Pathways of Care Longitudinal Study: Outcomes of Children and Young People in Out-of-Home Care. Research Report Number 6. Sydney. NSW Department of Family and Community Services.

³ Hafekost, Lawrence, O'Leary et al (2017) Maternal Alcohol Use Disorder and Subsequent child protection contact: A Record-linkage population cohort study, *Child Abuse and Neglect*, Vol 72 October 2017, pp 206-214.

⁴ Astley, S, Stachowiak, J, Clarren, S and Clausen, C. (2002) *Application of the fetal alcohol syndrome facial photographic screening tool in a foster care population*, *Journal of Paediatrics*, Vol 141 no 5.

⁵ Streissguth, A et al. (2004) *Risk Factors for Adverse Life Outcomes in Fetal Alcohol Syndrome and Fetal Alcohol Effects*, *Developmental and Behavioral Pediatrics*, Vol 25, no 4

⁶ Fuchs, D., Burnside, L., Marchenski, S. and Mudry, A. (2005) *Children with disabilities receiving services from child welfare agencies in Manitoba*. Winnipeg, MB: Center of Excellence for Child Welfare.

- A Norwegian study which found 11% of children diagnosed with FAS or FASD had been removed from their mother soon after birth due to her alcohol use.⁷
- In Saskatchewan, 72% of 207 individuals with FASD had resided in foster care for some period of their lives.⁸
- A French study in 2010 found that 18% of babies born to mothers who had not modified their alcohol consumption when pregnant were placed in foster care.⁹
- A study of 250 individuals with FASD identified that the majority of infants under 1 year of age in the sample were residing in the care of a child protection service.¹⁰

The WA study by Hafekost, Lawrence, O’Leary et al (2017) found that 13.4% of alcohol-exposed children entered care compared to 2.1% of controls.¹¹

3. FASD Is often missed among children in care

Chasnoff et al (2015) screened a sample of 547 children in care who had undergone a medical, behavioural or neurodevelopmental assessment and diagnosed 156 of those children with FASD. 86.5% of these children had either been mis-diagnosed or never diagnosed in the past.¹²

Gregory et al (2015) conducted an audit of children seen at UK community paediatric clinic between 2010-2013 where there was history of prenatal alcohol exposure. He identified:

- 72 children were diagnosed with FASD during this period
- 34% of children in out of home care had prenatal alcohol exposure
- 75% of children placed for adoption had prenatal alcohol exposure.¹³

4. FASD is a risk factor for young people entering the youth justice system

Hafekost, Lawrence, O’Leary et al (2017) in their WA data linkage study (cited above) also demonstrated that even when adjusting for risk factors such as social disadvantage, indigenous status and poor academic performance, exposure to maternal alcohol use disorder increases the risk of contact with the youth justice system.¹⁴

Multidisciplinary assessment of all young people aged 10-17 sentenced to youth detention in WA between May 2015 – Dec 2016 identified that 89% of young people had one domain of severe neurodevelopmental impairment, and 36 were diagnosed with FASD – a prevalence of 36%.¹⁵

⁷ Elgen, I, Brauroy, S and Laegreid, LM. (2007) *Lack of recognition and complexity of foetal alcohol neuroimpairments*, Acta Paediatrica 2007;96, pp1-5.

⁸ Habbick, BF et al. (1996) *Foetal alcohol syndrome in Saskatchewan: unchanged incidence in a 20 year period*, Can J Public Health, May-Jun;87(3):204-7.

⁹ Toutain, S. et al. (2010) *Consequences for the newborn of alcohol consumption during pregnancy*, Arch Pediatr, 2010 Sep;17(9):1273-80.

¹⁰ Slade, B. et al. (2009) *The Burden of Prenatal Exposure to Alcohol – revised measure of cost*. Can J Clin Pharmacol Vol 16(1) Winter 2009.

¹¹ Hafekost, Lawrence, O’Leary et al (2017) *Maternal Alcohol Use Disorder and Subsequent child protection contact: A Record-linkage population cohort study*, Child Abuse and Neglect, Vol 72 October 2017, pp 206-214.

¹² Chasnoff et al (2015) *Misdiagnosis and Missed Diagnoses in Foster and Adopted Children With Prenatal Alcohol Exposure.* PEDIATRICS 135, no. 2 (February 1, 2015): 264–70.

¹³ Gregory et al (2018) *Identifying children who are at risk of FASD in Peterborough: working in a community clinic without access to gold standard diagnosis, Adoption and Fostering*, Sept 2018.

¹⁴ Hafekost, Lawrence, O’Leary et al (2017) *Maternal Alcohol Use Disorder and Risk of Child Contact with the Justice System in Western Australia: A Population Cohort Record Linkage Study*, Alcohol Clin Exp Res, Vol 41, No 8, 2017 pp1452-1460.

¹⁵ Bower C, Watkins RE, Mutch RC, et al. *Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia*. BMJ Open 2018;8

5. Children and young people with undiagnosed FASD are placed at risk within the service system

When FASD is not recognised, or when children and young people with FASD don't receive appropriate supports and supervision, the risks of poor outcomes increase. When young people's behaviour is misunderstood or seen as intentional rather than as reflecting their underlying brain injury, with impairment in decision making, planning, and understanding the consequences of their actions, young people are placed at greater risk within the systems responsible for their care. These young people require systemic responses that recognise their disability and protect them from the risks of long term negative consequences.

Documented case studies of young people with FASD reflect these risks.

The lost battle to get help for a brain-damaged teen before he rioted at Don Dale¹⁶

Before the extra years were added to his sentence and before the trouble that led to them, authorities were warned that a teenage boy with severe cognitive impairments was deteriorating in Darwin's Don Dale youth detention centre and needed help.

Legal letters seen by the ABC formally requesting urgent intervention in then-16-year-old **Corey's*** "outrageous" treatment in the condemned facility were sent to the head of the Territory Families department and the NT Children's Commissioner in June last year.

Legal Aid lawyers told authorities that the teenager — who has foetal alcohol spectrum disorder (FASD) and a history of trauma starting from abandonment in hospital at birth — had been kept in effective isolation, with little fresh air, sunlight and schooling, and had been threatened and assaulted by other boys inside Don Dale.

They were told he was distressed, "very isolated" and his mental health was declining.

The advocates implored the department to immediately reverse Corey's sudden transfer weeks earlier from the crowded Alice Springs youth detention centre, where he was closer to family and his case worker.

But nothing was done and two weeks later the teenager joined in a riot at the centre, during which he set fire to the outside of another detainee's cell.

A few weeks ago, an extra four years were added to Corey's sentence for his actions on the night.

<https://www.abc.net.au/news/2019-09-08/lost-battle-to-help-fasd-don-dale-teen-before-violence/11345836>

They loved dancing, swimming, math and science: Portraits of young people who died in care

Brooklyn* liked participating in Indigenous ceremonies and enjoyed horseback riding, art, cooking and gardening. One of five siblings, her family experienced the "challenges faced by her First Nation community," including poverty, substance abuse, minimal supports and patchy access to education. She was taken into care before her first birthday, but maintained a lifelong connection with one sister. She was diagnosed with fetal alcohol syndrome and learning disabilities. A psychiatric assessment stressed the importance of a permanent placement for Brooklyn, but attempts to find stable kin or culturally appropriate care near home were unsuccessful. By the time she was 6, she'd lived in 17 foster homes in northern Ontario. She was then moved 800 kilometres away to another foster home. She stayed there for six years with her sister, the closest to permanency she would get. The placement ended abruptly due to reasons unrelated to the children. Eight more placements followed, and her education was in disarray. Brooklyn was exhibiting behaviour earlier assessments had warned of. She also had a history of starting fires. After a series of absences, staff at her foster home modified her bedroom window so she could not sneak out of the house. On the day of her death, Brooklyn, 16, upset over

¹⁶ <https://www.abc.net.au/news/2019-09-08/lost-battle-to-help-fasd-don-dale-teen-before-violence/11345836>

having Internet access withdrawn, pushed a mattress against her door and set it on fire. Her death by smoke inhalation was ruled accidental.¹⁷

Toronto Star, 25/9/2018

HLS¹⁸ was a 15 year old Aboriginal boy in Western Australia who was in care when he ran away from his remote placement and was subsequently found to have been killed by a crocodile. Coroner Ros Fogliani outlined the many steps taken by child protection and foster care services to provide appropriate services to HLS and to develop a safe placement for him. HLS was diagnosed with FASD early in life and due to an intellectual disability was eligible for Disability Services. The Coroner identified he didn't face the difficulties accessing services that less severely impaired children with FASD experience. She found that his death was "tragic and hard to predict" but that lack of knowledge about caring for children with FASD on the part of both child protection and the foster care agency contributed to him feeling unsettled and leaving his placement.¹⁹ She recommended regular screening of pregnant women and children at risk of FASD, and targeted FASD screening for children entering care in the Kimberley.

LCM²⁰, a 15 year old boy, was under the care of child protection in WA from the age of 6, having experienced a severely deprived and dysfunctional childhood. He and his 16 year old girlfriend had a baby in 2014, and child protection and the hospital were monitoring the baby's care. When the baby was three weeks old and still in hospital, LCM had a short unsupervised visit with his son and during that time, caused head injuries which led to the infant's death. LCM pleaded guilty to unlawfully killing his son and was sentenced to 10 years imprisonment. While in Banksia Hill Detention Centre he was assessed for FASD as part of the Bower et al (2018) study and this led to a reduction in his sentence to 7 years.

At the time LCM was sentenced, the State Prosecutor stated that LCM had provided no explanation for what he had done. He gave different and contradictory accounts of what might have happened. The prosecutor described psychological assessments of LCM that suggested that he was motivated by jealousy of the child and was competing for the mother's attention. LCM's lawyer outlined his chaotic childhood in which this conduct was "normalised".²¹

LCM's sentence was appealed on the basis of his subsequent diagnosis and he was re-sentenced to 7 years. The Court found that "there was significant mitigation in the case, having regard to the appellant's FASD, his dysfunctional upbringing and, of course, his youth. ... the prenatal brain damage suffered by the appellant has left him more vulnerable to the traumas he has suffered. ... If he is provided with appropriate mentoring and care, he has, ... some capacity for learning and positive change."²²

Coroner Sarah Linton in her inquest into the death of the infant known as Baby L stated:

The Court of Appeal found that LCM's powers of reasoning, logical thought and self-control were all compromised, as was his ability to deal with traumatic events. This was all in addition to the effects of his lived trauma, which itself compounded the effects of his FASD. The Court of Appeal found that LCM's irrational behaviour was in part a reflection of the impairments attributable to FASD.

¹⁷ <https://www.thestar.com/news/gta/2018/09/25/they-loved-dancing-swimming-math-and-science-portraits-of-young-people-who-died-in-care.html>

¹⁸ https://www.coronerscourt.wa.gov.au/_files/HLS%20finding.pdf

¹⁹ <https://www.theguardian.com/australia-news/2018/may/10/inquiry-into-teen-killed-by-crocodile-recommends-foetal-alcohol-screening>

²⁰ https://www.coronerscourt.wa.gov.au/_files/LCTM%20finding.pdf

²¹ <https://www.abc.net.au/news/2015-03-23/bunbury-teen-baby-death-sentencing/6340942>

²² https://www.dpp.wa.gov.au/_files/CC_2014.pdf

However, it was also accepted that his FASD and his traumatic life did not deprive him of the capacity to know that what he did was wrong.²³

In her findings, the Coroner identified that LCM's case manager did not know he had FASD and it was not "on our radar". Similarly his youth services worker was unaware and had no training about FASD prior to these events. Coroner Linton identified that there were a number of missed opportunities to diagnose LCM earlier and that this could have reduced the risk to Baby L.

It is quite clear that not enough was known about LCM's cognitive deficits and behavioural issues to have a full understanding of how these impacted on his ability to become a father and to parent safely. While I accept that the tragic events that unfolded were unpredictable, particularly while the baby was still in what was considered to be the relatively safe environment of the hospital, if more had been done to properly assess LCM the fact that he potentially posed a risk to Baby L might have become more apparent.²⁴

6. Children and young people with FASD are at increased risk of suicide

A Canadian study identified that the leading cause of death among people with Fetal Alcohol Syndrome in Alberta was suicide (15%) and the average life expectancy was 34 years.²⁵ Mattson et al (2011) identifies a connection between the symptoms of FASD and the increased risk of suicide:

Furthermore, the host of clinical difficulties associated with prenatal alcohol exposure, such as impulsivity, mood disorder, and substance abuse, place affected individuals at high risk for suicide, and research suggests that individuals with FASD have an increase in lifetime suicide attempts relative to the general population (Baldwin 2007; O'Malley and Huggins 2005; Streissguth et al. 1996). In one account, 43% of adults with FASD reported suicide threats and 23% reported a history of suicide attempts throughout the lifetime (Streissguth et al. 1996)²⁶

The WA Coronial Inquest in 2017 into the deaths of 13 children and young people in the Kimberley region reported that while none of the children had been formally diagnosed with FASD, a number of them were likely to have been on the FASD spectrum. The Coroner found:

A number of the children and young persons whose deaths have been investigated at the Inquest appear to have acted impulsively and I cannot exclude some of them having been on the spectrum for FASD with disturbances to their executive functions and affect regulation, making them more vulnerable to suicidal behaviour.²⁷

During the inquest, the WA Department of Communities submitted to the Coroner that:

...the approach to treatment for a child with FASD is the same as a child not diagnosed with FASD, but having some similar characteristics and behaviours such as a child with Attention Deficit Hyperactivity Disorder, Autism, Bipolar Disorder, Reactive Attachment Disorder and Sensory Integration Disorder. ... They posit that an assessment of a child's overall intelligence quotient (IQ)

²³ https://www.coronerscourt.wa.gov.au/_files/LCTM%20finding.pdf

²⁴ https://www.coronerscourt.wa.gov.au/_files/LCTM%20finding.pdf

²⁵ Thanh and Jonsson (2016) *Life expectancy of people with Fetal Alcohol Syndrome*, J Popul Ther Clin Pharmacol Vol 23(1):e53-e59; March 9, 2016

²⁶ Mattson, S, Crocker N & Nguyen, T. *Fetal Alcohol Spectrum Disorders: Neuropsychological and Behavioral Features* Neuropsychol Rev (2011) 21:81–101 DOI 10.1007/s11065-011-9167-9

²⁷ https://www.coronerscourt.wa.gov.au/_files/inquest-2019/13-Children-and-Young-Persons-in-the-Kimberley-Region-Finding.pdf

*and functional capacity can enable a more comprehensive and individualised treatment plan for the child and management for the carers.*²⁸

The Coroner concluded that while other factors co-existed for these children, including developmental trauma, a specific focus on FASD was warranted, and she recommended universal screening for FASD when children enter the child protection or justice systems for the first time.

Responses to FASD by Child Protection and Youth Justice Agencies

Child Protection and Youth Justice agencies have been slow to develop policies, programs, training or practice guides to assist or guide staff working with young people in care or in the justice system. The Banksia Hill study has led to development of training resources for custodial staff which have been well received and has led to greater awareness in WA.²⁹ However the need for better recognition, understanding and responses to children and young people with FASD is generally not reflected in current Australian statutory policy or practice.

A desktop audit of for information about FASD on government websites in Victoria indicates:

Organisation	Website	Search Terms	Results
DHHS Victoria	https://www.dhhs.vic.gov.au	FASD Foetal/Fetal alcohol Alcohol and pregnancy Alcohol Trauma	No results No results No results 20 results 9 results
Vic Government	https://www.vic.gov.au	FASD Fetal/Foetal Trauma	No results 1 result, obstetrics 21 results
Vic Dept of Justice and Community Safety	https://www.justice.vic.gov.au	FASD Fetal/Foetal Trauma Alcohol	No results No results 25 results 29 results
Victorian Commission for Children and Young People	https://ccyp.vic.gov.au/	FASD	4 results (see below)
Vic Child Protection Manual	https://www.cpmanual.vic.gov.au	FASD Fetal Alcohol Foetal alcohol	No results 9 results, one relevant resource(see below). 2 results - List of harm types includes foetal alcohol syndrome. - Parental substance use assessment tool which includes the question "Does (did) the baby have foetal alcohol syndrome?" There are no further references to FAS or FASD in the document.
NDIS	https://www.ndis.gov.au	FASD Fetal Alcohol Foetal Alcohol	1 result, list of acronyms 2 results, FASD included in 2 lists of conditions 1 result, list of acronyms
Google search		"FASD Victoria"	1 government source in first page results– Better Health Channel fact sheet. Other links are to submissions, inquiries, media reports but no Victorian resources.

²⁸ Ibid.

²⁹ <https://alcoholpregnancy.telethonkids.org.au/our-research/research-projects/Management-young-people-FASD-detention/>

A search of Community Organisations in Victoria revealed similar results:

Organisation	Website	Search Terms	Results
Centre for excellence in child and family welfare (Victorian peak body and training provider)	https://www.cfecfw.asn.au	FASD/Fetal/foetal	No results
Foster Care Association Victoria	https://www.fcav.org.au/	FASD/Fetal Alcohol Foetal Alcohol	No results 1 result: carer profile
Carer Kafe (provides training to kinship and foster carers)	https://www.carerkafe.org.au	FASD/Fetal/Foetal	No results
Out of Home Care Toolbox (resources for carers of children and young people aged 12-18), The Centre for Youth AOD Practice Development	https://www.oohtoolbox.org.au/	FASD/Fetal/Foetal	No results

Searching child protection agency websites across Australia reveals:

Organisation	Website	Search Terms	Results
NSW Communities and Justice	https://www.facs.nsw.gov.au	FASD/Fetal Foetal	No results 1 result – case study in 2016 publication
Qld Dept of Child Safety, Youth and Women	https://www.csyw.qld.gov.au/child-family	FASD Foetal	4 results, two in lists of disabilities 11 results, including above. Two practice guides list FASD as risk factor for infants.
WA Dept of Communities, Child Protection and Family Support	https://www.dcp.wa.gov.au	FASD Fetal Alcohol	12 results including fact sheets for carers, training workshops 24 results
SA Dept for Child Protection	https://www.childprotection.sa.gov.au	FASD/Fetal/Foetal	No results
Territory Families	https://territoryfamilies.nt.gov.au	FASD	7 results, 1 fact sheet, others referencing Alcohol policies and NT FASD action plan.
Tas Child Safety Service	https://www.communities.tas.gov.au/children	FASD/Fetal/Foetal	No results
ACT Community Services	https://www.communityservices.act.gov.au/ocyfs/children/child-and-youth-protection-services	FASD	5 results, one list of acronyms, other references in reports Towards Disability Justice in the ACT 2019 and Blueprint for Youth Justice 2019

In my submission to the 2012 inquiry I reported that FASD was under-recognised by governments and the community sector as:

- A contributing factor to children entering care
- A complicating factor in working with children where parents are consuming alcohol to risky levels and
- A condition which requires significant case management resources for children in care.

At this time I also reviewed child protection websites for information, resources and policies relevant to FASD and documented the following:

2012 Submission to FASD Inquiry

Studies focusing on the needs of children whose parents abuse alcohol tend to focus on factors such as: the effect on parenting capacity; risks of abuse or neglect due to alcohol related harms such as violence; health issues of parents; and financial stressors due to addiction. Long term harms to children are often identified as behavioural issues due to parenting deficits. However the issue of harm to the child's health and development through exposure to alcohol in-utero is not given sufficient prominence or attention.

- A literature review entitled *Parental alcohol misuse and the impact on children* published by the NSW Department of Community Services in 2006 makes only passing mention of Fetal Alcohol Syndrome and quotes only one reference.
- A practice paper produced by Queensland Government Department of Child Safety in 2007 entitled *Parental substance misuse and child protection: intervention strategies* makes no reference to FAS/FASD or pregnancy.
- A report on *Child Protection and Mothers in Substance Abuse Treatment* produced for the National Drug and Alcohol Research Centre, University of NSW in November 2011 makes no mention of FAS/FASD, although a proportion of mothers sought treatment due to pregnancy. Mothers were in treatment for opioid addiction but 21% had had an alcohol problem in the last 12 months.
- The paper, *Issues for the safety and wellbeing of children in families with multiple and complex problems: the co-occurrence of domestic violence, parental substance misuse, and mental health problems*, published by the National Child Protection Clearinghouse in 2010, mentions the negative impact of alcohol in conjunction with diet, drug use, stress and violence in pregnancy. However there is no reference to FAS/FASD.

Examples of resources where FASD is recognised include the Victorian DHS Specialist Assessment Guide for Assessing Parental Substance Use, 2000. This guide includes prompts around identification of FAS and states:

- *Newborn Infants diagnosed with foetal alcohol substance abuse symptoms are one of the highest protective risk categories for short and long term damage to their physical, social and emotional health and well being.*
- *The World Health Organisation estimates over 90% of pregnant women use some sort of drug during their pregnancy and that 2%-3% of all birth defects are due to drug use.*
- *The immediate and unique needs of these infants require parental care and skills not usually evident in substance abusing parents.*
- *These children are likely to require ongoing medical, community health and welfare services to overcome the damage cause to them prior to birth.*

More recent documents from Victoria, such as the DHS guide entitled *Infants and their Families: Best interests case practice model* (2010), reference FAS as a possible factor in assessments but miss an opportunity to provide child protection workers with a more detailed understanding of FASD and the complexities of assessment and case management.

Western Australia has become a leader in FASD research and the WA Department of Communities is the only statutory agency which includes a webpage on FASD and Fetal Alcohol Spectrum Disorder in the Child Protection System: Opportunities for Prevention and Intervention and an information brochure on FASD which outlines the signs and ways to support affected children. A Fostering Fact Sheet is also available outlining some of the issues involved in fostering children with FASD.³⁰

A further desktop audit of the documentation available online to assist child protection agencies to understand and respond to the needs of children and young people with FASD indicates that there has been very little change. I have reviewed documents from WA, NSW, Qld and Victoria to explore whether FASD is identified or mentioned in reports, studies or manuals relevant to child protection.

Western Australia:

Child Protection services in WA have benefitted from the work of Telethon Kids and the WA-based FASD programs particularly in relation to training for professionals and carers, and awareness of FASD is therefore likely to be greater than in other parts of Australia. Looking further into the FASD-related resources available on the government website:

- The one-page fact sheet on FASD for foster carers is the same version as in 2012. It refers to a publication which is no longer available and the other links to FASD information sheets redirect to resources produced by NOFASD.
- The *Guide to Completing the Needs Assessment Tool* includes FASD in a checklist of developmental risks, but gives no further guidance or instruction
- The *Child Development and Trauma Guide* (a Victorian Government publication reproduced by WA, undated) mentions Foetal Alcohol Syndrome twice as risk factor for child development but does not provide further guidance.
- *Safer Families, Safer Communities – Kimberley Family Violence Regional Plan 2015-2020* refers to FASD as a factor that co-occurs with family violence (one reference),
- The Department for Child Protection and Family Support *At Risk Youth Strategy (2015-2018)* has no mention of FASD. Young people are “At Risk” include the following indicators, which overlap considerably with FASD indicators:
 - Behavioural indicators - truancy, emotionally unstable, disruptive behaviour, displaying suicidal intent or self-harm, antisocial behaviour, violent or aggressive in the community, social isolation, juvenile offending, vandalism, drug and/or alcohol abuse, rejecting parental support, low self-esteem, lack of social and communication skills.
 - Situational indicators - unemployed, homeless, socially disadvantaged, family and domestic violence, alcohol and other drug use in the home, family breakdown, transient families, lower socio-economic families, abused children.
 - Educational indicators – underachieving academically, not coping in classroom situations, poor literacy and numeracy skills, suspended from school or excluded.

NSW:

- As per the table above, there is no specific mention of FASD in any documents which can be searched online
- *NSW Health - Formative evaluation of health assessment processes and coordination for children and young people entering statutory Out of Home Care: Final evaluation report, NSW Kids and Families 8 April 2014* – no mention of FASD

³⁰ http://www.aphref.aph.gov.au_house_committee_spla_fasd_subs_sub_029.pdf

- *Pathways of Care Longitudinal Study: Outcomes of Children and Young People in Out-of-Home Care Research Report No. 11, Aboriginal Children in Out-of-Home Care in NSW: Developmental Outcomes and Cultural and Family Connections* – this report identifies that 73% of Aboriginal children entering care were identified to have carer alcohol/drug use as a risk factor, and also identifies that Aboriginal children in care were more likely to be premature, of low birthweight and poor growth; and had higher rates of ADHD and behavioural problems. FASD is not mentioned in the report.
- *Pathways of Care Longitudinal Study Research Report No. 6, (2018) Literature Review: Factors Influencing the Outcomes of Children and Young People in Out-of-Home Care* – identifies a number of studies which identify the prevalence of parental drug and alcohol use as factors in children entering the care system, however there is no mention of FASD including in discussion of the impact of parental substance use.

Queensland:

- *Practice Paper: Parental substance misuse and child protection: Overview, indicators, impacts, risk and protective factors August 2007*. This paper includes 1.5 pages on Fetal Alcohol Syndrome and provides suggestions for professionals in how to support children and their families.
- *Qld Government: Child protection intervention with high-risk infants (undated, c2012)*. The section on Prenatal exposure to alcohol and drugs identifies that children born after fetal exposure to maternal alcohol use are at higher risk of neglect. There is no mention of FASD.

Victoria:

- The Child Protection Best Interests Framework has not been updated since 2007
- The updated Best Interests summary document (2012) does not mention FASD
- *Infants and their families : Best interests case practice model - Specialist practice resource (2012)* has the same information as the 2010 version discussed above.
- FASD is not a topic covered in the child protection learning and development calendar, although there are workshops on Autism and on the NDIS.

The Victorian Commission for Children and Young People Annual report 2014-15 states that the Commissioner for Aboriginal Children and Young People spoke about FASD at a regional workshop:

“We can all be part of the change in the understanding and prevention of FASD. Health professionals can routinely speak to women about their alcohol use and capture data on alcohol consumption during pregnancy; we can talk to our youth and parents about the impact of alcohol on unborn and newborn babies and health professionals can notice potential FASD and related disorders”.

The Annual report cites studies that indicate between 60-80% of children with FASD are not raised by their biological parents, and that there are potentially a large number of children with FASD in care. The report reflects on the evidence from Taskforce 1000 in relation to parental alcohol use as a driver for children entering out of home care. The report states:

It is critical that the Department of Health and Human Services considers this likelihood in health checks of babies and children who are entering care to ensure early diagnosis and intervention.³¹

In November 2018, the biannual meeting of the Australian and New Zealand Children’s Commissioners and Guardians released a communique that identified children and young people with FASD among other

³¹ <https://ccyp.vic.gov.au/assets/corporate-documents/CCYP-annual-report-2014-15.pdf>

vulnerable groups as needing greater attention, as they **“require much greater policy attention and access to specialist and mainstream program support”**.³² This is reported on the CCYP’s website.

A recent study by the Children’s Commission into the suicides of 35 children and young people known to child protection does not mention FASD or prenatal alcohol exposure as a possible risk factor for suicide and does not collect this data.

The report states:

- 89% of children had had contact with a mental health service, many for behavioural issues
- 12 children received an early mental health diagnosis (before age 7)
- Of these children,
 - 75% had a parent with a drug or alcohol addiction
 - 67% had an intellectual disability
 - 75% had a diagnosis of ADHD

The overlap between this group of children and those at risk for FASD needs to be recognised. Prenatal alcohol exposure needs to be included when identifying the factors that contribute to adverse outcomes for children and young people.³³

In summary, child protection agencies in Australia:

- Include FASD in checklists of risk factors but provide little or no guidance about how this should be managed
- Focus on FASD as a risk in infancy rather than across the lifespan, and do not identify it as a risk factor for parents
- Lack information about FASD indicators, screening, diagnosis or practice approaches
- Fail to integrate learnings about the risks of FASD into other risk assessment tools
- Focus on trauma to the exclusion of FASD.

I am not aware of any mainstream support services for families raising children with FASD including those in foster care. The needs of families for FASD-specific support cannot be over-stated. Carers for children with FASD spend a great deal of time in seeking appropriate services for their children who repeatedly fall through the gaps of the service system.

There is a great deal of interest in the service sector in learning more about FASD. Professionals are keen for information and resources, strategies. Priority areas in which professionals have expressed interest include:

- How to get a diagnosis, particularly in regional areas, and for adolescents and adults
- How to find services that can support families and carers
- What strategies are effective
- How can children be supported at school
- How to access NDIS services
- How to get funding for diagnosis if no local or public options exist
- How to support young people in the youth justice system
- How to distinguish between the effects of trauma and FASD
- How to integrate FASD and Trauma-informed practice
- How to find services for adults with FASD
- How to find evidence of pre-natal alcohol exposure
- How to talk to birth parents about a child’s FASD diagnosis

³² <https://www.humanrights.gov.au/our-work/childrens-rights/publications/australian-and-new-zealand-childrens-commissioners-and-0>

³³ <https://ccyp.vic.gov.au/assets/Publications-inquiries/CCYP-Lost-not-forgotten-web-final.PDF>

- How and when to talk to children and young people about diagnosis

Agencies such as NOFASD Australia, the FASD Hub, rrfada and Telethon Kids have produced resources and information on these topics. However implementation of FASD training for the statutory workforce is limited, particularly in Victoria. The Australian Institute of Family Studies has published practice papers on supporting children with FASD³⁴ and researchers such as Sara McLean have published resources for foster carers³⁵. These resources need to be taken up, utilised within child protection and youth justice services, and policies and practice guides need to be developed by these agencies in response to the needs of these children and young people.

The Australian Government Department of Health is currently implementing the National FASD Strategic Action Plan 2018-2028 which includes funding for training for professionals including youth justice, as well as resource development. These need to be expanded to include Child Protection services.

Recommendations:

That child protection and youth justice services in each state and territory be required to:

1. Develop FASD practice resources for identification, diagnosis, support, risk assessment and case management of children, young people and families affected by FASD;
2. Screen for prenatal alcohol exposure at the time of entry to child protection or youth justice services;
3. Develop specialist assessment, diagnosis and intervention guides for children and young people with FASD;
4. Integrate FASD informed practice into Trauma informed approaches to supporting children, young people and families;
5. Provide training and resources to foster carers and kinship carers receive to manage the care of children with FASD;
6. Develop a model of best practice for supporting children and young people with FASD who are at risk of abuse and neglect, are in care or in the youth justice system.

³⁴ <https://aifs.gov.au/cfca/publications/supporting-children-living-fetal-alcohol-spectrum-disorders-practice-principles>

³⁵ <https://emergingminds.com.au/resources/how-to-support-children-living-with-fasd/>

2. Addressing the stigma associated with FASD

FASD is a stigmatised condition. Professionals worry that it is a diagnosis that blames mothers. One carer told me that when they asked their GP if their child might have FASD, the response was, “why would you want your child to be diagnosed with that condition?” Other carers and parents have reported that their doctor “doesn’t believe in labels”. These comments reflect the view that a FASD diagnosis is unnecessary and or negative for children and families and are documented in Australian research:

... ‘he was born with very obvious signs of FASD, looking back, but the paediatrician was reluctant to hang that label on him because he thought it would make the child less able to find foster parents and, as he said to me, it’s not a nice label, you don’t want that label.’ Carer of child with FAS.³⁶

FASD needs to be de-stigmatised for many reasons:

- It is a medical diagnosis, not a label.
- Early diagnosis is a protective factor for individuals
- Without an accurate diagnosis, people with FASD are either not entitled to services, or do not receive the right services
- A FASD diagnosis provides important information in the justice system
- Birth parents are entitled to know that alcohol in pregnancy is harmful and need this information to make informed choices.

Carers want to know when and how they should tell their children about FASD, but worry about how this will be managed. Many carers have said they don’t want their child to be angry at their birth mother. Others have expressed reservations about their child telling others about their diagnosis and worry that this will lead to bullying or stigma.

Importantly, people with FASD are entitled to know about their diagnosis and what it means for them and their brain. There are very few disabilities where the majority of people affected don’t know they have it. The majority of adults living with FASD in Australia are undiagnosed, and while many are living in the community, others are over-represented in the service system (child protection, justice, corrections, AOD treatment, mental health services). The long term outcomes for these adults would have been very different had they known they had a disability. Negative labels - non-compliant, chaotic, low-functioning, limited parenting capacity, lack of insight – could have been reframed by themselves and others as symptoms of FASD.

Individuals with FASD have spoken of the benefits of a diagnosis:

Francis was walked through the process of receiving and making sense of his diagnosis of FAS. Following his formal diagnosis of FAS, Francis felt that he was finally able to understand the reason behind his challenges. This was like a weight being lifted off of his shoulders and he was able to let go of long held bitterness. Armed with the knowledge of FAS, Francis has made adjustments to his life routine in order to be more successful³⁷.

Children with FASD go through enough of a battle on a daily basis, why should they not receive the support they desperately need? Without it the future of these amazing individuals is bleak. They

³⁶ Breen, C and Burns, C. (2012). *Improving Services to families affected by FASD*, NDARC, University of NSW.

³⁷ Erb, A. The Life Stories of Individuals Who as Adults were Identified as Experiencing the Effects of Fetal Alcohol Spectrum Disorder, University of Pennsylvania, Spring 5-18-2015 , retrieved 28/11/2019

http://repository.upenn.edu/cgi/viewcontent.cgi?article=1064&context=edissertations_sp2

*need a diagnosis, not to be labelled, but to be acknowledged and supported as they grow. Adult with FASD.*³⁸

When conducting FASD workshops, I conduct an exercise called “challenging conversations” where participants practice talking to young people and parents about prenatal alcohol exposure and FASD. Participants reflect that they have difficulty finding the words to speak comfortably about alcohol in pregnancy, and about the possibility that a child or a young person might need FASD assessment. While social workers might be struggling to find words, birth parents may be more matter of fact about alcohol in pregnancy, particularly those who drank before they knew they were pregnant, and are more likely to be focussed in getting their child the help they need.

SBS Insight: Drinking While Pregnant (2013)³⁹ features an interview by Jenny Brockie with Tammy, a woman whose daughter was diagnosed with FASD at age 17 after many years of mis-diagnosis.

JB: What was it like for you to get that diagnosis?

Tammy: For the first time in 17 years I actually felt as though I was a good mum, because prior to getting that diagnosis I thought that I was just a bad mum.

JB: And how did you feel about it being connected with the alcohol consumption when you were pregnant?

T: Initially... initially it was difficult, just for the first couple of days, I think, I was overridden by guilt, but after that I was more concerned about getting her support.

JB: And probably relieved you had an explanation for 17 years of multiple problems?

T: Yes, absolutely.

The degree of discomfort felt in talking about alcohol in pregnancy is a reflection of both social and personal stigma/shame around alcohol in pregnancy. We need to normalise discussion about alcohol in pregnancy and FASD diagnosis as we have in other issues previously experienced with shame and secrecy, such as family violence, sexual abuse or mental health. In the report *FASD: The Hidden Harm*, Dr Raewyn Mutch is quoted as follows;

*Autism was perceived as a diagnosis to be feared, I think. Now, in some places, it is a diagnosis that is warmly embraced because it is chased with high-level care and guaranteed aid and education. The stigma has fallen away as support, understanding and research has been provided, and allowing people to have this condition has elevated it to normality not stigma.*⁴⁰

FASD is an issue that affects the whole community, and we need to ensure that this is conveyed in our messaging around FASD. Finding a balance between community wide strategies and targeted interventions is important. We need to reinforce messages that FASD is not an Aboriginal issue, while acknowledging that FASD is more prevalent in communities where alcohol consumption is and these populations or groups may require different approaches. We need to ensure that responses to FASD in Aboriginal communities recognise the impact of intergenerational trauma and do not replicate the approaches that have contributed to marginalisation. Projects such as the Marulu strategy demonstrate the possibilities of community-driven and owned initiatives.

Another way in which FASD is stigmatised is through the use of negative messages and language. It is vital that governments recognise the risks associated with FASD for vulnerable children and families, as discussed above, in order to promote government action in these areas, but we also need to recognise that

³⁸ *Hear Our Voices*, May 2018, FASD UK Alliance, prepared by NOFAS-UK, http://www.nofas-uk.org/WP/wp-content/uploads/2018/05/HearOurVoicesPublication_FINAL2_ForWebsite.pdf

³⁹ *Drinking While Pregnant*, *Insight S2013 Ep 31*, SBS Catchup.

⁴⁰ *FASD: The Hidden Harm* p 97

FASD affects many people in the community who are undiagnosed, and for whom little is known about their lives and their outcomes.

FASD: The Hidden Harm reported:

According to the Australian Human Rights Commission (AHRC), international research reports poor long-term outcomes for children with FASD; 90 per cent will have mental health problems, 80 per cent will remain unemployed, 60 per cent will come into aggravated contact with the law and less than 10 per cent will be able to ... [live] independently by the age of 21.⁴¹

The original source for this data is a ground-breaking and often cited study *Risk Factors for Adverse Life Outcomes in FAS and FAE* (Streissguth et al 2004) which followed up 415 patients aged 6 and over who were diagnosed with Fetal Alcohol Syndrome or Fetal Alcohol Effects between 1972 and 1995. Interviews were conducted with parents and carers in 1995. Outcomes for the subjects aged 12 and over at the time of the interviews (n= 253) are the source for this data.⁴²

The original data is not as black and white as the summary above suggests:

- 60% of people had been in trouble with the law, but the majority were dealt with by juvenile courts. The contact was not all aggravated, but included lesser offences.
- Mental health problems (90%) were recorded if the person had ever seen a counsellor or therapist. The highest prevalence for any condition was attentional problems (60%), which would not now be considered a mental health issue but a primary symptom of FASD. Behaviour problems were also classified as mental health problems in the original study.
- 80% of people had problems with employment, including difficulty finding or keeping a job, or problems experienced in a job, but they were not necessarily unemployed long term.
- 43% of those aged over 21 lived with a partner, with their children or alone, but were considered to need help with daily living and therefore considered dependent.

The research identifies the significance of a range of risk and protective factors relating to adverse outcomes for individuals with FASD and these are still relevant today. However caution needs to be taken in generalising these risk factors and predicting that the same proportion of individuals living with FASD will experience these negative outcomes today. Streissguth wrote:

Finally, we remind the reader that this is a referred clinical sample, and as such, cannot be considered representative of all people born with FAS or FAE, or even all of those who have a diagnosis of FAS or FAE; this limits the generalizability of the findings... Except for those diagnosed at birth whose alcohol exposure history was the trigger for evaluation, there is always the possibility that the manifest problems of the patients brought them to the attention of a diagnostician. Additionally, both the inherent developmental disabilities and the personal characteristics associated with this CNS condition may have contributed to those affected offspring who are brought to a FAS clinic for evaluation. Looking at our data historically, we see that the severely retarded patients were disproportionately diagnosed in the 1970s when the diagnosis was new and before the Surgeon General's (1981) warning on abstaining from alcohol during a pregnancy or when planning a pregnancy.⁴³

We need to ensure that FASD is spoken and written about in ways that do not further stigmatise people with FASD. Rather than predicting that:

⁴¹ FASD: The Hidden Harm p 30.

⁴² Streissguth AP, Bookstein FL, Barr HM, et al. *Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects*. J Dev Behav Pediatr 2004;25:228–38.

⁴³ Streissguth et al (2004)

- 90 per cent will have mental health problems
- 80 per cent will remain unemployed
- 60 per cent will come into contact with the law,

We can focus on the protective factors identified in the study:

- Without early diagnosis, stability and a nurturing environment, children and young people with FASD are at greater risk of experiencing mental health issues, involvement in the justice system or problems finding and keeping a job. With the right supports, people with FASD experience greater stability and reach their potential.

Streissguth wrote:

...the larger goal of the study is to help families and communities raise the next generation of people born with this birth defect with more understanding, to protect them from the hazardous straits into which they are born, and to provide access to appropriate services so that each can develop to his/her own best potential.

In training professionals, it is not uncommon for workshop participants to disclose their own personal or family stories relating to prenatal alcohol use and FASD. This reinforces the need to use language which a person with FASD, a birth parent or a carer would find hopeful and empowering rather than negative. The Canadian research network CANFASD has developed a language guide aimed at promoting dignity for people with FASD which could be readily adapted for Australia.⁴⁴

To reduce stigma, we need:

- Voices and stories of children, young people and adults with FASD and birth families to be communicated through community education programs to show how FASD and prenatal alcohol exposure can be spoken of confidently, openly, and in a non-blaming/shaming way;
- Ensuring that FASD voices and stories reflect the cultural and social diversity of metropolitan, rural and regional communities
- Involvement of people with FASD and their families in developing resource
- Language that promotes dignity of people with FASD
- A focus on strengths, hopefulness and potential.

Professionals need the tools and resources to have difficult conversations, including information about:

- effective and non-judgemental approaches to talking about alcohol in pregnancy;
- data about alcohol in pregnancy to help challenge stereotypes, for example the knowledge that 4/5 Australians consume alcohol, around 40% of pregnancies are unplanned, and that up to 60% of women consume some alcohol in pregnancy.⁴⁵
- Data about FASD prevalence estimates in the wider community, not just in the sub-populations assessed in FASD clinics.
- The impact of Australian values and attitudes towards alcohol, social determinants of health, and the relationship between alcohol and intergenerational trauma.

Since the last FASD Inquiry, video resources featuring children and young people, and parents and carers of children with FASD have been developed by the the Marulu Project, FASD Hub, Telethon Kids, Elizabeth

⁴⁴ Language Guide: Promoting dignity for those impacted by FASD, CANFASD <https://canfasd.ca/wp-content/uploads/2018/01/LAEO-Language-Guide.pdf>

⁴⁵ Muggli, E., O'Leary, C., Donath, S. *et al.* "Did you ever drink more?" A detailed description of pregnant women's drinking patterns. *BMC Public Health* **16**, 683 (2016)

Russell and others. These videos are invaluable. Hearing the lived experience of these individuals allows us to appreciate the complexity of FASD, for the person and their family. When families can see children speaking confidently about their FASD diagnosis with no shame or hesitation, it provides them with the confidence that they can talk about their child's diagnosis with the same attitude.

Myles Himmelreich, a motivational speaker and adult with FASD says:

*I struggle, but I also succeed. And that's where I try to keep my vision and my focus, is on my successes. Because that is who I am. Somebody who lives with FASD, who is successful.*⁴⁶

Recommendations:

1. Promotion of positive stories of individuals living with FASD, including interviews with children, young people and adults who have FASD, birth parents and carers, and family members. Video stories of individuals with FASD telling their stories should be included in FASD training resources.
2. Development of an Australian language guide for FASD, based on the CanFASD document to promote non-stigmatising language.

⁴⁶ Myles Himmelreich, (2017) FASD: I struggle, but I also succeed. Youtube
<https://www.youtube.com/watch?v=Dg0YXdLWu4k>