

FAS and FASD

Introduction

- 6.1 Fetal Alcohol Spectrum Disorder (FASD) and the more impacting fetal alcohol syndrome (FAS), is the clinical diagnoses of permanent damage to brain structure and function due to alcohol exposure in utero, i.e., when the pregnant mother drinks during pregnancy.¹
- 6.2 FASD is a 100 per cent preventable condition if there is no exposure to alcohol in utero. It is incurable and permanent. However, if children are assessed, diagnosed and treated early in life, therapeutic interventions may be helpful. If FASD is not diagnosed early it can have significant and profound impacts for a lifetime.²
- 6.3 FASD is not a problem only suffered by Aboriginal and Torres Strait Islander people; it affects all cultures where a woman might drink alcohol when pregnant.³
- 6.4 In Australia, there is low awareness of the effects of pre-natal exposure to alcohol. There are few places where FASD can be diagnosed and there is a general lack of awareness and misdiagnosis of the condition and how individuals are affected.
- 6.5 The National Indigenous Drug and Alcohol Committee (NIDAC) notes that both the frequency and intensity of alcohol consumption affect the risk of FASD. Risk to the fetus may occur from moderate levels of prenatal

1 Telethon Kids Institute, *Submission 74*, p. 3.

2 National Aboriginal and Torres Strait Islander Legal Services and the Human Rights Law Centre, *Submission 58*, p. 14.

3 Aboriginal Drug and Alcohol Council (SA) Inc. (ADAC), *Submission 40*, p. 5.

alcohol consumption, including occasional heavy episodic drinking. Lower levels of alcohol consumption can still result in permanent disability in the fetus.⁴

- 6.6 The Australian Guidelines to Reduce Health Risks from Drinking Alcohol (2009) advise in Guideline 4 that:
- ... maternal alcohol consumption can harm the developing foetus or breastfeeding baby and that for women who are pregnant or planning a pregnancy, or breastfeeding, not drinking is the safest option.⁵
- 6.7 The Northern Territory (NT) Government notes that due to lack of information or education there continues to be a lack of understanding about the harm that can be caused by alcohol consumption during pregnancy.⁶
- 6.8 The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) express concern that one in five Australians continue to drink alcohol once their pregnancy is confirmed despite the fact that there is no known safe level of alcohol consumption in pregnancy.⁷
- 6.9 In this chapter, the reality of life with FASD in Australia is considered, with a focus on the difficulties with obtaining a diagnosis and the consequences of not recognising FASD as a disability.

Symptoms of FASD and FAS

- 6.10 FASD can be diagnosed with or without the recognisable characteristics of changed facial features, growth impairment and other defects. The children diagnosed with FAS and FASD have varying degrees of brain damage. The disabilities associated with FAS and FASD include behavioural disorders such as poor impulse control, developmental delay, impaired language and communication, and social and emotional development delays.⁸ The consistent feature of FAS and FASD is lifelong learning and behavioural impairment.⁹
- 6.11 Ninety per cent of adults with FAS demonstrate mental health problems, 60 per cent have trouble with the law and disrupted education, 40 per cent
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4 National Indigenous Drug and Alcohol Committee (NIDAC), *Submission 94*, p. 6.

5 NIDAC, *Submission 94*, p. 6; ADAC, *Submission 40*, p. 6.

6 NT Government, *Submission 60*, p. 18.

7 Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG), *Submission 66*, p. 2.

8 RANZCOG, *Submission 66*, p. 2.

9 Telethon Kids Institute, *Submission 74*, p. 3.

having substance abuse issues, and fewer than 10 per cent live or work independently by 21 years of age.¹⁰

- 6.12 The life of someone with FASD may also see them experiencing early life trauma and disadvantage in the early years, low socioeconomic status and welfare dependency, and exposure to household stressors including food insecurity, single parenthood, domestic violence, and mental health issues in a parent or carer.¹¹

Rates of FASD and FAS

- 6.13 FAS occurs across all cultures and socio-economic levels, and is not confined to Aboriginal and Torres Strait Islander people.¹² Aboriginal and Torres Strait Islander women are less likely to consume alcohol than non-Indigenous women but those who do are more likely to consume harmful amounts. The limited data suggests FAS is up to four times more prevalent in Aboriginal and Torres Strait Islander people at 2.767 to 4.75 per 1000 live births.¹³
- 6.14 NIDAC states that generally the expression of full FAS characteristics results from the consumption of large amounts of alcohol during pregnancy where there is a history of either chronic heavy alcohol use or frequent intermittent heavy alcohol use.¹⁴
- 6.15 The Lililwan Project Team reports that the main determinants of maternal alcohol consumption, are a lack of knowledge about harms to the fetus, stress, domestic violence, loss of land and culture, and unresolved historical trauma.¹⁵ Other determinants were identified as overcrowded living conditions, poor education and access to health care, unemployment, and exposure to violence and alcohol use in the home and community.¹⁶
- 6.16 Prevalence of FASD varies internationally. International data suggest that one to two per cent of the population in the US are affected by FASD. In Australia, it is most likely that FASD prevalence (0.68 per 1000 births) has been underestimated. Higher prevalence is observed in communities with high-risk drinking patterns.¹⁷

10 Telethon Kids Institute, *Submission 74*, p. 3.

11 Telethon Kids Institute, *Submission 74*, p. 3.

12 ADAC, *Submission 40*, p. 5.

13 RANZCOG, *Submission 66*, p. 2.

14 NIDAC, *Submission 94*, p. 6.

15 Lililwan Project Team, *Submission 90*, p. 3.

16 Lililwan Project Team, *Submission 90*, p. 3.

17 Telethon Kids Institute, *Submission 74*, p. 3.

- 6.17 The Foundation for Alcohol Research and Education (FARE) notes current Australian data that suggests prevalence rates for FAS, one of the conditions within the spectrum, in the Aboriginal and Torres Strait Islander population is between 2.8 and 4.7 per 1000 births.¹⁸
- 6.18 The Department of the Prime Minister and Cabinet (PM&C) notes that the community of Fitzroy Crossing Valley in WA was recently the focus of a prevalence study of FASD known as the Lililwan project, led by the George Institute for Global Health.¹⁹ The study looked at children living in the area born between 2002 and 2003, and the recently released data reported the rates of FAS (120 per 1000 children aged seven to nine) to be the highest in Australia and among the highest in the world.²⁰

Drinking alcohol when pregnant or breastfeeding

- 6.19 While Aboriginal and Torres Strait Islander women are less likely than men to consume alcohol at harmful levels, significant numbers of women continue to drink while they are pregnant or breastfeeding.
- 6.20 The Australian Institute of Health and Welfare (AIHW) notes that, in 2008, 3.3 per cent of mothers of Aboriginal and Torres Strait Islander children aged 0–3 years drank more or the same amount of alcohol during pregnancy, while 16.3 per cent drank less.²¹ There is no more recent data available.
- 6.21 It is likely that national statistics on maternal alcohol consumption mask more serious problems in certain communities, where harmful alcohol consumption is widespread. For example, it was reported that in Fitzroy Crossing, over 55 per cent of the mothers surveyed drank high levels of alcohol during their pregnancies.²²
- 6.22 Women who have an undiagnosed FASD may also be at significant risk of drinking when pregnant. Professor Elizabeth Elliot observes that, in some communities, there are generations of people with FASDs and that:

18 Foundation for Alcohol Research and Education (FARE), *Submission 83*, p. 25.

19 Department of Prime Minister and Cabinet (PM&C), *Submission 102*, p. 13.

20 PM&C, *Submission 102*, p. 13; Dale Owens, 'Nation's highest rate of fetal alcohol syndrome documented in WA's Fitzroy Valley', 19 January 2015, ABC News <http://www.abc.net.au/news/2015-01-16/fitzroy-valley-fetal-alcohol-research/6022430> viewed 10 June 2015; Telethon Kids Institute, 'Community is tackling FAS in the Fitzroy Valley', *Media Release*, 17 January 2015.

21 Australian Institute of Health and Welfare (AIHW), *Submission 19*, p. 5.

22 Professor Elizabeth Elliott, Paediatrician, Westmead Children's Hospital and the University of Sydney, *Committee Hansard*, Sydney, 5 September 2014, p. 2.

... some mothers who are giving birth to children with a foetal alcohol spectrum disorder may themselves have been damaged by alcohol in utero.²³

- 6.23 Education for women about the dangers of drinking when pregnant was emphasised during the inquiry.²⁴ FAS and FASD are 100 per cent preventable if the mother does not drink when pregnant. As well, it was found that there is little or no detox or support for pregnant women who try to reduce their alcohol consumption.

Conclusion

- 6.24 The committee is concerned that there continues to be such a low level of awareness of the harms caused by drinking when pregnant.
- 6.25 There has been little change in public awareness with the message from the National Health and Medical Research Council (NHMRC) Guidelines not being widely known or disseminated, especially by relevant health professionals.
- 6.26 The committee is concerned that popular magazines, such as the Women's Weekly²⁵, publish stories that give the impression that drinking during pregnancy is safe, even curative. The committee believes that promotion of such messages is irresponsible and misleading.
- 6.27 The committee is concerned that despite the several years since the release of the 2012 report *FASD: The Hidden Harm - Inquiry into the prevention, diagnosis and management of Fetal Alcohol Spectrum Disorders* by the House Standing Committee on Social Policy and Legal Affairs little has changed in relation to the promotion of the message that there is no safe level of alcohol consumption in pregnancy.
- 6.28 There needs to be a public awareness campaign, beyond the doctors surgery, that informs the wider community that women who are pregnant or planning to get pregnant or breastfeeding should not consume any alcohol for that time.

23 Professor Elliott, Westmead Children's Hospital and the University of Sydney, *Committee Hansard*, Sydney, 5 September 2014, p. 4.

24 See, for example: RANZCOG, *Submission 66*, p. 2; Lililwan Project Team, *Submission 90*, p. 7.

25 Australian Women's Weekly, February 2015.

Recommendation 16

- 6.29 That the Commonwealth, as a matter of urgency, increase its efforts to ensure that consistent messages:
- about the risks of consuming any alcohol during pregnancy, and
 - about the importance of supporting women to abstain from alcohol when planning pregnancy, when pregnant or breastfeeding
- to reduce the risk of Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorder are provided to the whole community.

FASD in Australia

- 6.30 Across Australia the awareness of FAS and FASD in the community and amongst health professionals continues to be low. Evidence received by the committee indicates that this lack of awareness has significant implications for those with FASD.²⁶
- 6.31 Lack of awareness extends from medical to educational, law and other professionals. The current prevalence rates are also thought to be greatly underestimated.²⁷
- 6.32 NIDAC highlight the lack of awareness and understanding of FASD within the Australian community. They state that there are many people still unaware of the risk to the fetus or baby if the mother consumes alcohol while pregnant or breastfeeding, particularly with low to medium levels of drinking or occasional or episodic use.²⁸
- 6.33 The Australian Human Rights Commission (AHRC) notes that many of the issues and difficulties that stand in the way of successful prevention and support programs stems from the lack of understanding of FASD.²⁹
- 6.34 FARE contends that there are significant gaps in awareness, knowledge, data, diagnosis and service delivery relating to FASD.³⁰

26 NIDAC, *Submission 94*, Attachment 2, p. 17.

27 NIDAC, *Submission 94*, Attachment 2, p. 9.

28 NIDAC, *Submission 94*, Attachment 2, p. 17.

29 Australian Human Rights Commission (AHRC), *Submission 31*, p. 7.

30 FARE, *Submission 83*, p. 30.

- 6.35 The Aboriginal Legal Rights Movement notes that information about the prevalence of FAS and FASD in Aboriginal and Torres Strait Islander communities may cause shame or distress to community members if the information from a particular community is made public.³¹ Other Aboriginal and Torres Strait Islander communities are making strenuous efforts, through music, art and dance, to highlight dangers to the unborn if drinking.
- 6.36 Research indicates that health professionals in particular do not have a high level of awareness of FASD. The most accurate data on awareness of the diagnostic criteria indicates that only 12 to 15 per cent of health professionals surveyed are aware of the four diagnostic features of FAS.³²
- 6.37 Ms Amanda Hand from the Gurriny Yealamucka Health Service explains that in Queensland, there has not been much training, nor is there a great understanding across the clinical population in both Aboriginal and Torres Strait Islander medical services and in the mainstream of the condition, the syndrome, the spectrum or of what therapies can be applied.³³
- 6.38 The Aboriginal Health Council of Western Australia (AHCWA) noted that as well as a lack of awareness of FASD, there is still reluctance from health professionals to address the issue of alcohol consumption:
- ... there are a number of practitioners who lack up to date information, who spread misinformation or who are reluctant to raise the topic of alcohol consumption with women who are pregnant or planning to become pregnant. This is a serious failing and is no doubt a major contributor to the lack of public awareness of the risks of FASD, and to the myths and the misinformation that currently exist across the wider community.³⁴
- 6.39 Mrs Catherine Crawford explains however that there is increasing awareness of FASD in practitioners in the Children's Court of Western Australia.³⁵ Broadly, however, she considers that there is awareness but no depth of knowledge.³⁶

31 Aboriginal Legal Rights Movement, *Submission 25*, p. 12.

32 Dr James Fitzpatrick, Paediatrician and Senior Clinical Research Fellow, Telethon Kids Institute, *Committee Hansard*, Perth, 30 June 2014, p. 40.

33 Ms Amanda Hand, Clinical Director, Gurriny Yealamucka Health Service, *Committee Hansard*, Cairns, 7 April 2015, p. 36.

34 Aboriginal Health Council of Western Australia (AHCWA), *Submission 69*, p. 39.

35 Ms Catherine Crawford, *Committee Hansard*, Perth, 30 June 2014, p. 55.

36 Ms Crawford, *Committee Hansard*, Perth, 30 June 2014, p. 55.

- 6.40 The Aboriginal Legal Service (NSW/ACT) states that there is little awareness of FASD as well as other disabilities in the criminal justice system.³⁷
- 6.41 Anyinginyi Health Aboriginal Corporation in Tennant Creek ran a FASD awareness program in town which they consider was highly successful. They note, however, that there are no pathways for diagnosis or treatment in their health system if FAS or FASD is suspected.³⁸

Diagnosis of FASD

- 6.42 It is very difficult to obtain a diagnosis of FASD in Australia. There are very few appropriately trained professionals, very few clinics and overall a lack of awareness in the health sector and the general community.
- 6.43 Ideally a diagnosis of FASD requires a multidisciplinary team which ideally comprises a paediatrician, psychologist, occupational therapist, speech pathologist, physiotherapist and social worker.³⁹
- 6.44 A diagnosis of FASD usually requires that significant impairment of three or more neurocognitive domains or two domains plus structural central nervous system abnormality.⁴⁰ Neurocognitive domains include cognition, memory, and executive function in planning and language for example.⁴¹
- 6.45 There are very few clinics in Australia that have formal diagnostic capacity. The committee was made aware of one at the Sydney Children's Hospitals Network (Westmead) and one at the Gold Coast Hospital and Health Service.
- 6.46 FARE consider that Australia lags well behind the rest of the world in preventing, diagnosing and managing FASD.⁴²
- 6.47 Ms Prue Walker contends that children with FASD/FAS are rarely diagnosed in Australia.⁴³
- 6.48 NIDAC asserts that early diagnosis and intervention is crucial in reducing or preventing secondary disability from FASD.⁴⁴ Secondary disability can include mental health problems, trouble with the law, dropping out of

37 Ms Sarah Crellin, Deputy Principal Legal Officer, Aboriginal Legal Service (NSW/ACT) Limited, *Committee Hansard*, Sydney, 5 September 2014, p. 23.

38 Mr Trevor Sanders, General Manager, Anyinginyi Health Aboriginal Corporation, *Committee Hansard*, Tennant Creek, 1 April 2014, p. 16.

39 Telethon Kids Institute, *Submission 74*, p. 3.

40 Telethon Kids Institute, *Submission 74*, p. 3.

41 Dr Fitzpatrick, Telethon Kids Institute, *Committee Hansard*, Perth, 30 June 2014, p. 43.

42 FARE, *Submission 83*, p. 28.

43 Ms Prue Walker, *Submission 86*, p. 11.

44 NIDAC, *Submission 94*, Attachment 2, p. 11.

school, becoming unemployed, homeless and having unwanted pregnancies or developing alcohol and drug problems.

- 6.49 The Commonwealth Government has funded a development of a FASD diagnostic tool for specialist clinicians and resources to support diagnosis and early management of FASD as part of the *Responding to the Impact of Fetal Alcohol Spectrum Disorders in Australia – A Commonwealth Action Plan*.⁴⁵
- 6.50 The diagnostic tool is currently being prepared for use, with training for health professionals and an implementation plan being developed.⁴⁶

Training clinicians

- 6.51 A critical factor in the diagnosis of FASD is access to trained clinicians who are able to perform a diagnosis.
- 6.52 Dr Doug Shelton contends that FASD training for clinicians in Australia is poor or non-existent.⁴⁷
- 6.53 Professor Elizabeth Elliott notes that as a professor of paediatrics she has been including FASD in the curriculum at Sydney Medical School. She adds that FASD teaching was being poorly addressed throughout the curricula and that she has been encouraging deans of medical schools to incorporate it into their curriculum.⁴⁸
- 6.54 The Royal Australasian College of Physicians (RACP) have been asked to include FASD as one of the continuing professional education modules. There is also an educational module available through the RACP website for paediatricians which includes sections on FASD.⁴⁹
- 6.55 Gurriny Yealamucka Health Service commends local paediatricians who work in their service but they assert that good training of clinicians is required to ensure that they are appropriately recognising the condition and diagnosing to enable support.⁵⁰
- 6.56 BushMob note that there is no relevant FASD training in the Northern Territory to help them manage the high percentage of their clients

45 Details of the plan can be found at www.health.gov.au

46 Ms Heather Jones, Manager, FASD Projects, Telethon Kids Institute, *Committee Hansard*, Perth, 30 June 2014, p. 40.

47 Dr Doug Shelton, *Submission 117*, p. 1.

48 Professor Elliott, Westmead Children's Hospital and the University of Sydney, *Committee Hansard*, Sydney, 5 September 2015, p. 1.

49 Professor Elliott, Westmead Children's Hospital and the University of Sydney, *Committee Hansard*, Sydney, 5 September 2015, p. 1.

50 Ms Hand, Gurriny Yealamucka Health Service, *Committee Hansard*, Cairns, 17 February 2015, p. 36.

suspected to have FASD, other than word of mouth and through the internet.⁵¹

- 6.57 Dr James Fitzpatrick recommends an approach which trains clinicians as well as approaching the major colleges and mandating that FAS and FASD training become part of their curriculum.⁵²

Conclusion

- 6.58 The committee is concerned that there is still a low level of awareness of FASD by health professionals and the wider community, despite a National Strategy now in its second year of implementation.
- 6.59 Despite the excellent work of several medical institutions who are committed to raising the profile of FASD in Australia, it is almost impossible for most parents and carers to obtain a diagnosis or support if FAS or FASD is present.
- 6.60 The fact that FASD is still being poorly addressed in medical school curriculums means that the issue is unlikely to be resolved soon. The committee believes that all medical students need to be aware of the impacts of alcohol exposure on the fetus and have an understanding of the condition to ensure that early diagnoses are made.
- 6.61 The committee considers it necessary for all health professionals to have an awareness of FAS and FASD.
- 6.62 Although there has been some progress with the Australian diagnostic tool, the committee is concerned that the rollout and evaluation has been subject to ongoing delays which has meant that it is still not available for health professionals to use.
- 6.63 The launch of the 2014 FASD Action Plan in July 2014 was a good first step but the committee is concerned that the Action Plan does not address all the key recommendations of the 2012 report *FASD: The Hidden Harm - Inquiry into the prevention, diagnosis and management of Fetal Alcohol Spectrum Disorders* by the House Standing Committee on Social Policy and Legal Affairs, in particular the need for prevention strategies that will provide information and education programs and support for pregnant women with drinking problems.

51 BushMob, *Submission 12*, p. 1.

52 Dr Fitzpatrick, Telethon Kids Institute, *Committee Hansard*, Perth, 30 June 2014, p. 40.

- 6.64 The committee sees that awareness of FASD must be raised, particularly with health professionals, the criminal justice system and in the wider community.
- 6.65 The committee believes that one of the best ways to ensure this is to release the diagnostic tool as soon as possible and ensure that its promotion and use is appropriately resourced.

Recommendation 17

That the Commonwealth, as a priority, ensure that the National FASD Diagnostic Tool and accompanying resource are released without any further delays.

Life for those with FASD

- 6.66 The physical and psychological wellbeing of individuals who have to live with FASD is made more difficult without early diagnosis and treatment. They will experience serious and life-long problems due to the complex behavioural, cognitive, physical and psychological impairments.⁵³
- 6.67 Individuals with FASD and FAS can have a range of needs and require a variety of intensive support throughout their life. The National Aboriginal and Torres Strait Islander Legal Services and the Human Rights Law Centre describe the all-encompassing role of caring for children and adults with FASD, as well as the significant financial cost of early intervention strategies.⁵⁴
- 6.68 National Congress of Australia's First Peoples note that FASD is a permanent, incurable, life-long condition which impacts on the individual's capacity to learn, justice and other services which in turn affects their carers in the community.⁵⁵

53 Synapse, *Submission 41*, p. 3.

54 National Aboriginal and Torres Strait Islander Legal Services and the Human Rights Law Centre, *Submission 58*, p. 15.

55 National Congress of Australia's First Peoples, *Submission 97*, p. 15.

- 6.69 AHCWA considers that FAS and FASD are now an intergenerational issue, which needs to be addressed using a whole of community approach.⁵⁶
- 6.70 As FAS and FASD are not officially recognised as a disability and are not easily diagnosed in Australia, there is no support specifically offered or designed to meet the needs of individuals with FAS or FASD.⁵⁷
- 6.71 Ms Walker notes that across the FASD spectrum there is a variety of presentations. She explains that some individuals may have an IQ over 70, while others have a significant intellectual disability. Additionally some individuals have clear neurological symptoms and delayed development, while others may only display difficulties when more advanced cognitive functions are required – such as making safe choices.⁵⁸
- 6.72 FARE highlight that difficulties in achieving a diagnosis mean it is a struggle to access disability support services and funding from social services, education and training systems, justice and health agencies.⁵⁹
- 6.73 BushMob, a group in Alice Springs who work with young people who are affected by alcohol and drugs note:
- All the young people who enter Bushmob are complex high needs clients with significant primary health care issues. We estimate that 30 per cent of our clients are affected by Fetal Alcohol Spectrum Disorder (FASD) issues.⁶⁰
- 6.74 The Aboriginal Drug and Alcohol Council (SA) Inc. (ADAC) are concerned that people affected by FASD, who do not have the appropriate support, are at a high risk of developing secondary disabilities. ADAC note that this can result in significant costs to society the individual. Victims of FAS and FASD are estimated to be significantly overrepresented in prison populations.⁶¹
- 6.75 Synapse are concerned that people with FASD remain undiagnosed despite 40 years of reliable evidence.⁶² Synapse states that people with FASD have been misunderstood and not well served by the disability, education and criminal justice sector.⁶³

56 AHCWA, *Submission 69*, p. 37.

57 Ms Prue Walker, *Submission 86*, p. 12.

58 Ms Prue Walker, *Submission 86*, p. 12.

59 FARE, *Submission 83*, p. 29.

60 BushMob, *Submission 12*, p. 1.

61 ADAC, *Submission 40*, Attachment 5, p. 1.

62 Synapse, *Submission 41*, p. 3.

63 Synapse, *Submission 41*, p. 3.

FASD as a recognised disability

- 6.76 The overwhelming evidence suggests that FASD needs to be an officially recognised disability. Access to better support and funding, carer support, recognition by education and criminal justice systems and the community would then follow.
- 6.77 Professor Conigrave, Dr Lee and Mr Jack believe the result of this recognition would be:
- ... greater support for carers of children with FAS and FASD, improved detection and early intervention for individuals suffering FASD, and encourage more compassionate handling of offenders with FASD by the justice system.⁶⁴
- 6.78 FARE considers that FASD needs greater recognition in the social security system. They propose that:
- FASD should be recognised as a cognitive impairment to allow access to support services⁶⁵
 - FASD should be included in the Impairment Tables for disability support pensions, acknowledged in the NDIS and included in the list of recognised disabilities for carer payments,⁶⁶ and
 - FASD should be included in the Better Start for Children with a Disability initiative.⁶⁷
- 6.79 FARE also explains that declaring FASD a disability will enable it to be included in disability policy and services development and reform in accordance with the Convention on the Rights of Persons with Disabilities.⁶⁸
- 6.80 AHCWA asserts that the government needs to recognise FASD as a disability to ensure that parents and carers are given the same support and recognition as others with children with disabilities.⁶⁹
- 6.81 CAALAS argue that best argument for declaring FAS and FASD as disabilities is that children with FAS or a FASD might be identified earlier

64 Professor Kate Conigrave, Dr Kylie Lee and Mr Peter Jack, University of Sydney, Discipline of Addiction Medicine, *Submission 38*, p. 6.

65 FARE, *Submission 83*, p. 9.

66 FARE, *Submission 83*, p. 9.

67 FARE, *Submission 83*, p. 28.

68 Synapse, *Submission 41*, p. 3.

69 AHCWA, *Submission 69*, p. 40.

and might be given the support they need to avoid contact with the criminal justice system.⁷⁰

- 6.82 The Lililwan Project consider the implications of declaring FASD as a disability would include:
- better support for families and caregivers
 - better access to educational and health supports, and
 - better understanding of the capabilities of individuals with FASD and their ability to function normally and negotiate the justice and education systems.⁷¹
- 6.83 St Vincent's Alcohol and Drug Service consider that declaring FAS and FASD as disabilities is one step towards ensuring people with these conditions get the adequate care and support necessary.⁷²

Accessing support

- 6.84 Although there is a list of recognised disabilities which provide fast-track qualification for the Carer Allowance for children, FAS or FASD are not included on this list.⁷³ Other spectrum disorders however such as Autism Spectrum Disorder and Autistic Disorder or Asperger's Disorder are included on this list.⁷⁴ There is evidence that children are given these diagnoses in order that some support is then forth coming.
- 6.85 The Law Society of the Northern Territory, in answer to the concern that FASD is difficult to define being a spectrum disorder, notes that Asperger's is also a spectrum disorder which is a recognised disability.⁷⁵
- 6.86 FARE is concerned that the use of the Impairment Tables for accessing the Disability Support Pension may mean that people with FASD who may have an IQ above 70, may not meet the criteria for Table 9 Intellectual function and could be assessed under Table 7 Brain Function.⁷⁶ The brain damage in FAS and FASD victims is cognitive rather than intellectual.
- 6.87 PM&C note that the Impairment Tables cover both intellectual and cognitive impairment.⁷⁷
- 6.88 In some cases the Impairment Tables also list examples of conditions that can be assessed with over 70 IQ, for example Table 7 Brain Function states:

70 Central Australian Aboriginal Legal Aid Services (CAALAS), *Submission 56*, p. 11.

71 Lililwan Project Team, *Submission 90*, p. 9.

72 The Alcohol & Drug Service, St Vincent's Hospital, Sydney, *Submission 63*, p. 13.

73 See www.dss.gov.au Guide to the List of Recognised Disabilities viewed on 20 May 2015.

74 See www.dss.gov.au Guide to the List of Recognised Disabilities viewed on 20 May 2015.

75 Law Society of the Northern Territory, *Submission 89*, p. 11.

76 FARE, *Submission 83*, p. 29.

77 PM&C, *Submission 102.1*, Answer to Question on Notice, p. 3.

A person with Autism Spectrum Disorder who does not have a low IQ should be assessed under this Table.⁷⁸

- 6.89 Ms Cregan explains that a barrier to recognition of FASD is that much of the law and policy has developed around the needs of people with mental illness or intellectual disability but people with cognitive disorders such as FASD are at greater risk of not receiving help.⁷⁹
- 6.90 She notes that use of terms such as mental impairment, intellectual impairment, cognitive disorder or disorder of the mind in criteria to access services can be confusing.
- 6.91 Ms Cregan notes that there are no definitions for these terms in legislation or supporting documents. This may mean a decision on whether a person can receive funding for services is left to the interpretation of such terms by an official who is assessing a claim without the formality of a diagnosis.⁸⁰
- 6.92 Ms Laura Lombardo suggests that a model definition of cognitive impairment be developed which is inclusive of all forms of disability arising from impairment of the brain.⁸¹ This could serve all Commonwealth and state and territory law and policy.
- 6.93 Ms Lombardo proposes a review of Commonwealth law and policy to identify where eligibility criteria need to change to ensure that people with FASD and other cognitive impairment are included.⁸²

FASD support

- 6.94 NIDAC believes eligibility for government-funded support and services should include criteria that reflect the functional and behavioural deficits of developmental disorders like FASD.⁸³
- 6.95 Synapse identifies the support needed for those people with FASD:
- Interventions should be centred on a neurobehavioural accommodation model with a comprehensive, intrasectoral model of care and support. This will include well resourced, evidence based and culturally appropriate prevention and early intervention strategies as well ongoing, highly specialised co-

78 *Social Security (Tables for the Assessment of Work-related Impairment for Disability Support Pension) Determination 2011*

79 Ms Anne Cregan, *Committee Hansard*, Sydney, 5 September 2014, p. 56.

80 Ms Cregan, *Committee Hansard*, Sydney, 5 September 2014, p. 56.

81 Ms Laura Lombardo, Pro-bono coordinator and Senior Associate, Ashurst Australia, *Committee Hansard*, Sydney, 5 September 2014, p. 57.

82 Ms Lombardo, Ashurst Australia, *Committee Hansard*, Sydney, 5 September 2014, p. 57.

83 NIDAC, *Submission 94*, Attachment 2, p. 19.

ordinated support services in areas including health, housing, employment and justice.⁸⁴

- 6.96 The AHRC proposes that a ‘social model’ of disability be adopted as a response to FASD.⁸⁵ This recognises that disability is an evolving concept and requires early access to services as well as recognising the interactions between the impairment and the environment and attitudinal barriers that hinder full participation.⁸⁶
- 6.97 St Vincent’s Alcohol and Drug Service believes that prevention, screening and early detection, and access to appropriate intervention are crucial to responding to FAS and FASD and to minimising the complex problem behaviour, neurodevelopment and intergenerational impacts of FAS and FASD.⁸⁷
- 6.98 The New South Wales Government notes that there needs to be access to culturally appropriate support particularly for Aboriginal and Torres Strait Islander women and children with the condition.⁸⁸

Early intervention

- 6.99 There is evidence that screening and early intervention for children suspected of having FASD can make a significant difference to their life-long outcomes.⁸⁹
- 6.100 Dr Fitzpatrick made an important observation about the nature of conditions included on funding lists such as Better Start:
- The Better Start funding list includes cerebral palsy, because it has been shown that therapy for children with cerebral palsy improves their outcomes. But most children with cerebral palsy have an IQ above 70. The list also includes Fragile X syndrome, Rett syndrome and other syndromes that can be seen as quite obscure but have made their way onto the list because it has been showed that therapeutic intervention improves long-term outcomes.⁹⁰
- 6.101 Dr Fitzpatrick argues that FASD should also be included on the Better Start funding list since, similar to the conditions on the list, it has a

84 Synapse, *Submission 41*, p. [5].

85 AHRC, *Submission 31*, p. 8.

86 AHRC, *Submission 31*, p. 8.

87 The Alcohol & Drug Service, St Vincent’s Hospital, Sydney, *Submission 63*, p. 13.

88 NSW Government, *Submission 62*, p. 8.

89 Victorian Aboriginal Community Controlled Health Organisation (VACCHO), *Submission 33*, p. [5]

90 Dr Fitzpatrick, Telethon Kids Institute, *Committee Hansard*, Perth, 30 June 2014, p. 43.

- rigorous diagnostic process and therapeutic intervention will improve long-term outcomes.⁹¹
- 6.102 FARE support this, noting that there needs to be funding support for parents and foster carers to support those who care for people with FASD.⁹²
- 6.103 Ms Walker recommends that specific behavioural management services be provided for families and carers of children with FASD given traditional parenting interventions often do not work due to the specific nature of the brain injury.⁹³
- 6.104 Telethon Kids Institute notes that NDIS operational guidelines for therapy support estimate that \$12,000-\$16,000 in therapy per annum would be required to provide early intervention support for a child aged 0-6 years. With FASD diagnosis is often delayed, so it is important that any disability support funding should extend eligibility age to 8-10 years.⁹⁴
- 6.105 FAS is included in the Operational Guidelines for the National Disability Insurance Agency (NDIA), however, FASD is not.⁹⁵ PM&C note that further consideration to include FASD in the NDIA's Operational Guidelines should occur once the diagnostic tool and clinical guidelines have been finalised and approved and there is sufficient data about the needs of FASD participants and carers.⁹⁶
- 6.106 In Tennant Creek, the Anyinginyi Aboriginal Health Centre describe what happens when awareness of FASD is raised in the community:
- One of the good things, to us, is that we now get ladies coming into our health centre saying, 'I think my child has FASD,' which shows the awareness is there.⁹⁷
- 6.107 They note that diagnosis is not the only answer if there is no follow-up support:
- Then it leads us to, 'Where to from here?' What we need here is an early intervention service. We do not have a visiting paediatrician. We do not have visiting speech therapists, OTs, psychologists and all the rest. Asking 'where to from here?' is the next step.

91 Dr Fitzpatrick, Telethon Kids Institute, *Committee Hansard*, Perth, 30 June 2014, p. 43.

92 FARE, *Submission 83*, p. 9.

93 Ms Prue Walker, *Submission 86*, p. 35.

94 Telethon Kids Institute, *Submission 74*, p. 4.

95 PM&C, *Submission 102.1*, Answer to Question on Notice, p. 5.

96 PM&C, *Submission 102.1*, Answer to Question on Notice, p. 5.

97 Mr Sanders, Anyinginyi Health Aboriginal Corporation, *Committee Hansard*, Tennant Creek, 1 April 2014, p. 16.

Someone – not us – needs to develop the clinical pathways and tell us what best practice is so that we can follow it.⁹⁸

6.108 CAAPU make the point that early diagnosis and intervention can also lead to better informed parents and may help prevent further alcohol affected children being born in the family.⁹⁹

6.109 Dr James Fitzpatrick described his experience in Western Australia:

The most powerful thing about diagnosis – and this has been the experience in North America – is that it drives prevention, because the people say, 'Ah, these problems are probably related to alcohol exposure in pregnancy, so we had better not do that next time.'¹⁰⁰

Education and FAS - FASD

6.110 Children and young people with FASD have specific educational requirements and behaviours which need to be taken into account in educational planning.

6.111 There is a call for the development and support of programs that address how best to educate children in the classroom with FASD, while minimising disruption to other students, including support for the training of special education teachers.¹⁰¹

6.112 Groups such as the Lililwan Project Team found that alternative pathways for children who have FASD should be considered. These pathways should focus on the children's capacities as well as their needs.¹⁰²

6.113 Professor Langton, Ms Smith and Dr Chenhall recommend that the number of special needs teachers should be assessed to meet the education requirements of children who have behavioural issues, including FASD-related conditions.¹⁰³

6.114 Aboriginal Peak Organisations of the Northern Territory (APO NT) note that there is little intensive school or learning support for children with FASD in remote communities.¹⁰⁴

98 Mr Sanders, Anyinginyi Health Aboriginal Corporation, *Committee Hansard*, Tennant Creek, 1 April 2014, p. 16.

99 Central Australian Aboriginal Alcohol Programmes Unit (CAAAPU), *Submission 73*, p. [11].

100 Dr Fitzpatrick, Telethon Kids Institute, *Committee Hansard*, Perth, 30 June 2014, p. 45.

101 Professor Langton, Dr Chenhall, Ms Smith, *Submission 44*, p. 6.

102 Lililwan Project Team, *Submission 90*, p. 8.

103 Professor Langton, Dr Chenhall, Ms Smith, *Submission 44*, p. 6.

104 Aboriginal Peak Organisations of the Northern Territory (APO NT), *Submission 72*, Attachment 4, p. 17.

Conclusion

6.115 The committee heard of the importance of schools and education systems being aware of FAS and FASD and having the appropriate level of training for staff. The specific requirements of children with FAS and FASD require a level of understanding from the education system about the best way forward.

Recommendation 18

6.116 **That states' and territories' teacher training, education and in-service systems provide:**

- **information and education on alcohol and drug exposed children's behaviour, and**
- **details of the impact on the child's mental health and their achievement at school.**

6.117 The official recognition of FASD as a disability is not the only solution, however it would ensure that parents and carers of children who have FAS and FASD would more easily be able to access early intervention and support that is so necessary to reduce secondary disabilities.

6.118 Prevention of the condition is the key, however, screening and early detection, as well as access to appropriate interventions are critical for minimising the complex anti-social behaviour, neurodevelopment and intergenerational impacts of FAS/FASD.

6.119 The value of early intervention cannot be underestimated. The committee took evidence about how therapeutic intervention can make a significant difference in the life of a child with FASD.

6.120 The committee recommends parents and carers should easily be able to access the most appropriate early intervention for FASD. The committee is concerned about the experience of people in Tennant Creek who have awareness of FASD in their community but do not have the intervention services needed.

6.121 FASD is not included in the Operational Guidelines for the NDIA. The committee was told it may be included in the future, following the introduction of the diagnostic tool and collection of data on FASD participants. However, the committee believes there is sufficient data on FASD prevalence internationally and now in Fitzroy Crossing WA to

ensure that Australia does not need to further delay critical early intervention for individuals with FASD.

- 6.122 The committee argues that the Commonwealth should ensure that FASD is included in the Operational Guidelines for the NDIA as soon as possible.

Recommendation 19

6.123 **That the Commonwealth:**

- **include FAS and FASD as recognised disabilities for Carer's allowance to allow fast-tracking of the application**
- **include FAS and FASD as a recognised disabilities in the Better Start for Children with a Disability initiative, and**
- **include FASD in the operational Guidelines for the National Disability Insurance Agency.**

Out of home care

- 6.124 International data suggests that up to 25 per cent of children in foster care may have FASD.¹⁰⁵
- 6.125 Ms Catherine Crawford asserts that children with FASD are overrepresented in foster care and group care systems.¹⁰⁶ She adds that there may have been a number of placements of children with untrained caregivers.¹⁰⁷
- 6.126 Foster carers may not suspect FASD is affecting infants, as it may not be apparent for some time that a child is not meeting developmental milestones and the alcohol consumption of the mother when pregnant is not disclosed. This can impact on joining waiting lists and accessing services.¹⁰⁸
- 6.127 If a child is in kinship care, the carers may not be experienced in identifying development delays and FASD may be considered too stigmatising to suggest to other carers.¹⁰⁹

105 Ms Jones, Telethon Kids Institute, *Committee Hansard*, Perth, 30 June 2014, p. 39.

106 Ms Catherine Crawford, *Submission 103*, p. 3.

107 Ms Catherine Crawford, *Submission 103*, p. 3.

108 Ms Prue Walker, *Submission 86*, p. 16.

109 Ms Prue Walker, *Submission 86*, p. 16.

- 6.128 Ms Walker notes that changes and transitions can be difficult for children with FASD. Each time there is a movement between the family of origin, kinship care and foster care, there may be a change in culture, language and location.¹¹⁰
- 6.129 Ms Walker described the dichotomy of home and foster care for Aboriginal and Torres Strait Islander children. The connection with family is critical but can have effects on overall behaviour. She explains:
- When a child with FASD goes into foster care, after a time they will settle down. Then they will have contact with their family and the carer will come back and say they are unmanageable – they have gone back six months in their behaviours. What do we do with that?¹¹¹
- 6.130 It is clear that the foster system and kinship caring is often reduced to crisis managing when trying to parent children with FAS and FASD, with little or no support.

FAS and FASD and the Criminal Justice system

- 6.131 It is widely recognised that FASD is a significant problem in the criminal justice system.
- 6.132 There is a strong link between FAS and FASD and contact with the criminal justice system.¹¹² This link is often not officially recognised, however, as CAALAS states:
- ... it is still quite rare for us to see a client with a formal diagnosis.¹¹³
- 6.133 Ms Catherine Crawford asserts that the failure to diagnose FASD in a young person involved in the criminal justice system has unintended and far-reaching consequences:
- ... causes injustice to the individual young person and exposes the family and community to a repetition of that unlawful behaviour and indeed, likely escalation of the offending, as the young person grows physically, suffers secondary disabilities and those dealing with the young person are unable to handle the behaviours.¹¹⁴
- 6.134 Synapse notes that FASD manifests in a range of difficulties, including:
- being able to link actions to consequences

110 Ms Prue Walker, *Submission 86*, p. 17.

111 Ms Prue Walker, *Committee Hansard*, Melbourne, 30 May 2014, p. 43.

112 CAALAS, *Submission 56*, p. 2.

113 CAALAS, *Submission 56*, p. 2.

114 Ms Catherine Crawford, *Submission 103*, p. 1.

- controlling impulses, and
 - being easily led.¹¹⁵
- 6.135 Synapse added that many become involved in the juvenile justice system and ultimately the adult criminal justice system. They are concerned that this is often a cyclical and transgenerational phenomenon which culminates in the onset of chronic disease and poor mental health including high incidence of self-harm and suicide.¹¹⁶
- 6.136 NIDAC states that people with FASD often have poor memory and can be highly suggestible. This suggestibility makes them an unreliable witness or mean they provide inaccurate information when being questioned by police.¹¹⁷
- 6.137 Ms Cregan notes that a person with an intellectual disability or mental illness is more likely to have their disability taken into account in determining their culpability or in sentencing, than a person with FASD who has cognitive impairment.¹¹⁸
- 6.138 FASD brain damage or impairment to cognitive function may be such that the person is not fit to plead. The general assumption, is that a person is fit to plead unless found otherwise by a court. Evidence needs to be provided by a suitably qualified expert based on set criteria.¹¹⁹ This is almost impossible to obtain for those suspected of having FASD in remote Australia.
- 6.139 Currently in Western Australia, there are no means for obtaining a diagnosis of FASD for a youth involved in the criminal justice system. A report from a psychiatrist or neuropsychologist may report that there are signs consistent with FASD but that does not constitute a diagnosis.¹²⁰
- 6.140 If an individual pleads guilty to one or more offences they must be sentenced and unless there is evidence, the court is unable to take into account that the individual has FASD when sentencing.¹²¹
- 6.141 Ms Crawford asserts:
- Diagnosis is the gateway for a court to consider FASD as a mitigating factor for sentencing purposes.¹²²
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115 Synapse, *Submission 41*, p. [3].

116 Synapse, *Submission 41*, p. [3].

117 NIDAC, *Submission 94*, Attachment 2, p. 10.

118 Ms Cregan, *Committee Hansard*, Sydney, 5 September 2014, p. 56

119 Ms Catherine Crawford, *Submission 103*, p. 4.

120 Ms Catherine Crawford, *Submission 103*, pp. 4–5.

121 Ms Catherine Crawford, *Submission 103*, p. 4.

122 Ms Catherine Crawford, *Submission 103*, p. 5.

- 6.142 She notes that without a diagnosis, a youth affected with FASD will be treated as a fully-functional individual who has made choices about their behaviour, understands the consequences of their actions and can learn from their mistakes.¹²³ This is not the case with a victim of FAS or FASD.
- 6.143 Professor Douglas highlights that diagnoses costs and who pays for it as well as the lack of suitable diagnostic facilities for youths in juvenile detention or adults is a major problem.¹²⁴
- 6.144 Without the recognition of FASD as a disability Professor Douglas considers little will change:
- It is a bit of a double-edged sword: until you start recognising it in formal situations as a disability, things grow – it is part of a chicken-or-egg question really.¹²⁵
- 6.145 She added:
- ... the literature in Canada and the US tells us that the best way to help kids avoid criminal justice is through diagnosis and support.¹²⁶

Conclusion

- 6.146 There was significant evidence throughout the inquiry that making FASD a recognised disability is a necessary step in order that supports are provided, and unfair treatment of sufferers is avoided.
- 6.147 The committee heard how important it is that FASD is recognised as a disability in the social security system.
- 6.148 There was evidence that when the education and criminal justice systems cannot take FASD into account because there is no official diagnosis of a recognised disability, the individual is severely disadvantaged. The requirements for FASD to be considered in the courts are quite stringent and without a diagnosis, FASD cannot be seen to be a mitigating factor in the persons defence.
- 6.149 The benefits to be gained in recognising FASD as a disability are too great to continue to overlook. It is also a human rights issue.
- 6.150 The Commonwealth should include FASD as a recognised disability for Carer's allowance and Best Start as soon as possible.

123 Ms Catherine Crawford, *Submission 103*, p. 5.

124 Professor Heather Douglas, *Committee Hansard*, Brisbane, 20 June 2014, p. 22.

125 Professor Douglas, *Committee Hansard*, Brisbane, 20 June 2014, p. 22.

126 Professor Douglas, *Committee Hansard*, Brisbane, 20 June 2014, p. 23.

- 6.151 Including FASD as an example on the Impairment Tables for the Disability Support Pension would be a simple step in providing a guide for how the Impairment Tables could be best used to assess an individual who has the condition. This would streamline assistance for those with FASD and their carers.

Recommendation 20

- 6.152 **That the Commonwealth, in consultation with the FASD Technical Network, include in the appropriate table in the Social Security Tables for the Assessment of Work-related Impairment for Disability Support Pension Determination 2011:**
- **A person with Fetal Alcohol Spectrum Disorder who does not have an IQ below 80 should be assessed under this Table.**

Recommendation 21

- 6.153 **That the Commonwealth, in consultation with the FASD Technical Network, and relevant organisations from the criminal justice system:**
- **develop a model definition for cognitive impairment, and**
 - **conduct a review of Commonwealth law and policy to identify where eligibility criteria need to change to ensure that people with FAS and FASD and other cognitive impairments can be included.**