The Senate

Community Affairs References Committee

Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

March 2021

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Table of Contents

Terms of Reference

Effective approaches to prevention and diagnosis of FASD, strategies for optimising life outcomes for people with FASD and supporting carers, and the prevalence and management of FASD, including in vulnerable populations, in the education system, and in the criminal justice system – with particular reference to:

(a) the level of community awareness of risks of alcohol consumption during pregnancy;

(b) the adequacy of the health advice provided to women planning a pregnancy, pregnant women and women who are breastfeeding, about the risks of alcohol consumption;

(c) barriers that may prevent women receiving accurate, timely and culturally/ethnically appropriate information and advice on alcohol and pregnancy;

(d) provision of diagnostic services in Australia including capacity, training, integration and diagnostic models in current use;

(e) the prevalence and nature of co-occurring conditions and of misdiagnosis of FASD;

(f) international best practice in preventing, diagnosing and managing FASD;

(g) awareness of FASD in schools, and the effectiveness of systems to identify and support affected students;

(h) the prevalence of, and approaches to, FASD in vulnerable populations, including children in foster and state care, migrant communities and Indigenous communities;

(i) the recognition of, and approaches to, FASD in the criminal justice system and adequacy of rehabilitation responses;

(j) the social and economic costs of FASD in Australia, including health, education, welfare and criminal justice;

(k) access, availability and adequacy of FASD support available through the National Disability Insurance Scheme, including access to effective and early intervention services for individuals diagnosed with FASD;

(l) support for adults with FASD and for parents and carers of children with FASD;

(m) progress on outstanding recommendations of the House of Representatives Standing Committee on Social Policy and Legal Affairs report, FASD: The Hidden Harm, tabled on 29 November 2012;

(n) the effectiveness of the National FASD Action Plan 2018-2028, including gaps in ensuring a nationally co-ordinated response and adequacy of funding;

(o) the need for improved perinatal data collection and statistical reporting on FASD and maternal drinking; and

(p) any other related matters.

Executive Summary

Fetal Alcohol Spectrum Disorder (FASD) is an entirely preventable permanent disability. FASD includes a range of physical and neurological impairments, occurring due to brain damage caused by exposing a fetus to alcohol during pregnancy. As a spectrum disorder, FASD manifests in a range of ways, and conditions can range from very mild to severe.

An invisible epidemic

The committee found that FASD is still not well understood or recognised in Australia and has been called an 'invisible epidemic'. Although there is an absence of reliable prevalence figures and the social and economic costs remain unknown, the evidence indicates that the human, social and economic costs are immense. The committee considers there is a critical need for prevalence data and a robust study of the economic and social impact of FASD to ensure budgetary measures and policy efforts are appropriate and effective.

Alcohol and pregnancy

There is no safe level of alcohol that can be consumed during pregnancy. Unfortunately, Australia has one of the highest rates of maternal alcohol consumption in the world. Myths regarding the 'safe' use of alcohol during pregnancy have been perpetuated in the community, including by health professionals, and the alcohol industry.

Prevention

Prevention efforts must fundamentally aim to shift societal attitudes and behaviour around alcohol consumption in the broader Australian community. The Australian Government's announcement during this inquiry of funding for three years for a national education campaign is welcome. Given the scale of the task, the committee recommends a longer-term strategy and funding for FASD awareness and education, including in secondary school curriculums. The announcement of mandatory pregnancy warning labels on all alcohol products and packaging during this inquiry was a long time coming. The committee urges alcohol companies to promptly implement the mandatory labels before the deadline in July 2023.

Health professionals

Health professionals play a key role in prevention, diagnosis and support for people with FASD and their families. Interactions with pregnant women and women of child-bearing age provide opportunities to educate women and their partners of the risks of maternal alcohol consumption and influence behaviour change. However, for a range of reasons including stigma and a lack of understanding, health professionals do not always discuss alcohol with women or provide accurate advice or referrals. The committee is of the view that building the capacity of health

professionals to identify and prevent harmful alcohol consumption during pregnancy should be prioritised.

Diagnosis

FASD is often not identified early in life, if at all, and as a result many people do not receive recognition of their disability or access to support. Diagnosing FASD is complex and involves a multi-disciplinary team. The committee heard that there are limited multi-disciplinary FASD diagnostic services in Australia and wait lists are long. There is a clear need to ensure FASD diagnosis is more widely available across Australia. This includes building and training the health workforce involved in FASD diagnosis and exploring alternative models of assessment and the use of technology.

Support and assistance

Supports for a person with FASD will be necessary over the entire course of their life. Unfortunately, support services in Australia are limited and can be cost prohibitive. Throughout the inquiry, the committee was made aware of the difficulties accessing support through the education system, National Disability Insurance Scheme (NDIS) and social security system. The committee agrees with submitters that FASD must be specifically recognised as a disability by the Australian Government and the social security system. Access to assistance must be urgently improved to help people with FASD and their families to meet the extensive costs of FASD supports. The committee was moved by the challenges faced by parents and carers of children with FASD, pointing to the need for improved access to practical parenting programs, and for carers, more assistance from State and Territory child protection authorities.

Child Protection and justice systems

The committee heard that there is a high prevalence of FASD amongst children in contact with the child protection and justice systems, and that these children face further barriers to diagnosis and support. The committee considers that there should be routine screening for FASD within the youth justice and child protection systems. It is apparent that traditional approaches to justice are not adequate for people with FASD, and those working in the justice system need further training in FASD, and diversion programs and therapeutic models of detention must be further explored and expanded.

First Nations communities

Alcohol-related harm in First Nations communities is strongly linked to the impacts of colonisation, entrenched poverty and inter-generational trauma. The committee recognises the importance of a community-led approaches and was impressed by the initiatives of First Nations communities to prevent and manage FASD. The committee considers that the Australian Government must provide adequate and

longer-term investment for these projects and future proposals for holistic and community-led approaches

Conclusion

The committee received a wealth of information and evidence throughout the inquiry and thanks all those who participated, especially those with lived experience who had the courage to share their experiences and knowledge with the committee. As a result, the committee has made 32 recommendations, which aim at significantly improving the prevention, diagnosis, and management of FASD. We must continue to expose the devastating harms caused by prenatal alcohol exposure.

Abbreviations

ACCHOs	Aboriginal Community Controlled Health Organisations
ACCHSs	Aboriginal Community Controlled Health Services
ACM	Australian College of Midwives
ADHD	Attention-Deficit/Hyperactivity Disorder
AHRC	Australian Human Rights Commission
AIHW	Australian Institute of Health and Welfare
AMA	Australian Medical Association
AMSANT	Aboriginal Medical Services Alliance of the Northern Territory
ANFPP	Australian Nurse Family Partnership Program
AQUA	Asking Questions about Alcohol in Pregnancy
ASD	Autism Spectrum Disorder
ASQ-TRAK	Ages and Stages Questionnaire
AUDIT-C	Alcohol Use Disorders Identification Test – Consumption
CAYLUS	Central Australia Youth Link Up Service
Congress	Central Australian Aboriginal Congress
CWLA	Catholic Women's League Australia
CYATS	Child and Youth Assessment and Treatment Service
DOH	Department of Health
ECEI	Early Childhood Early Intervention
FARE	Foundation for Alcohol Research and Education
FAS	Fetal Alcohol Syndrome
FASD	Fetal Alcohol Spectrum Disorder
GPs	general practitioners
Hidden Harm report	FASD: The Hidden Harm: Inquiry into the Prevention, Diagnosis and Management of Fetal Alcohol Spectrum Disorders
KAMS	Kimberley Aboriginal Medical Services
MBS	Medicare Benefits Schedule
MBS	Medicare Benefits Scheme
NAAJA	North Australian Aboriginal Justice Agency
NACCHO	National Aboriginal Community Controlled Health Organisations
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NDIS Act	*National Disability Insurance Scheme Act 2013*
NHMRC	National Health and Medical Research Council
NOFASD	National Organisation for Fetal Alcohol Spectrum Disorder
NPDC	National Perinatal Data Collection

NT	Northern Territory
PHAA	Public Health Association Australia
RACGP	Royal Australian College of General Practitioners
RACP	Royal Australian College of Physicians
RANZCOG	Royal Australian and New Zealand College of Obstetricians and Gynaecologists
RANZCP	Royal Australian and New Zealand College of Psychiatrists
TSPs	Typical Support Packages
VicFAS	Victorian Fetal Alcohol Service
WA	Western Australia
WANADA	Western Australian Network of Alcohol and other Drug Agencies

List of Recommendations

Recommendation 1

2.119 The committee recommends that the Australian Government provide long-term funding for the national FASD case register and develop a multi-year strategy and budget for data collection and related research activities.

Recommendation 2

2.120 The committee recommends that the Australian Government fund a FASD Prevalence Study to determine the national prevalence of FASD cases, including both known cases and those considered 'at risk' of FASD in the Australian population.

Recommendation 3

2.122 The committee recommends that the Australian Government in consultation with State and Territory Governments implement mandatory reporting on standardised data for maternal alcohol consumption in the Perinatal National Minimum Data Set.

Recommendation 4

2.125 The committee recommends that the Australian Government fund an independent study into the social and economic cost of FASD in Australia.

Recommendation 5

3.145 The committee recommends that the Australian Government develop a broader strategy and budget for a national public education campaign over the life of the *National Fetal Alcohol Spectrum Disorder (FASD) strategic action plan 2018–2028*.

Recommendation 6

3.147 The committee recommends that the Department of Health fund the development of FASD education resources to be used in secondary school curriculums.

Recommendation 7

3.149 The committee recommends that the *Australian Clinical Practice Guidelines: Pregnancy care* are updated as a matter of priority to ensure consistency with the 2020 *Australian guidelines to reduce health risks from drinking alcohol*.

Recommendation 8

3.151 The committee recommends that the medical profession, including the various medical colleges, acknowledge the critical role they play in education and awareness-raising of the dangers of consumption of alcohol for both women and men, particularly as it relates to consumption in relation to pregnancy.

Recommendation 9

3.154 The committee recommends that the Australian Government provide funding for professional development training for all health professionals involved in antenatal care, in order to embed routine FASD screening practices and tools, including AUDIT-C.

Recommendation 10

3.156 The committee recommends that the Australian Government implement as a matter of priority marketing, pricing and taxation reforms as set out in the *National alcohol strategy 2019–2028*.

Recommendation 11

3.158 The committee recommends that the Australian Government run a specific public education campaign with respect to the roll-out of mandatory pregnancy warning labels.

Recommendation 12

3.162 The committee recommends that the Australian Government fund a National Prevention Strategy to be developed and delivered in collaboration with State and Territory Governments.

Recommendation 13

4.114 The committee recommends that the Australian Government undertake a national audit of current FASD diagnostic services and funding to identify priority areas and inform a longer-term and sustainable funding model.

Recommendation 14

4.116 The committee recommends that the Medicare Benefits Schedule (MBS) Review Taskforce recommends including MBS Items that cover the range of clinical practices involved in FASD assessments, diagnoses and treatments.

Recommendation 15

4.119 The committee recommends that the Australian Government fund:

- **an evaluation of tiered models of assessment and use of technology to improve accessibility to diagnostic services, including in rural and remote communities; and**
- **the implementation of a trial for a model of tiered FASD assessment utilising primary health care services.**

Recommendation 16

4.121 The committee recommends that the Australian Government allocate funding for FASD diagnostic training, including:

- **for the expansion of the delivery of practical training courses provided by clinical services; and**
- **for scholarships and/or subsidies to increase the number of practitioners with a Graduate Certificate in the Diagnosis and Assessment of Fetal Alcohol Spectrum Disorders (FASD).**

Recommendation 17

4.122 The committee recommends that Australian universities ensure that FASD modules are included in university curriculums for relevant occupations, including those for education and teaching, medicine, midwifery, psychology, social work, occupational therapy, speech and language pathology.

Recommendation 18

4.124 The committee recommends that the Australian Government allocate funding for a project to disseminate the *Australian guide to the diagnosis of FASD* immediately following its revision and to train health professionals in its use.

Recommendation 19

5.128 The committee recommends that the National Disability Insurance Agency implement improvements to the Early Childhood Early Intervention program to streamline access and documentary evidence requirements.

Recommendation 20

5.130 The committee recommends that the National Disability Insurance Agency ensure that the planned Early Childhood Early Intervention Reset focus on improving access to support for children throughout key developmental stages.

Recommendation 21

5.136 The committee recommends that the Australian Government include FASD in the List of Recognised Disabilities.

Recommendation 22

5.137 The committee recommends that the eligibility requirements for the Disability Support Pension be reviewed to include individuals with FASD with an IQ above the low range (between 70 and 85).

Recommendation 23

5.139 The committee recommends that the Australian Government work with State and Territory Governments to provide all educators with professional development training in the awareness, understanding and management of FASD.

Recommendation 24

5.140 The committee recommends that the Australian Government work with State and Territory Governments to ensure all schools can deploy and resource FASD-specific strategies and assistance to support educators and to support students with FASD and suspected FASD, irrespective of IQ level.

Recommendation 25

5.142 The committee recommends that the Australian Government allocate funding for the development and delivery of practical parenting programs to complement existing supports and the FASD hotline.

Recommendation 26

5.144 The committee recommends that all children and young people entering the youth justice and child protection systems are screened for FASD.

Recommendation 27

5.145 The committee recommends that the Australian Government, in partnership with State and Territory Governments, develop and trial protocols for screening children and young people within child protection and youth justice systems for FASD.

Recommendation 28

5.147 The committee recommends that the Australian Government provides further funding to train custodial officers in FASD-specific strategies for dealing with youth with FASD or suspected FASD in correctional facilities.

Recommendation 29

5.150 The committee recommends that the Australian Government fund an independent study into best-practice diversionary programs and alternative therapeutic facilities for individuals with FASD or suspected FASD within the justice system.

Recommendation 30

5.152 The committee recommends that more funding and support is provided by State and Territory Child Protection authorities to carers who are caring for and supporting children with FASD.

Recommendation 31

6.75 The committee recommends the NDIA undertake consultation and a co-design process with First Nations organisations to improve its Remote Community Connectors Program to enable better access to disability support services for eligible NDIS participants living in remote Australia.

Recommendation 32

6.82 The committee recommends the Department of Health allocate specific funding aimed at supporting First Nations community-led projects to prevent and manage FASD.

Chapter 1
Introduction

1.1 Fetal Alcohol Spectrum Disorder (FASD) is a lifelong condition with no cure. The central nervous system damage which the child is born with is irreversible and permanent, and current treatment options are predominantly supportive.[1]

1.2 In 2012, a House of Representatives inquiry into the prevention, diagnosis and management of FASD produced a series of landmark recommendations.[2] Since then, there have been a number of other inquiries by the Australian, state and territory parliaments, concerned directly or substantially with FASD.[3] There have also been multiple policy initiatives and funding commitments involving public and private organisations and individuals working together to promote better ways of preventing, diagnosing and managing FASD.[4]

1.3 Whilst these efforts reflect a national willingness to understand FASD, broaden public understanding, and support the development of pioneering programs and models of care in local communities, FASD remains a serious yet entirely preventable disability that continues to have profound and long-lasting consequences for individuals and their families, carers and communities across Australia. Overall, FASD interventions have been ad hoc and inconsistently applied across Australia, and there is still limited awareness of FASD in the community.

1.4 The aim of this inquiry is to examine the effectiveness of programs and models for preventing, diagnosing and managing FASD, and consider ways to achieve a more coordinated and effective national response. It comes at a time of increased national attention on FASD, and alcohol-related harms more broadly. The focus of this report therefore is what we have learnt from the past

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1 Northern Territory (NT) Government, *Submission 2*, p. 9.

2 House of Representatives Standing Committee on Social Policy and Legal Affairs, *FASD: The hidden harm: Inquiry into the prevention, diagnosis and management of Fetal Alcohol Spectrum Disorders* (Hidden Harm report), November 2012.

3 See, for example, Standing Committee on Indigenous Affairs, *Inquiry into the harmful use of alcohol in Aboriginal and Torres Strait Islander communities,* February 2014; House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs, *Inquiry into the high level of involvement of Indigenous juveniles and young adults in the criminal justice system*, November 2009; Parliament of Western Australia, Education and Health Standing Committee, *Foetal Alcohol Spectrum Disorder: The invisible disability*, September 2012; NT Legislative Assembly, Select Committee on Action to Prevent Foetal Alcohol Spectrum Disorder, *The preventable disability*, March 2014; NT Government, *Northern Territory alcohol harm minimisation action plan 2018–2019*, February 2018.

4 These are summarised below, and includes the current *National FASD strategic action plan 2018–2028*.

decade, and how the national effort can be better targeted to address areas of need and the longer term challenge of making FASD history.

1.5 This chapter provides an overview of FASD and its effects in the community and explores the previous inquiries, policy and budget measures that have been initiated in relation to FASD.

An invisible epidemic

1.6 FASD is a diagnostic term used to describe a range of birth defects and neurodevelopmental impairments that may occur as a result of exposing the fetus to alcohol during pregnancy.[5] The harm done by alcohol may not be evident at birth, but the central nervous system damage which the child is born with is irreversible and permanent.[6]

1.7 FASD remains largely invisible and under-recognised in Australia.[7] However it is one of the leading causes of preventable birth defects and intellectual disability.[8] Whilst there are no reliable figures on the prevalence of FASD in Australia, experts estimate that it affects up to five per cent of the population, and that potentially between two and nine per cent of babies are born with FASD each year.[9]

1.8 FASD is not confined to a particular community or demographic; it is a disorder that crosses socio-economic, cultural and education boundaries. However certain groups are more likely to be vulnerable to FASD due to patterns of alcohol consumption.[10] Despite national guidelines recommending total abstinence of alcohol during pregnancy, the risks are still not well understood by the community, and amongst health professionals.[11] In fact,

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5 National Health and Medical Research Council (NHMRC), *Australian guidelines to reduce health risks from drinking alcohol*, 2020, p. 50.

6 NT Government, *Submission 2*, p. 9.

7 Dr Katrina Harris, Head of Victorian Fetal Alcohol Service (VicFAS), Monash Health, *Committee Hansard,* 24 June 2020, p. 18.

8 National Drug Research Institute, *Submission 1,* Appendix 3, [p. 12]; Foundation for Alcohol Research and Education (FARE), *Submission 50*, p. 5.

9 Food Regulation Standing Committee, *Decision Regulation Impact Statement: Pregnancy Warning Labels on Packaged Alcoholic Beverages*, October 2018, p. 26; Senator the Hon Richard Colbeck, Minister for Aged Care and Senior Australians and Minister for Youth and Sport, *Letter to the President of the Senate in response to Senate Order for Production of Documents No. 601,* [p. 17] (tabled 12 June 2020); FARE, *Submission 50*, p. 5. See further discussion in Chapter 2, paragraphs 2.55–2.59.

10 Australian Medical Association (AMA), *Submission 5*, p. 2. See further discussion in Chapter 2, paragraphs 2.29–2.30, 2.47–2.51 and 2.63–2.75.

11 NHMRC, *Australian guidelines to reduce health risks from drinking alcohol*, 2020, p. 46; Alcohol Policy Coalition, *Submission 19*, p. 2; National Alliance for Action on Alcohol, *Submission 27*, [p. 1]. Professor Elizabeth Elliott, Co-Director, FASD Research Australia Centre of Research Excellence,

Australia has one of the highest rates of prenatal alcohol exposure in the world.[12]

1.9 Obtaining a FASD diagnosis is notoriously difficult, and access to diagnostic and treatment services are limited in Australia, particularly in rural and remote areas.[13] Failure to identify children at risk and to diagnose FASD means that many individuals do not receive recognition or support for their impairments through the health, education and justice systems.[14]

1.10 People with FASD experience lifelong challenges, including learning difficulties and disrupted education, mental illness and drug and alcohol problems.[15] The average life expectancy for a child with FASD is 34 years.[16] Significantly, children with FASD are over-represented in the child protection and youth justice systems.[17]

Previous inquiries

Hidden Harm report (2012)

1.11 The House of Representatives 2012 Hidden Harm inquiry found that there was little awareness of FASD or the risks of alcohol consumption during pregnancy amongst health professionals and the wider community. It also found that Australia was lagging behind other countries in standardising FASD diagnostic criteria and prevalence data, and urged the rollout of a nationally-approved diagnostic tool to ensure early intervention and minimise the impact of FASD in later life.[18]

1.12 The report concluded that the Australian Government needed to lead the way in recognising FASD as a legitimate and serious disability, and that a cohesive

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Telethon Kids Institute, *Committee Hansard*, 19 May 2020, p. 27. See discussion in Chapter 2, paragraphs 2.39–2.41 and Chapter 3, paragraphs 3.8–3.12.

12 NHMRC, *Australian guidelines to reduce health risks from drinking alcohol*, p. 47.

13 See discussion in Chapter 4, paragraphs 4.15–4.53 and Chapter 5, paragraphs 5.17–5.22.

14 See discussion in Chapter 5, paragraphs 5.3–5.5 and 5.73–5.75.

15 National Organisation for Fetal Alcohol Spectrum Disorder (NOFASD), answer to questions on notice, p. 14; Department of Health, *National Fetal Alcohol Spectrum Disorder strategic action plan 2018–2028*, p. 24. See discussion in Chapter 5 at paragraph 5.13.

16 AMA, *Fetal Alcohol Spectrum Disorder (FASD)—2016*, 24 August 2016, https://ama.com.au/position-statement/fetal-alcohol-spectrum-disorder-fasd-2016 (accessed 13 October 2020).

17 Ms Prue Walker, *Submission 47*, p. 3; Joint submission by Professor Harry Blagg, Mrs Suzie May, Dr Tamara Tulich, Dr Robyn Williams, *Submission 22*, p. 3. See discussion in Chapter 2, at paragraphs 2.70–2.75.

18 Hidden Harm report, pp. 103 and 116. The report noted that, internationally, the majority of clinics providing diagnostic and assessment services at that time were located in North America, with some in South Africa, Europe and South America.

national approach was necessary.[19] It contained 19 recommendations, with clear timeframes, focusing on national level policy and coordination efforts. It recommended that the Australian Government:

- implement a National Plan of Action and a FASD Reference Group;
- improve data collection on alcohol consumption by health professionals during pregnancy or at the time of birth;
- develop a FASD diagnostic tool and training manual;
- implement awareness campaigns for the general public and specific to youth and Indigenous communities;
- implement health advisory labels on pregnancy and ovulation testing kits and on alcoholic beverages;
- commission independent research into alcohol marketing, pricing and availability; and
- recognise FASD on the List of Recognised Disabilities.[20]

1.13 The inquiry was a catalyst for key national measures to address FASD and prompted greater awareness of FASD amongst health professionals and decision-makers.[21]

1.14 The introduction of a national action plan in 2013, and a FASD Technical Network, which oversaw the implementation of the plan and provided advice on how Australia could achieve a strategic coordinated approach to FASD, was a direct result of the inquiry. The publication of the Australian FASD Diagnostic tool after the inquiry provided the necessary foundation for broad scale diagnosis and the allocation of resources for individual and population-level interventions and supports.[22]

1.15 Although a significant step forward, these initiatives were part of a larger vision for a national and cohesive approach to FASD. Evidence before this inquiry suggests the response to some recommendations has been slow, incomplete, or non-existent.[23] Some of the report's key recommendations regarding data collection, public awareness campaigns and research with respect to alcohol marketing, pricing and availability, are yet to be addressed.[24]

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19 Hidden Harm report, p. xvii.

20 Hidden Harm report, p. xvii–xxii.

21 FARE, *Submission 50*, p. 9.

22 FARE, *Submission 50*, p. 37.

23 FARE, *Submission 50*, pp. 36–45.

24 FARE, *Submission 50*, pp. 36–45.

The Invisible Disability report (2012)

1.16 The WA Legislative Assembly examined FASD in the context of the Education and Health Standing Committee's inquiry into Improving Educational Outcomes for Western Australians of All Ages.[25]

1.17 The committee's report, *The invisible disability*, drew attention to the broad-ranging impacts of FASD in WA, including the impact on education and justice outcomes.[26] The committee noted a lack of public awareness, understanding and funding for FASD in Australia and examined overseas experience, and other disabilities such as autism.[27]

1.18 At the time of the report, a national diagnostic tool was yet to be adopted in Australia, and the report noted a lack of prevalence data and research about FASD.[28] *The invisible disability* report made broad-ranging recommendations covering prevention, awareness, screening, interventions and support for FASD.[29]

The Preventable Disability report (2015)

1.19 The NT Legislative Assembly's 2015 inquiry examined the problem of FASD within the Territory context, noting the NT has the highest rate of risky alcohol consumption in the country and a higher rate of consumption than any other country in the OECD.[30]

1.20 The inquiry's final report, *FASD: The preventable disability*, made recommendations aimed at reducing harm through alcohol management and support services, sexual health, pregnancy support, early childhood support and education services, and FASD diagnostics. Of particular significance for

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[25] Parliament of Western Australia, Education and Health Standing Committee, *Foetal Alcohol Spectrum Disorder: The Invisible Disability*, September 2012.

[26] Parliament of Western Australia, Education and Health Standing Committee, *Foetal Alcohol Spectrum Disorder: The Invisible Disability*, September 2012, p. 73.

[27] Parliament of Western Australia, Education and Health Standing Committee, *Foetal Alcohol Spectrum Disorder: The Invisible Disability*, September 2012, pp. 45 and 67. See, for example, Chapter 6, 'The economic costs of FASD' and Chapter 8, 'Lessons to be learned from Autism Spectrum Disorder'.

[28] Parliament of Western Australia, Education and Health Standing Committee, *Foetal Alcohol Spectrum Disorder: The Invisible Disability*, September 2012, p. 33. See, Chapter 4 'Diagnosing FASD'.

[29] Parliament of Western Australia, Education and Health Standing Committee, *Foetal Alcohol Spectrum Disorder: The Invisible Disability*, September 2012, p. vii.

[30] Legislative Assembly of the Northern Territory, Select Committee on Action to Prevent Foetal Alcohol Spectrum Disorder, *The Preventable Disability*, 2015, February 2015, p. 4.

subsequent policy reforms, however, was the report's focus on prevention through alcohol management and the restriction of supply.[31]

1.21 In recognition of the problem of alcohol abuse in the NT the committee recommended a range of measures intended to restrict alcohol supply, including, for example, setting targets for reducing alcohol-related harm, amending the *Liquor Act* to implement a minimum floor price on standard drinks, and restricting the trading of alcohol at certain times.[32]

Inquiries into alcohol and the criminal justice system

1.22 FASD has also been explored in inquiries into the criminal justice system and the impact of alcohol on communities more broadly.

1.23 An inquiry by the Standing Committee on Aboriginal and Torres Strait Affairs highlighted the link between FASD and the criminal justice system in its 2009 report *Indigenous juveniles and young adults in the criminal justice system.*[33]

1.24 The report recommended the urgent implementation of diagnostic tools and therapies in partnership with First Nations health organisations, and that FASD be recognised as a disability and condition eligible for health and education supports.[34]

1.25 In 2015, the Standing Committee on Indigenous Affairs reported on FASD in the context of its inquiry *Alcohol, hurting people and harming communities*.[35] The report contained six FASD specific recommendations, including:

- that the Australian Government increase its efforts to ensure consistent messaging about the risks of consuming alcohol during pregnancy and the importance of abstaining when planning pregnancy, when pregnant and when breastfeeding; and

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[31] Legislative Assembly of the Northern Territory, Select Committee on Action to Prevent Foetal Alcohol Spectrum Disorder, *The Preventable Disability*, 2015, February 2015, p. 5.

[32] Legislative Assembly of the Northern Territory, Select Committee on Action to Prevent Foetal Alcohol Spectrum Disorder, *The Preventable Disability*, 2015, February 2015, p. 18. See recommendations 15 to 20. For further discussion about alcohol reforms introduced in the NT, see Chapter 6, Box 6.1.

[33] House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs, *Inquiry into the high level of involvement of Indigenous juveniles and young adults in the criminal justice system*, November 2009, pp. 96–103.

[34] House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs, *Inquiry into the high level of involvement of Indigenous juveniles and young adults in the criminal justice system*, November 2009, pp. 96–103.

[35] House of Representatives Standing Committee on Indigenous Affairs, *Alcohol, Hurting People and Harming Communities*, June 2015.

- the need for FASD to be included as a recognised disability to assist with access to government allowances and support under the National Disability Insurance Scheme.[36]

Policy initiatives and funding

FASD action plan 2013–14 to 2016–17

1.26 As discussed above, the Australian Government's *FASD action plan* was introduced in 2013 in response to the 2012 Hidden Harm report. Over 2013–14 to 2016–17 the *FASD action plan* received $9.2 million of funding.[37]

1.27 Programs funded under the plan were aimed at improving better diagnosis and management and developing best practice interventions and services to support high-risk women. This included:

- prevention and awareness campaigns (the Women Want to Know and Pregnant Pause initiatives and funding for National Organisation for FASD, or NOFASD, awareness campaigns);
- health promotion resources and organisations (including the web-accessible FASD Hub); and
- funding for national data collection and national FASD case register intended to monitor FASD prevalence trends over time.[38]

Taking More Action on FASD (2016–17 to 2019–20)

1.28 The Taking More Action on FASD program ($10.5 million over 2016−17 to 2019−20) built on the achievements of the *FASD action plan* and provided funding for additional prevention activities and on-the-ground FASD diagnostic services in communities of high need.[39]

1.29 Funding under the program has been directed toward:

- diagnostic services and models of care projects;
- a NOFASD telephone and online counselling activity; and
- support for parents and caregivers through the Russell Family Fetal Alcohol Disorders Association.[40]

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[36] House of Representatives Standing Committee on Indigenous Affairs, *Alcohol, Hurting People and Harming Communities*, June 2015, p. xviiii. See Recommendations 16–21.

[37] Department of Health, *Submission 25*, p. 3.

[38] Department of Health, *Submission 25*, pp. 3−5. See further discussion in Chapter 2, paragraphs 2.81–2.111.

[39] Department of Health, *Submission 25*, pp. 5−6.

[40] Department of Health, *Submission 25*, pp. 5−6.

National FASD strategic action plan 2018–2028

1.30 In November 2018, the *National Fetal Alcohol Spectrum Disorder (FASD) Strategic action plan 2018–2028* (*National FASD strategic action plan*) was launched as a sub-strategy of the *National alcohol strategy*. The plan was initiated in response to a review of the *FASD action plan 2013−14 to 2016−17* by a roundtable of key FASD stakeholders and government agencies in December 2016.[41]

1.31 The plan has received $7.2 million in funding over four years to support prevention, diagnosis, support and management of FASD in Australia. The plan, which is not solely the responsibility of government bodies, is overseen by the Ministerial Drug and Alcohol Forum and supported by the National Drug Strategy Committee, which includes a FASD Advisory Group established to monitor implementation of the plan.[42]

1.32 Funding under this plan is intended for several existing FASD initiatives including the national FASD case register, FASD Hub, Women Want to Know and Pregnant Pause programs. Funding will also be provided for other awareness raising and education activities and resources, including in the education and justice sectors, and will fund a review and update of the FASD diagnostic tool.[43]

1.33 On 9 September 2020, the Minister for Health announced a further $24 million under the *National FASD strategic action plan* for FASD diagnostic and support services to improve wait times and support.[44]

National alcohol strategy 2019–2028

1.34 The *National alcohol strategy 2019–2028* was endorsed by all states and territories through the Ministerial Drug and Alcohol Forum in November 2019.[45]

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41 Department of Health, *National Fetal Alcohol Spectrum Disorder strategic action plan 2018–2028*, November 2018, pp. 3−5); Department of Health, *Submission 25*, p. 2. The plan is informed by an analysis of existing FASD policy and service frameworks, data and research evidence and extensive consultation with key stakeholders, and is expected to align with and inform a number of other key national health strategies and frameworks, including the *National drug strategy 2017−2026*; *National alcohol strategy 2018−2026*; *National Aboriginal and Torres Strait Islander peoples' drug strategy 2014−2019*; *National strategic framework for chronic conditions* (published 2017); and *National Aboriginal and Torres Strait Islander health plan 2013−2023*.

42 Department of Health, *Submission 25*, pp. 6−8.

43 Department of Health, *Submission 25*, pp. 6−7; Department of Health, answers to questions on notice – IQ20-000234, (received 12 June 2020).

44 The Hon. Greg Hunt MP, Minister for Health, 'Australia leading the fight against FASD', *Media Release*, 9 September 2020, https://www.health.gov.au/ministers/the-hon-greg-hunt-mp/media/australia-leading-the-fight-against-fasd (accessed 18 November 2020).

45 Department of Health, answers to questions on notice – IQ20-000672, (received 16 October 2020).

1.35 The *National alcohol strategy* provides a national framework for governments, communities, organisations and industry to reduce the harms of alcohol on the Australian community. One of its key aims is a 10 per cent reduction in harmful drinking.[46]

1.36 The *National alcohol strategy* includes the following FASD-related objectives:

- improve FASD prevention through community awareness, and improved FASD detection, diagnosis and access to therapy;
- increase awareness of the full range of treatment options for at-risk women, including outpatient counselling and relapse prevention medicines for dependence;
- educate around the harms to a developing baby as a result of maternal alcohol consumption in school and post-secondary and tertiary education;
- disseminate, promote and provide training to support the use of established resources; and
- improve access to support services, including through the National Disability Insurance Scheme.[47]

1.37 The *National alcohol strategy* notes that responsibility for implementing policy measures, including decisions of funding, legislation and programs, is shared by the Commonwealth and States:

> It is expected that in taking action to support implementation of this Strategy that jurisdictions will apply an evidence based approach to contribute to the objectives of the Strategy. The mix of actions adopted in individual jurisdictions and the details of their implementation may vary to reflect local and/or national priorities.[48]

1.38 In December 2019, the Australian Government announced $25 million over four years for the Foundation for Alcohol Research and Education to implement a national awareness campaign for pregnancy and breastfeeding women.[49]

State and Territory policies and funding

1.39 The committee heard that there has been a modest investment by state and territory governments in FASD specific policies.[50]

1.40 The NT is the only jurisdiction with a dedicated FASD action plan, which it released in 2018.[51]

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46 Department of Health, answers to questions on notice – IQ20-000672, (received 16 October 2020).

47 Department of Health, *National alcohol strategy 2019–2028*, November 2019, p. 26.

48 Department of Health, *National alcohol strategy 2019–2028*, November 2019, p. 3.

49 Department of Health, answers to questions on notice – IQ20-000672, (received 16 October 2020).

50 FARE, *Submission 50*, p. 11.

1.41 In WA, the state government has launched a FASD model of care and implementation framework, and addressed FASD specifically in its *Alcohol and drug interagency strategy 2018–22*.[52]

1.42 Local communities, like Fitzroy Crossing in WA, have developed their own FASD action plans and have initiated research projects and pilot programs to address the impact of FASD.[53]

Reflecting on the past decade

1.43 Since the Hidden Harm report, the establishment of a national policy and coordinating mechanism, as well as funding for research, prevention, diagnosis and support, represents a significant step forward in the national response to FASD.[54]

1.44 The publication of the *Australian guide to the diagnosis of Fetal Alcohol Spectrum Disorders* in 2016 was a key milestone. Australia has also seen an increasing number of diagnostic services and there is a growing but patchy body of data on cases of FASD nationally.[55]

1.45 The investment in research and innovative programs in the past decade has seen Australia move to the forefront in international efforts for FASD prevention, diagnosis and support.[56] The first prevalence study in Australia was undertaken in Fitzroy Crossing, WA, and has resulted in a world class community-led Marulu strategy and programs.[57]

1.46 Despite this progress, there is still a limited awareness of FASD in the community and mixed messages about drinking during pregnancy in the general population and from health professionals.[58] A lack of FASD prevalence data continues to undermine policy efforts and the limited diagnostic and support services available across the country are struggling to keep up with

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51 FARE, *Submission 50*, p. 11; NT Department of Health, *Addressing Fetal Alcohol Spectrum Disorder (FASD) in the Northern Territory 2018–2024*, December 2018.

52 FARE, *Submission 50*, p. 11; WA Mental Health Commission, *Western Australian alcohol and drug interagency strategy 2018–2022*, January 2019.

53 FARE, *Submission 50*, p. 11.

54 FARE, *Submission* 50, p. 10.

55 FARE, *Submission* 50, p. 10.

56 FARE, *Submission* 50, p. 10; NOFASD, *Submission 40*, p. 16.

57 FARE, *Submission* 50, p. 10.

58 See discussion in Chapter 2, paragraphs 2.39–2.41. See also, for example, Amy Sheehan, 'Health experts warn Aussie drinking culture is causing hidden epidemic in children', *ABC News*, 6 February 2020 (accessed 4 February 2021).

demand.[59] There are also growing concerns about the prevalence of FASD in the child protection and justice systems, and the potentially immense social and economic cost of FASD for the community more broadly.[60]

1.47 Since the committee started its inquiry in November 2019, several significant FASD policy and budget announcements have been made, relevant to the inquiry's terms of reference. This includes the *National alcohol strategy* announced in November 2019, and additional Australian Government funding with a combined value of $49 million for FASD diagnostic and treatment services, and for a national education campaign.

1.48 In addition, in July 2020, the Australia and New Zealand Ministerial Forum on Food Regulation agreed on a standard mandatory pregnancy warning label for all alcohol and packaging, eight years after its recommendation in the Hidden Harm report.[61]

Senate inquiry

1.49 On 9 September 2019, the Senate referred an inquiry into effective approaches to prevention and diagnosis of FASD, strategies for optimising life outcomes for people with FASD and supporting carers, and the prevalence and management of FASD, including in vulnerable populations, in the education system, and in the criminal justice system, for inquiry and report by 15 June 2020. The full terms of reference are available on the website.[62]

1.50 On 23 March 2020 the Senate granted an extension of time for reporting until 9 September 2020; and on 2 April 2020 the Senate granted a further extension to 2 December 2020. On 2 September 2020, the Senate granted an extension of time for reporting until the second last sitting day in March 2021.

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[59] See further the discussion in Chapter 2, paragraphs 2.81–2.111 and Chapter 4, paragraphs 4.9–4.36 and 4.43–4.46. See also, for example, Katherine Gregory, 'FASD: Family finally gets answers in fetal alcohol spectrum disorder diagnosis', *ABC News*, 14 January 2018 (accessed 4 February 2021); Carol Raabus, 'FASD has no cure and is often misdiagnosed, but there is hope and help for those affected', *ABC News*, 1 February 2021 (accessed 4 February 2021).

[60] See discussion in Chapter 2, paragraphs 2.63–2.80. See also, for example, Debbie Andalo, 'How foetal alcohol spectrum disorder affects the care system', The Guardian, 9 February 2016 (accessed 4 February 2021); Anonymous contributor, ''I became a foster mum for my brother's baby. 6 years in, I feel like I'm drowning', *Mamamia online*, 6 November 2020 (accessed 4 February 2021); 'Mario Christodoulou, 'Expert casts doubt on Gene Gibson murder confession, wants FASD assessment', ABC News, 2 November 2015 (accessed 4 February 2021); Marian Faa, 'Link between Foetal Alcohol Spectrum Disorder and youth crime sparks calls for change', *ABC News*, 23 November 2020 (accessed 4 February 2021).

[61] Australia and New Zealand Ministerial Forum on Food Regulation, *Communiqué*, 17 July 2020.See discussion in Chapter 3, paragraph 3.124–3.129.

[62] Community Affairs References Committee, *Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder*, https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/FetalAlcoholSpectrumDi (accessed 9 February 2021).

Report structure

1.51 This report is presented in six chapters:

- Chapter 1 introduces the significant impact of FASD in Australia, and what has been done to improve FASD prevention, diagnosis and support through parliamentary inquiries and national policies and funding;
- Chapter 2 discusses factors influencing maternal alcohol consumption and the prevalence and social and economic impact of FASD;
- Chapter 3 focuses on prevention efforts, the role of health professionals, prevention and awareness initiatives, and the issue of alcohol availability;
- Chapter 4 considers obstacles to diagnosis and early intervention, the use of diagnostic tools, and case studies of successful programs;
- Chapter 5 examines management and support services for FASD, including access to the National Disability Insurance Scheme; and
- Chapter 6 discusses the link between FASD and inter-generational trauma amongst First Nations communities, and successful community-led initiatives.

Conduct of the inquiry

1.52 The inquiry was advertised on the committee's website and the committee wrote to relevant organisations inviting submissions by 29 November 2019.

1.53 The committee published a media release on 11 September 2019 calling for submissions to the inquiry.

1.54 The committee received a total of 69 public submissions, including one submission with the name withheld. A list of submissions received by the committee is available at Appendix 1 and copies of public submissions can be accessed on the committee's website.

1.55 The committee held seven public hearings in Canberra on 19 May 2020, 24 June 2020, 25 June 2020, 16 September 2020; 14 October 2020; 4 December 2020 and 10 March 2021.

1.56 The committee is disappointed that its planned visit to Alice Springs and Fitzroy Crossing was delayed, and subsequently cancelled, due to the COVID-19 pandemic. However, evidence provided by witnesses in these locations via submissions, answers to questions on notice, and remote participation in Canberra-based hearings, has been invaluable to the inquiry.

1.57 A list of witnesses who provided evidence at the public hearings is available at Appendix 2.

Acknowledgements

1.58 The committee thanks all of the individuals and organisations who submitted to the inquiry and appeared as witnesses.

Notes on terminology and references

1.59 References in this report to *Committee Hansard* are to the official transcripts. Page numbers may vary between the proof and official transcripts.

Chapter 2
Alcohol, pregnancy and FASD

> Australian and international guidelines advise that there is no safe level of maternal alcohol consumption during pregnancy.[1]

2.1 FASD is still not well understood in Australia and there are low levels of awareness about the risks of consuming alcohol when pregnant. This chapter examines this issue, and what we currently know about the link between alcohol and pregnancy, and the prevalence of FASD in Australia.

2.2 The next chapter will explore the range of prevention approaches that are needed to address the lack of awareness and understanding of FASD in the community and medical professionals, the availability of alcohol and the role of the alcohol industry.

Understanding FASD

What is FASD?

2.3 FASD encompasses a spectrum of disorders that can arise from alcohol exposure in utero. The spectrum covers physical, neural, behavioural and learning difficulties from mild through to severe symptoms.[2]

2.4 For those with FASD, primary disabilities include poor impulse control, developmental delay, poor memory, difficulties with abstract concepts and difficulties with planning and following through on goals. These are symptoms of underlying brain dysfunction linked directly to brain damage, as distinct from a failure in rational decision making or choices.[3]

2.5 Perhaps the most clinically recognisable manifestation of FASD is Fetal Alcohol Syndrome (FAS), which is characterised by physical abnormalities including of the face.[4] In individuals with FAS, there has usually been exposure to alcohol during the first trimester of pregnancy, when the face and other bodily organs are forming.[5]

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1 Australian Medical Association (AMA), *Fetal Alcohol Spectrum Disorder (FASD)—2016*, 24 August 2016, https://ama.com.au/position-statement/fetal-alcohol-spectrum-disorder-fasd-2016 (accessed 13 October 2020).

2 Professor Elizabeth Elliot, *Transcript of Insight: Season 2013 Episode 31 'Drinking when Pregnant'*, Insight, SBS, 15 October 2013.

3 Foundation for Alcohol Research and Education (FARE), *Submission 50,* Attachment 3, p. 10.

4 FARE, *Submission 50,* Attachment 3, p. 10.

5 Professor Elizabeth Elliot, *Transcript of Insight: Season 2013 Episode 31 'Drinking when Pregnant'*, Insight, SBS, 15 October 2013.

FASD as a spectrum disorder

2.6 FASD includes a spectrum of possible conditions that may result from alcohol exposure in utero.[6] As a spectrum disorder, FASD may be difficult to diagnose because its effects on function can vary from person to person and range from mild to severe.[7]

2.7 Each condition, and its diagnosis, is based on the presentation of 'characteristic features which are unique to the individual' and which may be 'physical, developmental and/or neurobehavioral'.[8]

2.8 Dr Andrew Webster, Head of Clinical Governance at the Danila Dilba Health Service (NT), told the committee that the condition of FASD is incredibly broad and diverse and therefore:

> It's not like another condition where it's absolutely clear that you've got it or you don't. It's a real spectrum. That's why it's called a spectrum disorder.[9]

What causes FASD?

2.9 FASD is caused by prenatal exposure to alcohol.[10]

2.10 Alcohol is a teratogen, a substance that causes fetal abnormalities. When a pregnant woman drinks alcohol, it crosses the placenta, and the fetus experiences a blood alcohol concentration similar to the mother.[11]

2.11 When exposed to alcohol, the developing embryo and fetus may experience irreparable damage to the brain and other organs.[12]

2.12 The severity of the harm caused by consuming alcohol when pregnant depends on how much alcohol the pregnant woman drinks, the pattern of drinking, and the stage of pregnancy when the drinking occurs.[13]

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6 National Health and Medical Research Council (NHMRC), *Australian guidelines to reduce health risks from drinking alcohol*, p. 50; Professor Elizabeth Elliott, 'Fetal alcohol spectrum disorders in Australia – the future is prevention', *Public Health Research and Practice*, vol. 25(2): e2521516, 2015, p. 2.

7 AMA, answer to written questions on notice (received 21 October 2020), p. 2. Diagnosing FASD, and some of the challenges, are discussed further in Chapter 4, paragraphs 4.15 and 4.54–4.61.

8 Drug and Alcohol Nurses of Australasia, *Submission 7,* Attachment 1, [p. 2].

9 Dr Andrew Webster, Head of Clinical Governance, Danila Dilba Health Service, *Committee Hansard,* 14 October 2020, p. 8.

10 NHMRC, *Australian guidelines to reduce health risks from drinking alcohol*, p. 47; Professor Elizabeth Elliott, 'Fetal alcohol spectrum disorders in Australia – the future is prevention', *Public Health Research and Practice*, vol. 25(2): e2521516, 2015, p. 2.

11 NHMRC, *Australian guidelines to reduce health risks from drinking alcohol*, p. 47.

12 Professor Elizabeth Elliott, 'Fetal alcohol spectrum disorders in Australia – the future is prevention', *Public Health Research and Practice*, vol. 25(2): e2521516, 2015, p. 2.

How much is too much?

2.13 The *Australian guidelines to reduce health risks from drinking alcohol* (2020) advise that to prevent harm from alcohol to their unborn child, women who are pregnant or planning a pregnancy should not drink alcohol.[14]

2.14 It is well established in the research that any amount of alcohol can risk harm to a developing embryo and fetus, and that the risk of harm increases the more alcohol the mother consumes and the more frequently she drinks.[15]

2.15 The committee heard there are a variety of maternal and fetal factors that can affect the risks from drinking alcohol while pregnant such as genetic factors, metabolic rates, maternal diet and the woman's biochemical and inflammatory responses to alcohol.[16]

2.16 The National Health and Medical Research Council (NHMRC) notes that some genotypes confer an increased risk of harm and others provide protection:

> Genetic factors influence maternal and fetal metabolic rates, their risk of reacting adversely to alcohol breakdown products, and their biochemical and inflammatory responses to alcohol at a cellular level. The likely variation in risk factors among mothers and babies makes it difficult to predict the level of risk from alcohol in each individual pregnancy.[17]

Drinking during the different stages of pregnancy

2.17 There is a growing body of evidence on the influence of alcohol on all stages of fetal development, emphasising the importance of alcohol abstinence.[18]

2.18 Research suggests that exposure to alcohol in early pregnancy may lead to structural brain abnormalities and other birth defects, whereas later in pregnancy alcohol exposure may result in defects in growth and neurological development.[19]

2.19 Significantly, the Asking Questions about Alcohol in Pregnancy (AQUA) study of the longitudinal-term effects of common levels of alcohol consumption in the general community found measurable differences in facial shape with any alcohol exposure at any time.[20]

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13 NHMRC, *Australian guidelines to reduce health risks from drinking alcohol*, 2020, p. 47.

14 NHMRC, *Australian guidelines to reduce health risks from drinking alcohol*, 2020, p. 46.

15 NHMRC, *Australian guidelines to reduce health risks from drinking alcohol*, 2020, p. 48.

16 NHMRC, *Australian guidelines to reduce health risks from drinking alcohol*, 2020 p. 48.

17 NHMRC, *Australian guidelines to reduce health risks from drinking alcohol*, 2020, p. 48.

18 Murdoch Children's Research Institute, *Submission 30*, pp. 2–3.

19 FARE, *Submission 50*, Attachment 3, p. 11.

20 Ms Evelyne Muggli, Senior Research Officer, Murdoch Children's Research Institute, *Committee Hansard*, 19 May 2020, p. 23; Murdoch Children's Research Institute, *Submission 30*, p. 2.

Partner's drinking behaviour

2.20 Evidence shows that the drinking habits of a pregnant woman's partner will affect the pregnant woman's alcohol consumption and that preconception drinking by a male partner directly impacts fetal development.[21]

2.21 According to the Foundation for Alcohol Research and Education (FARE), research shows that 75 per cent of children with FASD have biological fathers who are heavy drinkers.[22]

Pregnancies exposed to alcohol

Rates of alcohol exposure

2.22 Australia has one of the highest rates of prenatal alcohol exposure in the world.[23]

2.23 A 2017 study found that 35.6 per cent of Australian women consume alcohol at some point during their pregnancy, compared to 9.8 per cent internationally.[24]

2.24 This research is consistent with findings from the National Drug Strategy Household Survey, which reported that 1 in 4 women surveyed continued to drink alcohol after finding out they were pregnant.[25] The *Australian guidelines to reduce health risks from drinking alcohol* suggest that self-reporting is likely to be underestimated.[26]

2.25 The National Organisation for Fetal Alcohol Spectrum Disorder (NOFASD) suggested that as much as 60 per cent of Australian pregnancies are exposed to alcohol, most in the period before identification of the pregnancy:

> Australian pregnancies are being alcohol exposed at alarming rates, very often in the early stages from conception to pregnancy identification. This places many children at risk of being born with FASD.[27]

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21 FARE, *Submission 50,* Attachment 3, p. 11.

22 FARE, *Submission 50,* Attachment 3, p. 11.

23 NHMRC, *Australian guidelines to reduce health risks from drinking alcohol*, p. 47.

24 FARE, *Submission 50,* p. 15 Svetlana Popova, Shannon Lange, Charlotte Probst, Gerrit Gmel, Jürgen Rehm, 'Estimation of national, regional, and global prevalence of alcohol use during pregnancy and fetal alcohol syndrome: a systemic review and meta-analysis', *The Lancet Global Health*, 2017, 5: e290-99, http://dx.doi.org/10.1016/S2214-109X(17)30021-9. Similar data was reported in the 2016 National Drug Strategy Household Survey, which found that 34.7 per cent of women self-reported drinking alcohol when pregnant. See NHMRC, *Australian guidelines to reduce health risks from drinking alcohol*, 2020, p. 16 citing AIHW, *National Drug Strategy Household Survey 2016*, July 2017.

25 AIHW, *National Drug Strategy Household Survey 2016: Detailed Findings*, July 2017, p. 116.

26 NHMRC, *Australian guidelines to reduce health risks from drinking alcohol*, p. 14.

27 NOFASD, *Submission 40,* p. 3–4.

2.26 It is estimated that at least half of all pregnancies in Australia are unplanned.[28] Women of child-bearing age who are sexually active and not using birth control effectively contribute to the 50 per cent of pregnancies which are unplanned in Australia.[29]

2.27 Birth data suggests that the majority of Australian births are to women aged between 24 and 37 years. Amongst this group, data from the National Drug Strategy Household Survey suggests an increasing proportion of women are drinking at 'risky levels' at least monthly (defined as four or more standard drink per occasion).[30]

Trends over time

2.28 According to data from the National Drug Strategy Household Survey, overall there has been a decline in the number of women drinking alcohol during pregnancy.[31] Data from the 2019 survey showed that most Australian women (65 per cent) abstain from alcohol when pregnant, an increase from 56 per cent in 2016.[32]

Demographics

2.29 According to a review of scientific literature by the National Drug Research Institute, Australian women who continue to drink alcohol during pregnancy are older and have a higher income, education and socio-economic status. They are also more likely to live in a rural and remote area.[33]

2.30 Women under 25 are much more likely to stop drinking after they became aware of their pregnancy.[34] A study of National Drug Strategy Household Survey data showed 91.3 per cent of women under the age of 25 would cease drinking when they learnt of their pregnancy, compared to 51.3 per cent of women over 36 years.[35]

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[28] NOFASD, *Submission 40*, p. 3; Gold Coast Hospital and Health Service, Child Development Service, *Submission 35*, p. 4.

[29] NOFASD, *Submission 40*, pp. 3–4.

[30] National Drug Research Institute, *Submission 1*, [p. 3] citing AIHW, *National Drug Strategy Household Survey 2016: Detailed Findings*, July 2017. The 2016 survey noted an increase in the proportion of women from 20.95 per cent in 2013 to 24.05 per cent in 2016.

[31] AIHW, *National Drug Strategy Household Survey 2019*, July 2020, p. 72.

[32] AIHW, *National Drug Strategy Household Survey 2019*, July 2020, p. 72.

[33] National Drug Research Institute, *Submission 1*, [pp. 3–4].

[34] FARE, *Submission 50*, p. 15.

[35] FARE, *Submission 50*, p. 15.

Factors influencing alcohol consumption during pregnancy

Drinking culture

2.31 Alcohol consumption during pregnancy must be situated within the broader context of alcohol consumption in Australia, the committee heard.[36]

2.32 Inquiry participants commented on the 'pervasive drinking culture' in Australia, and the 'social tolerance and widespread use of alcohol' impacting on individual and community attitudes towards drinking during pregnancy.[37]

2.33 Professor Jenny Gamble of the Australian College of Midwives observed that the broader drinking culture is impacting health practitioners ability to raise the issue of drinking during pregnancy:

> We're a big drinking culture … If you yourself drink, drink to excess or drink during pregnancy—you have to situate health practitioners in the context of their broader environment, and all of those things confound their ability to raise issues if they conflict with personal views or personal experience. I think it's an unpicking thing, and we need to contextualise alcohol consumption in the whole community relative to the prevention and treatment of FASD.[38]

Changing patterns of alcohol consumption in Australia

2.34 Patterns of alcohol consumption appear to have been changing over the past ten years, suggesting a move in Australians' attitudes towards drinking.[39]

2.35 According to the NHMRC, Australians are drinking less frequently and the proportion of people drinking daily or weekly has declined between 2007/08 and 2017/18. This is due largely to a drive by younger people, with consumption among those over 40 years of age relatively unchanged.[40]

2.36 The most recent National Drug Strategy Household Survey found, however, that overall the proportion of people drinking at risky levels remains relatively unchanged. In 2019, 1 in 4 people drank at a risky level on a single occasion at least monthly.[41]

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[36] Professor Jenny Gamble, Member, Australian College of Midwives (ACM), *Committee Hansard*, 16 September 2020, p. 13.

[37] See, for example, Associate Professor Nyanda McBride, Leader, Prevention and Early Intervention Program, National Drug Research Institute, *Committee Hansard,* 19 May 2020, p. 18; Danila Dilba Health Service, *Submission 61,* p. 10; Northern Territory (NT) Government, *Submission 2*, p. 13.

[38] Professor Jenny Gamble, Member, ACM, *Committee Hansard*, 16 September 2020, p. 13.

[39] NHMRC, *Australian guidelines to reduce health risks from drinking alcohol*, p. 15.

[40] NHMRC, *Australian guidelines to reduce health risks from drinking alcohol*, p. 15.

[41] AIHW, *National Drug Strategy Household Survey 2019*, 2020, p. 72; AIHW, *National Drug Strategy Household Survey 2016: Detailed Findings,* July 2017, p. 116. NHMRC, *Australian guidelines to reduce health risks from drinking alcohol*, July 2020, p. 15. Risky drinking (single occasion risk) is defined for healthy men and women as no more than four standard drinks on a single occasion.

2.37 In addition, the committee heard concerns about the increased risk of alcohol consumption during pregnancy due to the COVID-19 pandemic.[42]

2.38 In its December 2020 report on alcohol, tobacco and other drugs in Australia, the Australian Institute of Health and Welfare (AIHW) noted mixed data on rates of alcohol consumption in Australian households during the COVID-19 pandemic. The report cites various studies, including polling by FARE which showed an increase in the consumption and sale of alcohol since early 2020.[43]

Low levels of awareness of the risks

2.39 There is an alarming lack of community awareness of the risks of alcohol consumption during pregnancy, with studies suggesting that 60 per cent of women drink at any time in pregnancy, and 40 per cent are unaware that alcohol could harm the fetus.[44]

2.40 A national survey of 1103 women found that, although 92.7 per cent of women surveyed thought that alcohol could affect the unborn child, 16.2 per cent of women did not know that the resulting disability could be life-long.[45]

2.41 The National Alliance for Action on Alcohol stated that low levels of population awareness mean that women are not supported to abstain from alcohol during pregnancy.[46]

Social and cultural pressure

2.42 Inquiry participants commented on the persuasive role of social and cultural pressures on a woman's drinking behaviours during pregnancy.[47]

2.43 According to one clinician that gave evidence to the committee, women face significant family and social pressures to drink:

> I work in both the public system and the private system and I still have very well educated women for whom I provide care who ask: 'It's okay to

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42 Ms Sarah Jackson, Senior Legal Policy Adviser, Cancer Council Victoria, *Committee Hansard*, 24 June 2020, p. 3; Dr Kathryn Antioch, Chief Executive Officer, Guidelines and Economists Network International, *Committee Hansard*, 16 September 2020, p. 25.

43 AIHW, *Web report: Alcohol, tobacco and other drugs in Australia*, 15 December 2020, https://www.aihw.gov.au/reports/alcohol/alcohol-tobacco-other-drugs-australia/contents/impact-of-covid-19-on-alcohol-and-other-drug-use (accessed 25 February 2021).

44 Alcohol Policy Coalition, *Submission 19*, p. 2; National Alliance for Action on Alcohol, *Submission 27*, [p. 1]; Professor Elizabeth Elliott, Co-Director, FASD Research Australia Centre of Research Excellence, Telethon Kids Institute, *Committee Hansard*, 19 May 2020, p. 27.

45 FASD Research Australia, *Submission 42*, p. 2.

46 National Alliance for Action on Alcohol, *Submission 27*, [p. 1].

47 See, for example, University of Queensland, *Submission 36*, p. 6; National Drug Research Institute, *Submission 1*, p. 8; Ms Evelyne Muggli, Senior Research Officer, Murdoch Children's Research Institute, *Committee Hansard*, 19 May 2020, p. 22.

> drink, isn't it? I think it's okay to have the odd drink when you're pregnant.' I think part of it is wishful thinking. There's enormous community pressure with alcohol use, a lot of family and social pressure, and people ask you hopefully.[48]

2.44 Ms Evelyne Muggli of the Murdoch Children's Research Institute told the committee that women who drink throughout pregnancy tend to believe that the amount they drink is without harm, or they do what family and friends with healthy children have done.[49]

2.45 A survey by NOFASD found that over half the women surveyed were encouraged to drink when they did not want to, a particular problem for women who chose not to announce their pregnancy in the first trimester. A third of women were encouraged to drink alcohol during their pregnancy.[50]

2.46 According to FARE, alcohol consumption during pregnancy is seen as 'somewhat acceptable'.[51] This belief appears to be underpinned by several factors, including a view that drinking during pregnancy is commonplace and less risky because family and friends have drank alcohol in pregnancy before with no apparent consequences.[52]

Environment and circumstances

2.47 Australian women living with poor mental health, high life stress, poverty, housing and legal issues, concurrent drug use and exposure to domestic and family violence and trauma are more likely to use alcohol during pregnancy.[53]

2.48 The National Drug Research Institute noted that the presence of anxiety and depression also increases the risk of alcohol consumption during pregnancy, and therefore increases the risk of FASD.[54]

2.49 Research also shows that women who drank prior to pregnancy or during a previous pregnancy, who smoke and use other drugs, are more likely to consume alcohol during pregnancy.[55]

2.50 The committee heard that there are several consistent environmental factors contributing to alcohol consumption during pregnancy internationally.[56]

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48 Professor Stephen Robson, Council Member, AMA, *Committee Hansard*, 16 September 2020, p. 5.

49 Ms Evelyne Muggli, Senior Research Officer, Murdoch Children's Research Institute, *Committee Hansard*, 19 May 2020, p. 22.

50 NOFASD, *Submission 40*, Attachment 1, [p. 4].

51 FARE, *Submission 50*, p. 14.

52 FARE, *Submission 50*, p. 14–15.

53 FARE, *Submission 50*, p. 17.

54 National Drug Research Institute, *Submission 1*, [pp. 7–8].

55 National Drug Research Institute, *Submission 1*, [pp. 1–4].

56 FARE, *Submission 50*, p. 6.

Studies in the US, Europe, New Zealand, Japan, Uganda and Australia have all shown that pre-pregnancy alcohol consumption, and exposure to abuse or violence, increases the likelihood of women using alcohol during pregnancy.[57]

2.51 The National Drug Research Institute cited several studies demonstrating that women were at greater risk of continued and/or binge drinking where there is problematic drinking amongst family and friends:

> These repeated findings provide strong evidence that psycho-education on the risks of alcohol consumption during pregnancy is as important for partners and family as it is for women.[58]

Incorrect and inconsistent messages

2.52 The committee heard that Australian women are receiving inconsistent messages about the risks of drinking alcohol during pregnancy from their family, friends and health providers.[59]

2.53 NOFASD found that half of the women it surveyed were told it is safe to drink during pregnancy. This information came from a wide range of sources – family, friends, other mothers including those who drank through pregnancy, online forums and doctors and obstetricians.[60]

2.54 As discussed in further detail in Chapter 3, despite an increasing level of awareness of FASD amongst health professionals, the risks of alcohol consumption are not well understood and as a result, women have received incorrect and inconsistent medical advice.[61]

Prevalence of FASD in Australia

Current estimates

2.55 The prevalence of FASD in Australia is still largely unknown and believed to be significantly underreported.[62]

2.56 Current estimates suggest FASD affects five per cent of the Australian population, with a potential range of between two and nine per cent of babies born with FASD each year.[63]

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57 FARE, *Submission 50*, p. 6.

58 National Drug Research Institute, *Submission 1*, [p. 7–8].

59 University of Queensland, *Submission 36*, p. 7.

60 NOFASD, *Submission 40*, Attachment 1, [p. 3].

61 See Chapter 2, paragraphs 3.8–3.12.

62 FARE, *Submission 50*, Attachment 1, p. 39.

63 Food Regulation Standing Committee, *Decision Regulation Impact Statement: Pregnancy Warning Labels on Packaged Alcoholic Beverages*, October 2018, p. 26; Senator the Hon Richard Colbeck, Minister for Aged Care and Senior Australians and Minister for Youth and Sport, *Letter to the*

2.57 Modelling for the Food Regulation Standing Committee undertaken in 2018 concluded that there is a plausible FASD incidence rate of five per cent of the Australian population, drawing upon a range of international data and research.[64]

2.58 The modelling notes that:

- FASD prevalence in the US is estimated to be between one and five per cent of school children. Australia's rate of alcohol consumption during pregnancy is three times that of the US and Canada;[65] and
- Other international prevalence estimates for FASD in school children are four to seven percent in Croatia, four to five per cent in Italy and six to 21 per cent in South Africa. Australia's rate of alcohol consumption in pregnancy is also higher than these countries.[66]

2.59 Mr Michael Frost of the AIHW commented on the challenge of prevalence figures in Australia:

> There are studies that people do to try to estimate levels, and I understand there are some advanced studies in Canada and the United States suggesting a five per cent prevalence of FASD. That's an estimate that people think might apply in Australia as a similar country to those two countries, but we don't have anything at the moment that provides a broad estimate of FASD.[67]

An intergenerational problem

2.60 Inquiry participants told the committee that FASD is becoming an intergenerational problem.[68]

2.61 The Gold Coast Hospital and Health Service, Child Development Service, reported intergenerational FASD amongst its patients:

> … we see within the clinic – on reviewing histories of the children – strong clinical indicators (including confirmed prenatal alcohol exposure) that biological parents had a high probability of having FASD.[69]

President of the Senate in response to Senate Order for Production of Documents No. 601, [p. 17] (tabled 12 June 2020); FARE, *Submission 50*, p. 5.

64 Food Regulation Standing Committee, *Decision Regulation Impact Statement: Pregnancy Warning Labels on Packaged Alcoholic Beverages*, October 2018, p. 26.

65 Food Regulation Standing Committee, *Decision Regulation Impact Statement: Pregnancy Warning Labels on Packaged Alcoholic Beverages*, October 2018, p. 26

66 Food Regulation Standing Committee, *Decision Regulation Impact Statement: Pregnancy Warning Labels on Packaged Alcoholic Beverages*, October 2018, p. 26.

67 Mr Michael Frost, Group Head, Primary and Maternal Health and Veterans Group, AIHW, *Committee Hansard*, 19 May 2020, p. 15.

68 See, for example, Gold Coast Hospital and Health Service, Child Health Service, *Submission 35*, p. 21; Royal Far West, *Submission 68*, p. 1; North Australian Aboriginal Justice Agency, *Submission 66*, p. 6.

2.62 Royal Far West told the committee that FASD is also having intergenerational impacts in regional, remote and rural communities:

> For children, adolescents and families in regional, remote and rural communities, it is likely that FASD contributes to already high rates of developmental and health problems, with potential lifespan and intergenerational impacts.[70]

Prevalence in vulnerable populations

2.63 FASD Research Australia estimates the prevalence of FASD to be 10 to 40 times higher amongst children in foster and state care, correctional facilities, special education, specialised clinics and First Nations populations than the general population.[71]

First Nations communities

2.64 Whilst the misuse of alcohol has translated into a high prevalence of FASD in some First Nations communities, the true prevalence of FASD in this group remains unknown.[72]

2.65 Fitzroy Crossing in the West Kimberley region of Western Australia (WA) has the highest reported prevalence of FASD in Australia with rates of FASD or partial FASD of 12 per 100 children. This is on par with the highest rates internationally.[73]

Northern Territory

2.66 The Northern Territory (NT) has the highest per capita consumption of alcohol in Australia.[74] Both First Nations people and the rest of the population suffer from the harms of risky alcohol consumption in the NT.[75]

2.67 Overall, alcohol consumption by First Nations people in the NT is much higher than the national average for First Nations people.[76]

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69 Gold Coast Hospital and Health Service, Child Health Service, *Submission 35*, p. 21.

70 Royal Far West, *Submission 68*, p. 1.

71 FASD Research Australia, *Submission 42,* p. 16. Statistics are based on systemic reviews of several Australian studies into First Nations communities and a youth detention center.

72 See, for example, Central Australian Aboriginal Congress (Congress), *Submission 59,* p. 17; Joint submission of Professor Harry Blagg, Mrs Suzie May, Dr Tamara Tulich, Dr Robyn Williams, *Submission 22,* p. 2; North Australian Aboriginal Justice Agency (NAAJA), *Submission 66,* p. 5.

73 Joint submission of Professor Harry Blagg, Mrs Suzie May, Dr Tamara Tulich, Dr Robyn Williams, *Submission 22,* p. 2.

74 Danila Dilba Health Service, *Submission 61,* p. 5.

75 Danila Dilba Health Service, *Submission 61,* p. 5.

76 Ms Prue Walker, *Submission 47,* Attachment 1, p. 4.

2.68 However, FASD prevalence in the NT is unknown.[77] Anecdotally, it is recognised that many NT children are experiencing learning difficulties, have difficulty controlling their emotions and impulses, and many young people are coming into contact with the juvenile system.[78]

2.69 The Central Australian Aboriginal Congress reported that in Central Australia, the Australian Early Developmental Index suggests a very high number of developmentally vulnerable First Nations children and concluded:

> While not all such children would have FASD, alcohol consumption either pre or post-birth would contribute a high proportion of these developmental vulnerabilities.[79]

Children in the justice system

2.70 In WA, a data linkage study has shown that exposure to alcohol during pregnancy increases the risk of contact with the youth justice system. This is the case even adjusting for risk factors such as social disadvantage, indigenous status and poor academic performance.[80]

2.71 A study conducted in the Banksia Hill Detention Centre in Perth, the only youth detention centre in WA, found a high prevalence of FASD (36 per cent) among detainees, most of which identified as First Nations peoples.[81] This is the highest reported prevalence of FASD in a youth setting in the world.[82]

2.72 Evidence before the committee suggests similar prevalence of FASD in the NT youth justice system. Dr Andrew Webster of the Danila Dilba Health Service commented on FASD in the Don Dale Youth Detention Centre in Darwin:

> While we cannot yet provide rigorous estimates of the prevalence of FASD in the Don Dale Youth Detention Centre, early indications from our staff are that it is at least as high as that found in the Banksia Hill study in Western Australia—that is, likely greater than a third of all detainees have FASD.[83]

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77 NT Government, *Submission 2*, p. [11].

78 NT Government, *Submission 2*, p. [11].

79 Congress, *Submission 59*, p. 17.

80 Ms Prue Walker, *Submission* 47, p. 4.

81 Joint submission by Professor Harry Blagg, Mrs Suzie May, Dr Tamara Tulich, Dr Robyn Williams, *Submission 22*, p. 3.

82 See discussion in Joint submission of Professor Harry Blagg, Mrs Suzie May, Dr Tamara Tulich, Dr Robyn Williams, *Submission 22*, p. 3.

83 Dr Andrew Webster, Head of Clinical Governance, Danila Dilba Health Service, *Committee Hansard*, 14 October 2020, p. 2.

Children in foster and state care

2.73 The committee heard that FASD is widely underdiagnosed in children in care.[84]

2.74 WA research linking birth data to subsequent child protection involvement found that the greatest risk to entry into child protection was where mothers had an alcohol diagnosis during pregnancy.[85] The research showed 13.4 per cent of alcohol-exposed children entered care compared to 2.1 per cent of controls.[86]

2.75 Of the 590 children with FASD recorded in the national FASD case register between 2015 and 2019, approximately 80 per cent live in out-of-home care. This includes children living with grandparents (20 per cent), extended family (9 per cent) and in foster or adoptive care (49 per cent).[87]

Social and economic costs of FASD

2.76 International research provides an indication of the scale of the economic and social burden of FASD.[88]

2.77 FASD Research Australia cited research from Canada that conservatively estimated the cost of FASD to be $1.8 billion CAD:

> This estimate considered direct costs associated with medical and health services, law enforcement, children and youth in care, special education, supportive housing, long term care, prevention and research, and indirect costs such as productivity losses due to increased morbidity and premature mortality. Productivity losses were the highest contributor at 41% of the total costs, followed by corrective services at 29%, and health care at 10%.[89]

2.78 The Australian College of Midwives (ACM) submitted that the cost of FASD in Australia, just considering the health care and welfare systems, would be extensive:

> The cost to the Australian health care and welfare systems is likely to be in the order of billions of dollars. This is supported by the fact that FASD is a lifelong condition associated with a multitude of comorbidities, many of

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84 Ms Prue Walker, *Submission 47*, p. 3.

85 Ms Prue Walker, *Submission 47*, p. 3.

86 Ms Prue Walker, *Submission 47*, p. 4.

87 Professor Elizabeth Elliot, Co-Director, FASD Research Australia Centre of Research Excellence, Telethon Kids Institute, *Committee Hansard,* 19 May 2020, p. 28; FASD Research Australia, answers to questions on notice, [p. 2].

88 FASD Research Australia, answers to questions on notice, (received 5 June 2020), [p. 1].

89 FASD Research Australia, answers to questions on notice, (received 5 June 2020), [p. 1].

> which are known to increase a person's access to acute and chronic health care.[90]

2.79 The Gold Coast Hospital and Health Service, Child Development Service, suggested the potential cost of FASD in the Australian justice system would also be significant, noting:

- the current costs of keeping a juvenile in detention is estimated at $1500 a day;
- known rates of intellectual disability in the justice system are approximately 11 per cent; and
- the findings of the Banksia Hill Detention study, referred above, which showed that 36 per cent of juveniles in detention were diagnosed with FASD.[91]

2.80 According to FASD Research Australia, further investigation into the social and economic burden of FASD is needed in Australia, and it recommended further research using available WA government data:

> This data linkage capability in WA provides a unique opportunity to understand the associations between FASD and adverse outcomes across health, child protection, education and justice, and assess their economic impact, and identify the implications for policy, service delivery and prevention.[92]

Data on FASD and maternal alcohol consumption

2.81 Evidence before the committee outlined the importance of data on confirmed FASD cases, and maternal alcohol consumption, for prevention efforts.[93]

2.82 However, the committee heard that collection of both types of data is problematic and does not provide a full picture of FASD prevalence or the extent of maternal alcohol consumption.[94]

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90 Australian College of Midwives, *Submission 31,* [p. 7].

91 Gold Coast Hospital and Health Service, Child Development Service, *Submission 35*, p. 21. See paragraph 2.71 above for further discussion on the Banksia Hill Detention study.

92 FASD Research Australia, answers to questions on notice, [p. 1]. FASD Research Australia advised that in WA, availability of data means that FASD notifications to the Western Australian Register of Developmental Anomalies can be analysed with state data on mortality, hospital morbidity, intellectual disability, education, child protection and justice.

93 FARE, *Submission 50,* Attachment 2, p. 25.

94 See, for example, Australian Medical Association, *Submission 5*, p. 2; Jandu Yani U Project Team, *Submission 49,* p. 8.

Data on maternal alcohol consumption

Birth notifications and state/territory data collection

2.83 Alcohol consumption is part of the mandatory data collection for birth notification forms.[95] Notification forms are completed by midwives and other birth attendants, for every birth, using information from mothers, as well as hospital and other records.[96]

2.84 The AIHW told the committee that each state and territory has its own birth notification form and/or electronic system for collecting data on each birth. That data is then forwarded to the relevant state and territory health departments to form the state or territory perinatal data collection.[97]

2.85 The ACM explained that most women (99 per cent) birth within the mainstream health system and therefore their data is captured in 'routine information collection processes'.[98]

National Perinatal Data Collection

2.86 The National Perinatal Data Collection (NPDC) is a de-identified set of pregnancy and childbirth data provided by states and territories to the AIHW on an annual basis.[99]

2.87 The NPDC has included a 'voluntary non-standardised indicator on alcohol consumption' since 2009, although only three jurisdictions have contributed this information to date (Tasmania, the ACT and the NT).[100] The AIHW told the committee that 'the quality of the data has not been assessed'.[101]

2.88 In addition to voluntary data, the NPDC includes a subset of data items that form the Perinatal National Minimum Data Set. This is a set of data items agreed for mandatory collection and reporting at a national level.[102]

2.89 The inquiry heard that from 1 July 2019, the NPDC has been expanded to include six standardised indicators of maternal alcohol consumption during

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95 Australian College of Midwives, answers to questions on notice (received 16 October 2020), [p. 2].

96 AIHW, answers to questions on notice – IQ20-000243 (received 4 September 2020), [p. 2].

97 AIHW, answers to questions on notice – IQ20-000243, [p. 2].

98 Australian College of Midwives, answers to questions on notice, [p. 2].

99 AIHW, *Submission 6*, p. 3; AIHW, answers to questions on notice – IQ20-000241 (received 4 September 2020), [p. 1].

100 AIHW, *Submission 6*, p. 3.

101 AIHW, *Submission 6*, p. 3.

102 AIHW, answers to questions on notice – IQ20-000241 (received 4 September 2020), [p. 1].

pregnancy. This includes the number of standard drinks/frequency of consumption during the first 20 weeks of pregnancy.[103]

2.90 The AIHW told the committee that states and territories have agreed to collect the data, which is consistent with questions in the national diagnostic tool (AUDIT-C), however it is voluntary, and data will not be available until mid-2021.[104]

The need for mandatory national data collection

2.91 The Deeble Institute suggested the Perinatal National Minimum Dataset include mandatory collection and reporting of alcohol in pregnancy data, for contribution to the National Perinatal Data Collection.[105]

2.92 In WA, prenatal alcohol use has been a mandatory item on the Midwives Notification System since 2017.[106]

2.93 According to FASD Research Australia, mandatory inclusion of data on maternal alcohol use in the National Perinatal Data Collection has been recommended for many years.[107]

2.94 FARE suggested that the Government support the AIHW to implement mandatory recording of alcohol use during pregnancy.[108]

2.95 The NSW Government told the committee that it is 'supportive of the development of metadata standards' for reporting 'subject to national consensus'.[109]

Data on cases of FASD

National FASD case register

2.96 Cases of FASD are reported by paediatricians to the national FASD case register.[110]

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[103] AIHW, *Submission 6*, p. 3.

[104] Mr Michael Frost, Group Head, Primary and Maternal Health and Veterans Group, AIHW, *Committee Hansard*, 19 May 2020, p. 11. The AUDIT-C tool (Alcohol Use Disorders Identification Test – Consumption) is a validated screening tool used to collect information about consumption of alcohol during pregnancy, and is recommended by the *Australian guide to the diagnosis of FASD*. For further discussion about the routine use of the AUDIT-C tool, see Chapter 3, paragraphs 3.32–3.38.

[105] FARE, *Submission 50*, Attachment 2, p. 26.

[106] FASD Research Australia, *Submission 42*, p. 22.

[107] FASD Research Australia, *Submission 42*, p. 22.

[108] FARE, *Submission 50*, p. 9.

[109] NSW Government, *Submission 57*, p. 8.

[110] FASD Research Australia, *Submission 42*, p. 12.

2.97 The national FASD case register is managed and monitored at a national level by the Australian Paediatric Surveillance Unit. This project is led by FASD Research Australia at the University of Sydney and funded by the Australia Government.[111]

2.98 Several health clinics told the inquiry that they contribute to the data gathered by the Australian Paediatric Surveillance Unit.[112]

2.99 The University of Queensland submitted, however, that there were clear problems with the data:

> Diagnostic rates of FASD in Australia currently rely on paediatricians reporting to the Australian Paediatric Surveillance Unit. This will evidently be an underestimation of the true rates of diagnosis.[113]

2.100 FASD Research Australia told the committee that the national FASD case register relies on renewable competitive grant funding, and that the Australian Paediatric Surveillance Unit continues to operate the national FASD register despite the previous grant period having ceased.[114]

2.101 The Department of Health noted that funding over 2019–20 to 2022–23 had been allocated to continue the operation of the national FASD case register.[115]

National Congenital Anomalies Data Collection

2.102 The AIHW told the committee that it is re-establishing the National Congenital Anomalies Data Collection. The collection, which ceased in 2008, includes data on babies who have a diagnosed congenital anomaly and will be expanded to include fetal alcohol syndrome (FAS).[116]

2.103 The AIHW recommended that FASD be a notifiable condition in the state-and territory-based congenital anomaly conditions registers, a step which would improve the availability of data for the National Congenital Anomalies Data Collection.[117]

2.104 However, Mr Michael Frost of the AIHW, acknowledged that the collection is focused on FAS only, and would require substantial work to achieve consistency from all jurisdictions noting not all collect the same data:

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111 FASD Research Australia, *Submission 42*, p. 12.

112 Gold Coast Hospital and Health Service, Child Development Service, *Submission 35*, p. 2; VicFAS, *Submission 34*, p. 13.

113 University of Queensland, *Submission 36*, p. 17.

114 FASD Research Australia, answers to questions on notice (received 5 June 2020), [p. 2].

115 Department of Health, answer to questions on notice – IQ20-000234 (received 12 June 2020), [p. 4].

116 Mr Michael Frost, Group Head, Primary and Maternal Health and Veterans Group, AIHW, *Committee Hansard*, 19 May 2020, p. 11.

117 Mr Michael Frost, Group Head, Primary and Maternal Health and Veterans Group, AIHW, *Committee Hansard*, 19 May 2020, p. 12.

> This would require substantial system changes and, possibly, legislative and financial commitments to ensure that happens. To my knowledge there are no active discussions to make that happen, but we did recommend it.[118]

Other opportunities for improved data collection

2.105 The University of Queensland suggested that, given the availability of electronic health data, data linkages should be explored to capture diagnostic rates more efficiently and effectively.[119]

Lack of national data

2.106 The committee heard that a lack of comprehensive national data on the prevalence of FASD is a major impediment to developing effective policy responses.[120]

2.107 Emerging Minds told the committee that collecting data on prenatal alcohol consumption and the prevalence of FASD in Australia is crucial to understanding the scale of the problem and enabling the design of appropriate services and interventions.[121]

2.108 However, data collection is limited by several factors including a lack of diagnostic expertise resulting in large numbers of children awaiting assessment as well as missed or misdiagnosis.[122] Self-reporting of alcohol consumption via the National Drug Strategy Household surveys or midwives also contributes to data issues.[123]

2.109 The Australian Medical Association expressed concerns that the lack of data is perpetuating a general belief that FASD is not a problem in general population and may contribute to tolerant attitudes to alcohol consumption during pregnancy.[124]

2.110 The Jandu Yani Yu project, which provides FASD support to parents and carers in the Fitzroy Crossing area, commented that the focus on FASD and First Nations communities by policymakers gives the false impression that FASD is an 'indigenous problem':

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[118] Mr Michael Frost, Group Head, Primary and Maternal Health and Veterans Group, AIHW, *Committee Hansard,* 19 May 2020, p. 12.

[119] University of Queensland, *Submission 36,* p. 17.

[120] Australian Human Rights Commission, Submission 17, p. 9.

[121] Emerging Minds, *Submission 15*, [pp. 15–16].

[122] Emerging Minds, *Submission 15*, [pp. 15–16]. See Chapter 4 for further discussion on diagnosis of FASD and some of the prevailing obstacles.

[123] Emerging Minds, *Submission 15*, [pp. 15–6].

[124] Australian Medical Association, *Submission 5*, p. 2.

> Wider population screening, diagnosis and data collection is essential to elucidating the more accurate, cross-cultural challenge of FASD.[125]

2.111 The *National Fetal Alcohol Spectrum Disorder strategic action plan 2018–2028* recognises the difficulty of measuring FASD prevalence in Australia and suggests the need to 'continue to improve national prevalence data on FASD'.[126]

Committee view

2.112 The committee acknowledges the devastating impact of FASD for those living with FASD, their families and communities. Although there is a growing awareness of FASD, there is still widespread misunderstanding of the range of conditions and behaviours that may present in a person with FASD.

2.113 The committee notes that these conditions can affect each person in different ways and can range from mild to severe. Impaired decision making and impulse control for example has serious flow on effects for a person's ability to participate effectively in education and the workforce, leading to lifelong consequences without appropriate intervention and support.

Alcohol and pregnancy

2.114 The committee is concerned with the high rate of prenatal alcohol exposure in Australia. Although declining over recent years, there is still 35 per cent of women who have drank at some point during their pregnancy, thus putting the fetus at risk of FASD. The committee considers there is a much greater role for partners, family and friends, and the broader community, to reduce harmful alcohol consumption and support women to abstain during pregnancy.

2.115 The committee notes the growing evidence regarding risk factors for women who are more likely to consume alcohol during pregnancy as a result of a range of domestic studies. This work has, and will continue, to contribute tremendously to preventative efforts, as explored further in the next chapter.

2.116 It is clear that a major factor influencing alcohol consumption during pregnancy remains a lack of awareness of the risks. Of particular concern to the committee is the drinking culture in Australia and prevailing and distorted views about what constitutes 'harmful' drinking in the context of a pregnancy and more broadly. There is clear need to do more to educate the community, and health professionals, about the risks of alcohol and pregnancy. This is further explored in Chapter 3.

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[125] Jandu Yani U Project Team, *Submission 49*, p. 8.

[126] Department of Health, *National Fetal Alcohol Spectrum Disorder (FASD) strategic action plan 2018–2028*, p. 23.

Prevalence

2.117 There is a desperate need for prevalence data to support policy efforts. Without robust data on FASD prevalence, the committee notes that measuring progress against the *National FASD strategic action plan* and the *National alcohol strategy 2019–2028* will be very difficult.

2.118 The committee is of the view that the national FASD case register is collecting valuable data on the number of cases of FASD. However, it continues to be reliant on short-term funding through grants. The committee considers that the lack of investment in this important piece of national infrastructure represents a significant gap in the Australian Government's response to the Hidden Harm inquiry.

Recommendation 1

2.119 The committee recommends that the Australian Government provide long-term funding for the national FASD case register and develop a multi-year strategy and budget for data collection and related research activities.

Recommendation 2

2.120 The committee recommends that the Australian Government fund a FASD Prevalence Study to determine the national prevalence of FASD cases, including both known cases and those considered 'at risk' of FASD in the Australian population.

2.121 The committee commends the Commonwealth, states and territories for their recent move to collect standardised data on maternal alcohol consumption as a part of the National Perinatal Data Collection. However the committee has concerns that the reporting is voluntary.

Recommendation 3

2.122 The committee recommends that the Australian Government in consultation with State and Territory Governments implement mandatory reporting on standardised data for maternal alcohol consumption in the Perinatal National Minimum Data Set.

Social and economic costs

2.123 The social and economic costs of FASD in Australia are not yet quantified. However, the committee is of the view that considering conservative estimates of FASD prevalence, the costs are immense. The committee is concerned about the current and future impact of FASD on national infrastructure and resourcing associated with the justice system, education supports, healthcare services, and productivity losses.

2.124 The committee acknowledges the recent budgetary measures made by the Australian Government through the *National alcohol strategy 2019–2028* and the *National FASD strategic action plan*. However, it considers that without having undertaken a robust study of the economic and social burden of FASD in Australia, the budgetary measures may not be appropriately targeted.

Recommendation 4

2.125 The committee recommends that the Australian Government fund an independent study into the social and economic cost of FASD in Australia.

Chapter 3
Preventing FASD

> The decisions that are made now have the potential to impact the lives of future generations for the better. With a condition that is preventable and also lifelong, we all have a responsibility to put the health and wellbeing of families first, just as we are doing now as a community.[1]

3.1 Antenatal brain injury caused by alcohol consumption during pregnancy cannot be reversed, and therefore prevention must be the focus of FASD efforts. This chapter examines the role of health professionals, prevention and awareness initiatives, and the issue of alcohol availability and what more can be done to prevent FASD by the government and the alcohol industry.

The role of health professionals

3.2 A range of health professionals play a role in FASD prevention efforts, with midwives, general practitioners (GPs) and specialists involved from pre-conception, confirmation and throughout a woman's pregnancy to birth.[2]

Early contact with health services

3.3 The first time a woman makes contact with a health service regarding family planning and contraception is an opportune time to discuss the risks of alcohol consumption during pregnancy.[3]

3.4 However, concerns were raised during the inquiry that the opportunity to provide guidance around alcohol consumption is often missed or significantly delayed.[4] It is often the case that the first antenatal visit does not occur until well into a woman's first trimester.[5]

3.5 In the case of unplanned pregnancies, a woman's first antenatal visit can also be significantly delayed, by which time alcohol may have been consumed without the woman's knowledge of her pregnancy.[6]

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1 Ms Caterina Giorgi, Chief Executive Officer, Foundation for Alcohol Research and Education (FARE), *Committee* Hansard, 24 June 2020, pp. 1–2.

2 Alcohol and Drug Foundation, *Submission 37*, p. 4.

3 Alcohol and Drug Foundation, *Submission 37*, p. 4.

4 Catholic Women's League Australia (CWLA), *Submission 26*, p. 4; Professor Elizabeth Elliott, Fellow, Royal Australasian College of Physicians, *Committee Hansard*, 16 September 2020, p. 4; Professor Stephen Robson, Council Member, Australian Medical Association (AMA), *Committee Hansard*, 16 September 2020, p. 6.

5 CWLA, *Submission 26*, p. 4.

6 CWLA, *Submission 26*, p 4; Professor Elizabeth Elliott, Fellow, Royal Australasian College of Physicians, *Committee Hansard*, 16 September 2020, p. 4.

3.6 The Alcohol and Drug Foundation explained the important role that health professionals play:

> As a point of first contact, doctors, midwives and other health care practitioners are in a unique position to play a crucial role in the prevention and identification of FASD. Appropriate screening of prenatal alcohol use should be prioritized and completed for all women to help identify women who may be at risk prior to pregnancy.[7]

Barriers to discussing alcohol consumption

3.7 Research and evaluations conducted as a part of the *Women Want to Know* project found that health professionals face a range of barriers to discussing alcohol consumption with women, including:

- Lack of knowledge of the risks and consequences of alcohol consumption during pregnancy;
- fear of negative reactions;
- perceived lack of self-efficacy;
- lack of skills and tools to intervene;
- difficulty discussing alcohol consumption if there were pregnancy complications;
- an assumption that alcohol would be discussed by another health professional (where a woman sees multiple providers, such as a GP and a midwife); and
- a desire to provide reassurance where alcohol has been consumed during before pregnancy.[8]

A lack of understanding of the risks of alcohol consumption during pregnancy

3.8 The *Women Want to Know* project revealed that, despite a level of awareness of FASD, there are prevailing myths that persist amongst health professionals.[9]

3.9 This included the view that there was a 'safe time' to drink during pregnancy, a 'safe amount' of alcohol that could be consumed, and a 'safe type' of alcohol, that is, that some alcohol has a worse impact on the developing fetus.[10]

3.10 Studies have shown that although health professionals are broadly aware of the guidance that women should completely abstain from alcohol during pregnancy, there is a lack of understanding of the negative consequences, and as a result women are receiving poor advice.[11]

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7 Alcohol and Drug Foundation, *Submission 37*, p. 4. For further discussion on screening, see below, paragraphs 3.22–3.28.

8 FARE, *Submission 50*, p. 18.

9 FARE, *Submission 50*, p. 19.

10 FARE, *Submission 50*, p. 19.

11 FARE, *Submission 50*, p. 20.

3.11 According to a study of midwives in South Australia, the specific effects of alcohol consumption during pregnancy were not well understood amongst participants:

> … when it came to attitudes towards alcohol consumption during pregnancy several midwives expressed views divergent from the Alcohol Guidelines. They felt that small amounts of alcohol were unlikely to be harmful and some advised women that if they wanted an occasional drink, that would be acceptable.[12]

3.12 The mother of a teenage boy with FASD described to the committee how the combined advice of midwives, GPs and the national alcohol guidelines, during her pregnancy, suggested that drinking in moderation was safe:

> I visited the GP and he reassured me that I shouldn't be concerned and that was a massive relief. I read the guidelines from the National Health and Medical Research Council—this is prior to 2009. It was deemed safe to drink two standard drinks per day and no more than 10 per week. I asked my midwife about alcohol in pregnancy, and 'The odd one or two won't hurt,' was the reply. To give you an idea, I would drink one weak coffee a week, I would wash my salad and I would avoid soft cheese and pate for fear of causing harm to my developing baby. However, I still remember very clearly standing in my kitchen on a Friday night, as my treat, measuring one unit of wine.[13]

Stigma

3.13 The Australian Medical Association noted that clinicians are generally reluctant to discuss FASD with their patients because of the perceived stigma associated with consuming alcohol during pregnancy.[14]

3.14 Professor Elizabeth Elliott of the Royal Australasian College of Physicians explained:

> There ha[ve] been studies done specifically on this in Australia. Doctors tell us they are afraid to ask because they don't want to make the patient anxious and upset. They're worried about disrupting the doctor-patient relationship. Also, they don't know how to ask in a meaningful way. They don't know what questions to use, and, if they do find out that the woman is drinking alcohol, they don't necessarily know what to do about it and where to refer them.[15]

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[12] FARE, *Submission 50*, p. 20, citing Fiona Crawford-Williams, Mary Steen, Adrian Esterman, Andrea Fielder and Antonina Mikocka-Walus, '"If you can have one glass of wine now and then, why are you denying that to a woman with no evidence": Knowledge and practices of health professionals concerning alcohol consumption during pregnancy', *Women and Birth*, vol. 28, no. 4, 2015, pp. 329–335, https://doi.org/10.1016/j.wombi.2015.04.003.

[13] Sophie, Private capacity, *Committee Hansard*, 24 June 2020, p. 14.

[14] AMA, *Submission 5*, p. 3; AMA, answers to written questions on notice 29 September 2020 (received 21 October 2020), p. 2.

[15] Professor Elizabeth Elliott, Fellow, Royal Australasian College of Physicians, *Committee Hansard*, 16 September 2020, p. 74.

3.15 The National Organisation for Fetal Alcohol Spectrum Disorders (NOFASD) told the committee that the issue of stigma is complex and also affects how a pregnant woman will engage with her health provider:

> … as one birth mother said the stigma began with the unplanned pregnancy. Women at risk of an alcohol exposed pregnancy are potentially already experienced at avoiding contact with services because of the stigma associated with their alcohol use. Stigma, fear and shame will further drive patients in need away from services.[16]

3.16 According to the National Drug Research Institute, women overwhelmingly want health professionals to inform them about drinking during pregnancy and the risk of FASD, however, there is a hesitancy to do so due to the perceived sensitivity of the issue:

> This reluctance among the health profession to provide appropriate advice and information indicates the need for effective training so the needs of women and their families are met.[17]

Health professional's personal views and assumptions

3.17 Another barrier to women getting accurate, timely and appropriate advice on alcohol and pregnancy appears to be the belief held by health professionals that most women already know to reduce their consumption or to abstain from alcohol and therefore do not require advice.[18]

3.18 Whether or not a health practitioner will talk about alcohol consumption during pregnancy with a patient is also influenced by assumptions about a woman's social and economic circumstances, and in particular, the belief that women of lower socio-economic status are more likely to need advice.[19]

3.19 Research has found that older women in the higher socio-economic group were the most likely to continue drinking after finding out they were pregnant and yet they were the least likely to receive appropriate medical advice.[20]

3.20 A 2019 NSW study showed that women were more likely to receive advice and support if they had *not* gone to university, did not reside in an advantaged area, if it was their first pregnancy, and if they were from a regional/rural service location.[21]

3.21 Health practitioners report a reluctance to talk about FASD with patients displaying higher, problematic levels of alcohol consumption, as there they

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16 National Organisation for Fetal Alcohol Spectrum Disorders (NOFASD), *Submission 40*, p. 5.

17 National Drug Research Institute, *Submission 1*, [p. 6].

18 FASD Research Australia, *Submission 42*, p. 7.

19 FASD Research Australia, *Submission 42*, p. 7.

20 FASD Research Australia, *Submission 42*, p. 3.

21 FASD Research Australia, *Submission 42*, p. 8.

were assumed to be drinking in extenuating circumstances 'beyond the capacity of health professionals to address', such as socio-economic disadvantage, domestic violence and/or other substance use.[22]

Routine screening and brief intervention

3.22 International guidelines recommend screening and brief intervention to ensure that all women are asked about their alcohol use and that women who are drinking are offered advice.[23]

3.23 Screening involves asking questions to assist in assessing alcohol use and enables brief interventions which are aimed at identifying real or potential alcohol problems and motivating a person to do something about it.[24]

3.24 The Deeble Institute for Health Policy Research suggested that screening assessments should be used to provide tailored feedback to women about their alcohol use and enable referrals to appropriate supports and/or treatment services as required. In addition, screening should be underpinned by trauma-informed, person-centred and culturally secure care.[25]

3.25 The Foundation for Alcohol Research and Education (FARE) explained how routine screening and brief interventions can help inform and educate women:

> Questions about alcohol consumption should be asked along with other lifestyle questions about diet, exercise and whether the person smokes or not. These answers can give a better understanding of a person's health and allow for education on the risks associated with alcohol to take place in a non-judgemental manner.[26]

3.26 However, inquiry participants noted concerns that health professionals are not routinely asking women about their alcohol use during pregnancy or providing adequate medical advice.[27] FARE noted that there is 'no consistent implementation' of screening and brief intervention in maternity care in Australia.[28]

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22 FASD Research Australia, *Submission 42*, p. 7.

23 FARE, Submission 50, p. 12, citing the World Health Organization, *Guidelines for the identification and management of substance use and substance use disorders in pregnancy*, 2014 (accessed 11 February 2021).

24 World Health Organization, 'Management of substance abuse: screening and brief intervention or alcohol problems in primary health care', https://www.who.int/substance_abuse/activities/sbi/en/ (accessed 11 February 2021).

25 FARE, *Submission 50*, Attachment 2, p. 26.

26 FARE, *Submission 50*, Attachment 3, p. 16.

27 Australian College of Midwives (ACM), *Submission 31*, [p. 4]; NOFASD, *Submission 40*, Attachment 1, [p. 2].

28 FARE, *Submission 50*, p. 26.

3.27 Research suggests that only 45 per cent of health professionals routinely asked about a woman's alcohol use, and only 25 per cent provided information about the implications of drinking alcohol, suggesting that health professionals are acting on a presumption that a woman has stopped drinking alcohol.[29]

3.28 NOFASD reported similar statistics, with 47 per cent of women that participated in their online survey reporting that a GP had never spoken to them about alcohol use and pregnancy, and only 14 per cent reporting that they had received information before becoming pregnant.[30]

Contraception and family planning advice

3.29 The committee heard that advice on contraception, sexual health and pregnancy is not routinely provided by health professionals, even though women who drink alcohol during pregnancy are less likely to have planned the pregnancy.[31]

3.30 FARE told the committee that prevention strategies should include interventions that target both pre-pregnancy contraception and alcohol consumption before and during pregnancy.[32]

3.31 According to the Royal Australian College of General Practitioners all women who are pregnant or planning a pregnancy should be subject to screening, and referrals and advice provided as necessary, including contraceptive advice to reduce unplanned pregnancies.[33]

Use of the validated screening tool (AUDIT-C)

3.32 The Alcohol Use Disorders Identification Test–Consumption (AUDIT-C) tool is a validated screening tool used to collect information about consumption of alcohol during pregnancy, and is recommended by the *Australian guide to the diagnosis of FASD*.[34]

3.33 The University of Queensland suggested that the AUDIT-C tool should be used in all relevant clinical settings to standardise screening and the recording of antenatal alcohol use.[35] However, evidence put to the inquiry suggests that

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29 See, for example, ACM, *Submission 31*, [p. 4]; NOFASD, *Submission 40*, Attachment 1, [p. 2].

30 NOFASD, *Submission 40*, Attachment 1, [p. 1].

31 Emerging Minds, *Submission 15*, [p. 16].

32 FARE, *Submission 50*, p. 8.

33 Royal Australian College of General Practitioners, *Submission 53*, [p. 2].

34 Mr Michael Frost, Group Head, Primary and Maternal Health and Veterans Group, Australian Institute of Health and Welfare, *Committee Hansard*, 19 May 2020, p. 11. See Professor Carol Bower and Professor Elizabeth J Elliott AM, *Australian guide to the diagnosis of FASD*, 2016. Routine screening is discussed in further detail in Chapter 2, including how the AUDIT-C tool is currently used by primary health care workers to screen for alcohol use.

35 University of Queensland, *Submission 36*, p. 17.

the AUDIT-C tool, although well received and used in some jurisdictions and across disciplines, it is not routinely used throughout Australia.[36]

3.34 Inquiry participants outlined efforts to embed the AUDIT-C tool into templates and health records to help prompt routine discussions with pregnant women.[37]

3.35 For example, a project is underway in New South Wales (the Hunter New England project) to embed the AUDIT-C tool into e-maternity records to enable maternity services to ask about alcohol in a standardised way and provide advice and referral according to the estimated level of risk to the unborn child.[38]

3.36 Professor Elizabeth Elliott of the Royal Australasian College of Physicians told the committee that initiative prompts the obstetrician or the midwife to ask standardised questions and then enables further action:

> But what's really important is that it then tells them what risk category that woman is in and where they should seek help for that woman or refer that woman for treatment.[39]

3.37 Dr Susan Adams of the Royal Australasian College of Surgeons told the committee that once questions about alcohol use, or a form of screening, becomes routine it will become easier for health practitioners to discuss maternal alcohol consumption. She observed that 'it needs to become the norm'.[40]

3.38 The committee also heard that the AUDIT-C tool can help collect standardised data. However, greater awareness and training in the tool would be required

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[36] FARE, *Submission 50*, p. 28. Several submitters and witnesses discussed the use of AUDIT-C. See, for example, Emerging Minds, *Submission 15*, [p. 16]; NT Government, *Submission 2*, p. 14. In the NT, for example, primary health care providers use the AUDIT-C tool at every initial contact with an adolescent or woman of childbearing age.

[37] See, for example, Dr Tim Senior, Member, Royal Australian College of General Practitioners, *Committee Hansard*, 16 September 2020, p. 5. The committee heard that amongst GPs the AUDIT-C tool is referenced in preventative health guidelines and questions are being incorporated into computer templates to guide clinicians as they go through a consultation about what questions to ask. See also FASD Research Australia, *Submission 42*, p. 6.

[38] FASD Research Australia, *Submission 42*, p. 6. The Hunter New England project is a joint initiative by the University of Newcastle, University of Sydney, FARE and researchers from FASD Research Australia. It is funded through a grant by the National Health and Medical Research Council.

[39] Professor Elizabeth Elliott, Fellow, Royal Australasian College of Physicians, *Committee Hansard*, 16 September 2020, p. 5. See also FASD Research Australia, *Submission 42*, p. 6. The Hunter New England project is looking at whether there is any resulting behaviour change in women as a result of the intervention, and the committee heard that the approach, if successful, could be adopted nationally.

[40] Dr Susan Adams, Representative, Royal Australasian College of Surgeons and National Alliance for Action on Alcohol, *Committee Hansard*, 24 June 2020, p. 10.

and there may be adaptations needed locally, or regionally, to ensure implementation is optimised.[41]

How to talk to women to reduce the risk of underreporting

3.39 The committee heard that the approach to screening and brief intervention must be tailored to avoid potential underreporting, with research showing that the way a conversation takes place between a health professional and a woman will impact on disclosure rates of alcohol use during pregnancy.[42]

3.40 The *Women Want to Know* project suggests that advice should be based on an assessment of a woman's alcohol consumption before and during their pregnancy and that it is tailored to individual circumstances. Accordingly, consideration should be given to a woman's previous pregnancies, levels of stress and experiences of current or previous trauma and abuse.[43]

Continuity of care

3.41 The committee heard support for continuity of midwifery care as a model for supporting women to discuss alcohol consumption during pregnancy and make lifestyle and behaviour changes.[44]

3.42 The Australian College of Midwives (ACM) told the committee that through the continuity of care model, midwives can develop an ongoing and trusted relationship with pregnant women which enables a rich dialogue helping a midwife to identify and help the women self-manage many pregnancy issues and risks.[45]

3.43 Despite the recognition of the improved outcomes for women and their baby, however, the continuity of care model is not universally available in Australia.[46]

Building capacity in health care professionals

3.44 The committee heard that, a lack of understanding of referral, diagnosis and support strategies amongst health care professionals is the 'most significant barrier' to women receiving appropriate and timely information.[47]

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41 FARE, *Submission 50*, p. 9.

42 FARE, *Submission 50*, p. 27.

43 FARE, *Submission 50*, p. 17.

44 University of Queensland, *Submission 36*, p. 7; ACM, *Submission 31*, p. 6.

45 ACM, answers to questions on notice 29 September 2020 (received 16 October 2020), [p. 2].

46 ACM, answers to questions on notice 29 September 2020 (received 16 October 2020), [p. 2].

47 ACM, *Submission 31*, [p. 4].

3.45 The ACM submitted that there are several studies showing that health care professionals have insufficient training and education with respect to the effects of alcohol and FASD.[48]

3.46 Dr Chinar Goel of the Royal Australian and New Zealand College of Psychiatrists suggested that FASD is not sufficiently covered in medical education and training and therefore clinicians do not think of FASD as their first diagnosis:

> It isn't much covered in the medical education or in the training aspect. It wasn't covered when I was studying at my medical school, so obviously, if clinicians haven't been made aware of this, it's not something at the forefront of their mind.[49]

Training needs

3.47 Inquiry participants were broadly supportive of further training and awareness initiatives amongst health care professionals involved in antenatal care.[50]

3.48 For example, the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) suggested clinicians must be educated in interviewing and intervention regarding alcohol use in childbearing-aged women with an aim to reduce alcohol use and increase effective contraception.[51]

3.49 Dr Vijay Roach, President of RANZCOG, explained:

> We need to be taught not only about the importance of alcohol but also how to talk about it, what to ask and, importantly, how to follow up. The point was made before that we need structures in place to support us. We just can't be asked to talk to women about this issue without then having the opportunity to follow it up. Communication needs to be culturally sensitive and cross-cultural.[52]

3.50 The committee heard that to build the capacity of health professionals to effectively screen and provide advice to pregnant women, specific practitioners should be targeted. This includes GPs, gynaecologists, obstetricians, midwives, child health nurses and paediatricians.[53]

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48 ACM, *Submission 31*, [p. 4].

49 Dr Chinar Goel, Fellow, Royal Australian and New Zealand College of Psychiatrists, *Committee Hansard*, 16 September 2020, p. 13.

50 See, for example, Illawarra Shoalhaven Local Health District, *Submission 12*, p. 2; ACM, *Submission 31*, [p. 4].

51 Royal Australian and New Zealand College of Obstetricians and Gynaecologists, *Submission 10*, p. 2.

52 Dr Vijay Roach, President of the Royal Australian and New Zealand College of Obstetricians and Gynaecologists, *Committee Hansard*, 16 September 2020, p. 10.

53 FARE, *Submission 50*, Attachment 3, p. 27.

3.51 The Deeble Institute for Health Policy Research observed that professional bodies play an important role, and should partner with research bodies, tertiary training institutions, and service providers to identify capacity building initiatives.[54]

3.52 Ms Sarah Ward of FARE commented that any training efforts must be supported by a broader education and awareness campaign:

> … we have not consistently informed health professionals and women about alcohol consumption, which comes back to the need for a national campaign and national consistency on the issue … We all have a part to play in helping health professionals...[55]

Training resources

3.53 Evidence before the committee points to several successful initiatives that have helped raise health professionals' knowledge and confidence talking about alcohol during pregnancy.[56]

3.54 For example, training provided as a part of the Hunter New England study, discussed above, has resulted in an increase in nurses and doctors knowledge and confidence in asking, advising and making referrals regarding alcohol use in pregnancy.[57]

3.55 As a *Women Want to Know* project, a range of resources have been developed to support health practitioners discuss alcohol consumption during pregnancy. This includes videos, leaflets, printed and online resources, and accredited online training courses.[58]

3.56 However, an evaluation of the *Women Want to Know* project found 'mixed success' in attempts at training and awareness initiatives amongst health professionals.[59] Barriers included awareness of available training, the need for incentives other than continuing professional development, and a desire for more up-to-date evidence.[60]

3.57 The Deeble Institute for Health Policy Research suggested that, based on these findings, any capacity-building initiatives must be developed in consultation

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54 FARE, *Submission 50*, Attachment 3, p. 27.

55 Ms Sarah Ward, Acting Head, Health Promotion, FARE, *Committee Hansard*, 24 June 2020, p. 10.

56 Professor Elizabeth Elliott, Fellow, Royal Australasian College of Physicians, *Committee Hansard*, 16 September 2020, p. 8; Professor Stephen Robson, Council Member, Australian Medical Association *Committee Hansard*, 16 September 2020, p 7.

57 Professor Elizabeth Elliott, Fellow, Royal Australasian College of Physicians, *Committee Hansard*, 16 September 2020, p. 8. See also paragraphs 3.3–3.4 above.

58 Ms Sarah Ward, Acting Head, Health Promotion, FARE, *Committee Hansard*, 24 June 2020, p. 10.

59 FARE, *Submission 50*, Attachment 2, p. 19.

60 FARE, *Submission 50*, Attachment 2, p. 19.

with health professionals, tertiary training programs, and professional bodies, so that dissemination is supported and engagement and completion rates are maximised.[61]

3.58 The committee heard the Commonwealth has awarded FARE a multi-year grant over 2019–20 to 2022–23 to deliver best-practice resources for priority groups, including resources and screening tools for multidisciplinary teams to support and educate people in high-risk groups.[62]

Tertiary training and continuous professional development

3.59 Evidence to the committee stressed the importance of targeting education efforts at both undergraduate studies and continuous professional development.[63]

3.60 One inquiry participant suggested that there is limited specific information on FASD in undergraduate programs, including speech pathology, psychology, occupational therapy, physiotherapy, social work, nursing and medicine.[64]

3.61 There was support for strengthening the delivery of FASD coursework in undergraduate, postgraduate and pre-registration programs, including through the delivery of specialist programs.[65]

3.62 It was further suggested that FASD should be essential coursework for undergraduate students in in all health-related, justice-related and welfare-related disciplines.[66]

3.63 In addition, that the FASD curriculum, particularly in primary health care undergraduate courses, should be more thorough and taught as a multidisciplinary collaborative practice.[67]

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61 FARE, *Submission 50*, Attachment 2, p. 19.

62 Department of Health, answers to questions on notice IQ20-000381 19 May 2020 (received 20 July 2020), [p. 3–4].

63 Ms Sarah Ward, Acting Head, Health Promotion, FARE, *Committee Hansard*, 24 June 2020, p. 10; Professor Elizabeth Elliott, Fellow, Royal Australasian College of Physicians, *Committee Hansard*, 16 September 2020, p. 8.

64 Gold Coast Hospital and Health Service, Child Development Service, answers to written questions on notice 29 September 2020 (received 13 October 2020), p. 5.

65 Professor Jenny Gamble, Member, Australian College of Midwives, *Committee Hansard*, 16 September 2020, p. 13; Dr Chinar Goel, Fellow, Royal Australian and New Zealand College of Psychiatrists, *Committee Hansard*, 16 September 2020, p. 14.

66 GV Health, *Submission 18*, [p. 2].

67 Gold Coast Hospital and Health Service, Child Development Service, answers to written questions on notice 29 September 2020 (received 13 October 2020), p. 5.

Australian Clinical Practice Guidelines for pregnancy care

3.64 Ms Sarah Ward of FARE told the committee that the *Clinical Practice Guidelines: Pregnancy care*[68] still refers to out-of-date alcohol guidelines from 2001 and has been slow to incorporate current FASD tools and information:

> There is some information at the start of that chapter that refers to AUDIT-C; the FASD diagnostic tool; and the Women Want to Know resources. It did get updated a small amount after we requested it, but it is still considerably out of date.[69]

3.65 In its submission to the committee, FARE expressed concern that the failure to update the clinical guidance sends a broader message about that national commitment to FASD prevention:

> This omission in updating the Alcohol chapter suggests that alcohol harm is not forefront of mind and that, despite significant achievements, the issue of alcohol and pregnancy is still under-prioritised by Australian governments and health officials.[70]

Awareness and education initiatives

Commonwealth programs and funding

3.66 The Australian Government has funded several FASD awareness raising and education activities, including:

- The *Women Want to Know* project, discussed above, which aims to improve awareness of FASD information and resources to support health professionals to discuss and raise awareness about alcohol consumption during pregnant with pregnant women;
- the Pregnant Pause activity which aims to raise awareness of drinking alcohol during pregnancy, whilst breastfeeding or when planning a pregnancy; and
- related social media awareness campaigns, including discrete projects by bodies such as NOFASD.[71]

3.67 FASD Hub Australia, which is also funded by the Australian Government, was established in 2017 as a source of information and resources for health practitioners and the public. It includes a website with open access materials, and telephone and online counselling services for individuals and families.[72]

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[68] Department of Health, *Clinical Practice Guidelines: Pregnancy care: February 2020 edition*, 2020.

[69] Ms Sarah Ward, Acting Head, Health Promotion, FARE, *Committee Hansard*, 24 June 2020, p. 9.

[70] FARE, *Submission 50*, p. 18.

[71] Department of Health, *Submission 25*, pp. 2–4.

[72] Department of Health, *Submission 25*, pp. 2–4.

3.68 Commonwealth funding has also been provided for projects aimed at preventing FASD in First Nations communities. This includes tailored FASD resources, and health promotion messages translated into six languages and broadcast through the National Indigenous Radio Service for three months during the AFL season.[73]

Effectiveness of existing awareness and education initiatives

3.69 Despite the range of existing initiatives, awareness of FASD and the risks of alcohol consumption during pregnancy remain low in the general population and there are clear gaps in understanding across the health workforce contributing to inconsistent information being provided to women.[74]

3.70 The committee heard support for initiatives like Pregnant Pause as a community-focused initiative which encourages women to stop drinking during pregnancy and asks partners, friends and families to pledge to go alcohol-free in support.[75]

3.71 However, the Public Health Association of Australia told the committee that existing awareness campaigns are not sufficiently promoted:

> Various campaigns with the aim to promote the message of limiting alcohol during pregnancy and breastfeeding including *Women Want to Know* and *Pregnant Pause* are not well-established in the Australian media or online platforms.[76]

3.72 FARE, which was initially funded to run the Pregnant Pause campaign in the ACT, and later across Australia, recognised its limitations as a national campaign:

> Unfortunately, the impact of Pregnant Pause at a national level has been limited. Funding only provided for targeting of three eastern-state cities, and the campaign relied on social media.[77]

3.73 FARE suggested that the Pregnant Pause campaign should be further expanded:

> To be holistic, the target group of Pregnant Pause should be expanded to include the health professions supporting women, such as professionals providing family planning and contraceptive advice, GPs, pharmacists, obstetricians, and gynaecologists. It could also expand opportunities for

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[73] Department of Health, *Submission 25*, pp. 4–6.

[74] See discussion in Chapter 2, paragraphs 2.39–2.41 and 2.52–2.54.

[75] FASD Research Australia, *Submission 42*, pp. 2–3; Alcohol and Drug Foundation, *Submission 37*, p. 3.

[76] Public Health Association of Australia, *Submission 33*, p. 4.

[77] FARE, *Submission 50*, p. 22.

> the message about alcohol-free pregnancies through universities, childcare groups and other places where women frequent.[78]

3.74 According to FASD Research Australia, FASD Hub is widely used as a central repository of FASD information and resources.[79] However the committee heard that its ongoing role as a national resource remains subject to Commonwealth grants and that it needs adequate long term funding.[80]

Messaging on the risks of alcohol during pregnancy

3.75 The committee heard that the messaging around the risks of consuming alcohol during pregnancy has been ineffective.[81]

3.76 The ACM submitted that women are receiving mixed messages about the risks of alcohol consumption during pregnancy from their peers and health professionals:

> Messaging around the implications of consuming alcohol during pregnancy are often confusing, unclear and inconsistent as is the information that is shared both professionally and socially.[82]

3.77 The Public Health Association of Australia was critical of public health messaging which talked about alcohol consumption during pregnancy in terms of being 'frequent and heavy'. It said that these terms are an ineffective way to communicate the message that no alcohol should be consumed during pregnancy.[83]

Empowering not stigmatising

3.78 Several inquiry participants suggested that messaging in any FASD awareness campaign needs to be empowering for women, not further stigmatising.[84]

3.79 The committee heard that alarmist messages are ineffective, can negatively impact on mental health, and lead to uninformed decisions such as requests for termination of pregnancy.[85]

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78 FARE, *Submission 50*, p. 22.

79 FASD Research Australia, *Submission 42*, p. 4.

80 Professor Elizabeth Elliott, Fellow, Royal Australasian College of Physicians, *Committee Hansard*, 16 September 2020, p. 3.

81 Public Health Association of Australia, *Submission 33*, p. 5; ACM, *Submission 31*, [p. 2]; Emerging Minds, *Submission 15*, [p. 5].

82 ACM, *Submission 31*, [p. 2]. See also University of Queensland, *Submission 36*, p. 7.

83 Public Health Association of Australia, *Submission 33*, p. 5.

84 See, for example, Professor Jenny Gamble, Member, Australian College of Midwives, *Committee Hansard*, 16 September 2020, p. 11; Dr Vijay Roach, President of the Royal Australian and New Zealand College of Obstetricians and Gynaecologists, *Committee Hansard*, 16 September 2020, p. 11.

85 Dr Vijay Roach, President, Royal Australian and New Zealand College of Obstetricians and Gynaecologists, *Committee Hansard*, 16 September 2020, p. 11.

3.80 One witness commented on the stress and fear associated with the range of screening undertaken during pregnancy which can result in 'antenatal scare'.[86]

3.81 Dr Vijay Roach, President of RANZCOG, outlined the importance of messaging that is supportive, educative and clear that responsibility is shared by the broader community:

> … women already carry the burden of pregnancy and childrearing and the sorts of social pressures that go with that. There's enormous pressure to be a perfect mother, but no-one is perfect. I think that our premise should always be that a woman loves and cares for her child and that she will do everything that she can to protect that child. Punitive measures don't work. They're counterproductive. Therefore, our message should always be one of support, education and understanding. Ultimately, what we really need to underpin this is a whole-of-society cultural change.[87]

3.82 The committee was told that overseas, empowering public health campaigns have seen positive results.[88]

3.83 FARE gave the example of a national campaign in Norway which resulted in a 20 per cent reduction in the number of people in the general public who believed pregnant women could consume 'some alcohol with dinner':

> The Norwegian campaign is an example of how multifaceted, consumer-tested campaigns that focus on empowering women to not consume alcohol during pregnancy, can have a positive impact on attitudes towards alcohol use in pregnancy.[89]

Promoting the national alcohol guidelines

3.84 The committee heard concerns that the general public has a low level of awareness of the national alcohol guidelines.[90]

3.85 FARE told the inquiry that the guidelines 'zero alcohol' recommendation for women who are pregnant, planning a pregnancy or breastfeeding, is not well known, despite this recommendation having been the same for ten years.[91]

3.86 Community-wide polling commissioned by FARE shows that awareness of the 'zero alcohol' guidelines is slowly increasing over time, with 78 per cent of men and women aware of it in 2019, up from 67 per cent in 2012.[92]

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[86] Professor Jenny Gamble, Member, Australian College of Midwives, *Committee Hansard*, 16 September 2020, p. 11.

[87] Dr Vijay Roach, President, Royal Australian and New Zealand College of Obstetricians and Gynaecologists, *Committee Hansard*, 16 September 2020, p. 11.

[88] FARE, *Submission 50*, p. 12.

[89] FARE, *Submission 50*, p. 12.

[90] FARE, *Submission 50*, p. 13. See National Health and Medical Research Council, *Australian guidelines to reduce health risks from drinking alcohol*, 2020.

[91] FARE, *Submission 50*, p. 13.

3.87 FARE submitted that there is a limited awareness of the national alcohol guidelines due to a lack of promotion, and noted that, to date, there has been no national campaign to promote the guidelines to the general public.[93]

Industry-funded initiatives

3.88 DrinkWise, an industry-funded organisation, has implemented a FASD awareness-raising campaign.[94]

3.89 The campaign is aimed at creating greater awareness amongst Australians of FASD and the risks of drinking while pregnant, planning a pregnancy and breastfeeding.[95] DrinkWise initiatives include resources for GP waiting rooms, online materials, and school and community programs.[96]

3.90 However, inquiry participants suggested that DrinkWise is not an appropriate vehicle for alcohol education and that industry education consistently underperforms.[97]

3.91 FARE noted that the language used in some DrinkWise campaigns has 'suggested that it is unknown if alcohol is safe during pregnancy'.[98] Although DrinkWise has since revised the material following complaints, out-of-date material still features in clinics around Australia.[99]

National awareness campaign

3.92 Witnesses called for a national awareness campaign to raise the level of community awareness of the risks of alcohol consumption during pregnancy.[100]

3.93 In the course of the inquiry, the Australian Government announced an additional $25 million in funding for a national awareness campaign for

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92 FARE, *Submission 50*, p. 13.

93 FARE, *Submission 50*, p. 13.

94 DrinkWise, *Pregnant, planning a pregnancy or breastfeeding?* https://drinkwise.org.au/parents/how-alcohol-consumption-can-affect-your-baby/# (accessed 15 March 2021).

95 DrinkWise, *Pregnant, planning a pregnancy or breastfeeding?* https://drinkwise.org.au/parents/how-alcohol-consumption-can-affect-your-baby/# (accessed 15 March 2021).

96 DrinkWise, *Submission 38*, pp. 5–10.

97 See, for example, Ms Caterina Giorgi, Chief Executive Officer, FARE, *Committee Hansard*, 24 June 2020, pp. 5–6; FARE, *Submission 50*, p. 25.

98 FARE, *Submission 50*, p. 25.

99 FARE, *Submission 50*, p. 25.

100 See, for example, NOFASD, *Submission 40*, p. 3; ACM, *Submission 31*, [p. 6].

pregnancy and breastfeeding women.[101] A grant was awarded to FARE to deliver the project from July 2020 to June 2023.[102]

3.94 This campaign, the Fetal Alcohol Spectrum Disorder (FASD): National Awareness Campaign for Pregnancy and Breastfeeding Women, will be informed by consultation and subject to ongoing evaluation, and delivered in streams to four distinct target audiences:

- health professionals, by August 2021;
- general awareness, by September 2021;
- at-risk groups, by March 2022; and
- First Nations communities, by March 2022.[103]

3.95 According to the CEO of FARE, Ms Caterina Giorgi, the national campaign will be the largest campaign of its kind anywhere in the world and will provide an opportunity to communicate 'clear and consistent messages about alcoholic products, pregnancy and breastfeeding with the broader community and people who are most at risk'.[104]

3.96 In addition, NOFASD was also provided Australian Government funding to deliver a COVID-19 alcohol and pregnancy campaign addressing increased alcohol consumption leading to unplanned alcohol-exposed FASD pregnancies during the COVID-19 pandemic.[105]

Complementary activities

3.97 The committee heard that any national awareness campaign must be supported by targeted medical information to explain the rationale.[106]

3.98 It was suggested that any campaign must be multifaceted, with one aspect focusing on women and the general public, and another aspect focusing on health professionals.[107]

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[101] Ms Sharon Appleyard, First Assistant Secretary, Population Health and Sport Division, Department of Health, *Committee Hansard*, 19 May 2020, p. 2.

[102] FARE, *National campaign*, https://fare.org.au/national-campaign/ (accessed 27 February 2021).

[103] Ms Caterina Giorgi, Chief Executive Officer, FARE, *Committee Hansard*, 10 March 2021, p. 2.

[104] Ms Caterina Giorgi, Chief Executive Officer, FARE, *Committee Hansard*, 10 March 2021, p. 1.

[105] Ms Sharon Appleyard, First Assistant Secretary, Population Health and Sport Division, Department of Health, *Committee Hansard*, 19 May 2020, p. 2. In April 2020, additional funding of $6 million was announced for drug and alcohol services during the COVID-19 pandemic, for online and phone support services. As a part of this funding, NOFASD was given a grant to deliver a COVID-19 alcohol and pregnancy campaign.

[106] See, for example, ACM, *Submission 31*, [p. 6].

[107] ACM, *Submission 31*, [p. 6].

3.99 The Australian College of Midwives explained:

> … where woman sees a bus stop poster with a clear message to not drink during pregnancy and that message is supported by the midwife/GP/Obstetrician and family and friends giving similar messages.[108]

Targeting at-risk groups

3.100 FASD Research Australia told the committee that in designing an evidence-based awareness campaign, it is necessary to identify population subgroups based on factors such as behaviour, risk and attitudes towards alcohol:

> This will allow program developers and researchers to understand what awareness or health promotion campaigns should look like, and what they should set out to achieve. Without this first step, a campaign is unlikely to change attitudes or behaviour. Robust formative work and evaluation is crucial.[109]

3.101 The committee also heard that any health advice must be tailored to a woman's individual and community contexts:

> … blanket abstinence messages are often ineffective because the decision-making around alcohol use by pregnant women is influenced by their individual understanding and conceptualising of its potential harms. In addition, women's wider social and cultural environment impacts on their ability to abstain.[110]

3.102 Ms Prue Walker, FASD consultant and Service Coordinator at VicFAS, stressed the importance of campaigns for the broader community complementing any targeted initiatives:

> 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.[111]

3.103 In the context of its planning for a national education campaign, FARE outlined the importance of development work to ensure messaging has the greatest impact on influencing behaviour change and does not contribute to stigma relating to FASD and the use of alcohol products in pregnancy:

> … we're really carefully engaging with a range of groups across the women's sector, the disability sector, the health professionals sector and people with lived experience and are developing a really comprehensive

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[108] ACM, *Submission 31*, [p. 6].

[109] FASD Research Australia, *Submission 42*, p. 3.

[110] FASD Research Australia, *Submission 42*, p. 2.

[111] Ms Prue Walker, *Submission 47*, p. 16.

> stakeholder engagement framework to make sure that we can get all the information we need to make this campaign as effective as it can be.[112]

A focus on pre-conception

3.104 Inquiry participants suggested that any public education campaign must target women of childbearing age seeking family planning and contraception advice.[113]

3.105 The World Health Organization's *Prevention of harm caused by alcohol exposure during pregnancy* notes that interventions that target contraception and alcohol consumption are effective in reducing the risk of women drinking alcohol during pregnancy.[114]

3.106 NOFASD told the committee that this group requires a different approach, 'through different communication channels' in order to increase the success of prevention initiatives.[115]

3.107 In New Zealand, the 'Pre-Testie Bestie' campaign focuses on empowering women's female peers to encourage them to stop drinking alcohol if there is any chance that they could be pregnant.[116] At the March 2021 public hearing, FARE noted some concerns, however, about the effectiveness of this campaign, observing that overall there is a lack of evidence about effective campaigns and a need for careful consultation.[117]

Programs in schools

3.108 Several inquiry participants suggested that the secondary school curriculum should include information about the risks of alcohol consumption during pregnancy.[118]

3.109 The Alcohol and Drug Foundation told the committee that education about the risk of drinking before and after conception should be a 'mandatory aspect of the secondary school health education curriculum' along with education about sex, alcohol and other drug use.[119]

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[112] Ms Caterina Giorgi, Chief Executive Officer, FARE, *Committee Hansard*, 10 March 2021, p. 3. See further discussion above, paragraphs 3.93–3.95.

[113] FARE, *Submission 50*, p. 22; University of Queensland, *Submission 36*, p. 7.

[114] FARE, *Submission 50*, p. 12.

[115] NOFASD, *Submission 40*, p. 4.

[116] FARE, *Submission 50*, p. 22.

[117] Ms Caterina Giorgi, Chief Executive Officer, FARE, *Committee Hansard*, 10 March 2021, p. 2.

[118] See, for example, Murdoch Children's Research Institute, *Submission 30*, p. 3; Victorian FASD Special Interest Group, *Submission 29*, p. 3; Goulburn Valley Health, *Submission 18*, [p. 2].

[119] Alcohol and Drug Foundation, *Submission 37*, p. 8.

3.110 In 2018, the Australian Government provided DrinkWise with funding to produce education videos for students about FASD, peer pressure and the importance of not drinking until they are 18.[120]

3.111 DrinkWise told the committee that the videos have been made available to nearly 200,000 state secondary schools' alcohol as part of alcohol and other drugs curriculum.[121]

Reducing community-level alcohol consumption

3.112 The committee heard that FASD prevention must fundamentally address the role of community-level consumption and alcohol availability.[122]

3.113 This is particularly important given research showing that a woman's alcohol consumption during pregnancy is influenced by levels of pre-pregnancy drinking.[123]

Population-level responses

3.114 FARE told the committee that population-level responses to alcohol availability represent 'best buys' to reduce alcohol-related harm. These include increasing excise tax on alcohol beverages, regulating alcohol marketing, and enacting and enforcing physical restrictions on the availability of alcohol.[124]

3.115 The Western Australia Network of Alcohol and other Drug Agencies submitted that population-level restrictions are one of the most effective strategies to reduce alcohol-associated harm:

> These approaches recognise the need to provide an equitable policy response that addresses whole-of-community and environmental factors, rather than just focussing on an individual's behaviour.[125]

Tax and price reform

3.116 The committee heard that the low price of alcohol in Australia contributes to higher levels of alcohol consumption, resulting in higher levels of alcohol-related harm.[126]

3.117 It was suggested that the current alcohol tax system contributes to alcohol harm by incentivising the sale of cheap wine and wine-based products.[127]

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120 DrinkWise, *Submission 38*, p. 4.

121 DrinkWise, *Submission 38*, p. 4.

122 Western Australian Network of Alcohol and other Drug Agencies (WANADA), *Submission 39*, p. 2.

123 See Chapter 2, paragraph 2.49.

124 FARE, *Submission 50*, p. 29.

125 WANADA, *Submission 39*, p. 2.

126 National Alliance for Action on Alcohol, *Submission 27*, [p. 4].

3.118 The committee heard that tax and price reform measures could contribute to reducing alcohol harm, for example, through changes to the Wine Equalisation Tax:

> The Wine Equalisation Tax, along with its associated rebate, should be replaced with a volumetric tax set at a rate between beer and spirits. To date, at least 13 government and parliamentary reviews have concluded that wine should be taxed on a volumetric basis.[128]

3.119 The National Alliance for Action on Alcohol also suggested that to complement tax reform, states and territories have the power to introduce a minimum unit price and put controls on the use of discounts.[129]

3.120 The Northern Territory (NT) Government introduced a minimum unit price in 2017. Inquiry participants told the committee that the changes have contributed to reductions in alcohol-related violence, intimate partner violence and emergency department presentations.[130] The NT Government's alcohol reforms are discussed in further detail in Chapter 6.[131]

3.121 The *National alcohol strategy 2019–2028*, discussed further below, suggests a range of pricing and taxation reforms to reduce risky alcohol consumption. This includes:

- the introduction of a minimum floor price for alcohol;
- taxation reforms such as volumetric taxation; and
- direct revenue from alcohol taxation is to be put towards preventative health activities and alcohol and other drug treatment services.[132]

Alcohol marketing

3.122 The committee heard that the way women of child-bearing age are targeted by alcohol marketing is concerning:

> A really insidious strategy that's been really prevalent recently is marketing to women through social media, including using social media influencers such as mum bloggers. Women then often share this marketing, such as 'wine mum' memes, which promote alcohol as a coping mechanism. We've seen a lot of this recently during COVID-19 restrictions.[133]

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127 National Alliance for Action on Alcohol, *Submission 27*, [p. 4].

128 National Alliance for Action on Alcohol, *Submission 27*, [p. 4].

129 National Alliance for Action on Alcohol, *Submission 27*, [p. 4].

130 See, for example, FARE, *Submission 50*, p. 29.

131 See Chapter 6, Box 6.1.

132 Department of Health, *National alcohol strategy 2019–2028*, p. 21.

133 Ms Sarah Jackson, Senior Legal Policy Adviser, Cancer Council Victoria, *Committee Hansard*, 24 June 2020, p. 3. See also, for example, National Alliance for Action on Alcohol, *Submission 27*, [p. 3].

3.123 Concerns were also raised around online marketing, with the data from retailer memberships and individual's online purchasing history, being used to micro-target alcohol advertising.[134]

3.124 FARE commented that during the COVID-19 pandemic, their analysis of Facebook and Instagram during a one-hour period showed an alcohol ad every 35 seconds. Almost a quarter of those ads referenced the pandemic.[135]

3.125 Ms Caterina Giorgi, Chief Executive Officer of FARE, told the committee that further regulation is needed to address this new and emerging issue:

> … addressing this involves looking at regulatory structures across a range of different platforms. That's looking at the way that data is collected and used and also looking at the responsibility of platforms themselves and the responsibility of companies.[136]

3.126 Several inquiry participants criticised attempts by the industry to self-regulate alcohol advertising.[137] According to the National Alliance for Action on Alcohol:

> The obvious conflicts of interest mean the industry-managed processes could never restrict alcohol marketing in a genuinely effective manner. A new approach to controlling alcohol marketing is needed to prioritise the protection of young people and other vulnerable groups.[138]

3.127 Ms Sarah Jackson of Cancer Council Victoria argued for comprehensive legislation regulating alcohol advertising:

> It's really key that there's comprehensive legislation regulating alcohol advertising, as there is for tobacco advertising that's been in place for 20 years. We really have no legislation that regulates alcohol advertising in the country at the moment. We have a regulatory code at the federal level, but there are big loopholes in that code.[139]

3.128 Alcohol Change Victoria outlined explained that some of the loopholes in the co-regulatory Commercial Television Industry Code of Practice currently enable exposure of children to alcohol advertising, including during sporting events.[140]

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134 Ms Caterina Giorgi, Chief Executive Officer, FARE, *Committee Hansard*, 10 March 2021, p. 6.

135 Ms Caterina Giorgi, Chief Executive Officer, FARE, *Committee Hansard*, 10 March 2021, p. 6.

136 Ms Caterina Giorgi, Chief Executive Officer, FARE, *Committee Hansard*, 10 March 2021, p. 5.

137 Ms Caterina Giorgi, Chief Executive Officer, FARE, *Committee Hansard*, 10 March 2021, p. 6. National Alliance for Action on Alcohol, *Submission 27*, [p. 4].

138 National Alliance for Action on Alcohol, *Submission 27*, [p. 4].

139 Ms Sarah Jackson, Senior Legal Policy Adviser, Cancer Council Victoria, *Committee Hansard*, 24 June 2020, p. 8.

140 Alcohol Change Victoria, answers to questions taken on notice 24 June 2020 (received 10 July 2020), [p. 1].

3.129 The *National alcohol strategy 2019–2028* outlines the need to extend the single national advertising code to provide consistent protection of exposure to minors regardless of programming. It also outlines a set of shared measures to reduce promotions and discounts for low priced alcohol.[141]

3.130 The Department of Health told the committee that the national alcohol strategy has sufficient flexibility to enable all jurisdictions to target emerging issues in alcohol marketing as they arise over time.[142]

Pregnancy warning labels

3.131 Labelling on alcohol products and packaging was introduced in 2011 on a voluntary basis by the alcohol industry.[143]

3.132 In October 2018, the Australia and New Zealand Ministerial Forum on Food Regulation agreed on a mandatory labelling standard for pregnancy warning labels on packaged alcoholic beverages should be developed.[144]

3.133 In July 2020, the forum agreed upon a draft standard for pregnancy warning labels, and recommitted to mandatory labels on alcohol and packaging.[145]

3.134 The committee heard frustration at the time it has taken to achieve a mandatory pregnancy warning label.[146]

3.135 Inquiry participants advocated for a national education and awareness campaign to support the rollout of the pregnancy warning labels.[147]

3.136 FARE recommended that, immediately prior to the mandatory application of the pregnancy warning label, a comprehensive public education campaign should be implemented to inform consumers about the changes.[148]

3.137 The alcohol industry has three years from 31 July 2020 to comply with the new requirements.[149] The committee heard that some smaller alcohol companies

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[141] Department of Health, *National Alcohol Strategy 2019–2028*, pp. 21–22.

[142] Mr David Laffan, Acting First Assistant Secretary, Population Health Division, Department of Health, *Committee Hansard*, 10 March 2021, p. 21.

[143] DrinkWise, *Submission 38*, p. 10.

[144] Australia and New Zealand Ministerial Forum on Food Regulation, *Communiqué*, 11 October 2018.

[145] Australia and New Zealand Ministerial Forum on Food Regulation, *Communiqué*, 17 July 2020.

[146] Professor Carol Bower, Co-Director, FASD Research Australia Centre of Research Excellence and Telethon Kids Institute, *Committee Hansard*, 19 May 2020, p. 27.

[147] Dr Erin Lalor, Chief Executive Officer, Alcohol and Drug Foundation, *Committee Hansard*, 24 June 2020, p. 5; Ms Sarah Jackson, Senior Legal Policy Adviser, Cancer Council Victoria, *Committee Hansard*, 24 June 2020, p. 3.

[148] FARE, *Submission 50*, p. 9.

[149] Mr David Laffan, Acting First Assistant Secretary, Population Health Division, Department of Health, *Committee Hansard*, 10 March 2021, p. 14.

have already started to apply the warning label, and that larger companies have been encouraged to do the same ahead of the due date.[150]

A comprehensive national prevention strategy

3.138 The committee heard that Australia needs an overarching prevention program and that this must be sufficiently funded in order to be effective.[151]

3.139 The committee heard that current efforts have involved funding and initiatives that are on a small scale, piecemeal and inconsistent. FARE argued that 'with such restrained commitment, these activities are not able to reach their full potential'.[152]

3.140 The Australian College of Midwives argues that prevention strategies are most effective when they are approached from a collaborative, multifactorial, widespread approach. This includes legislative changes, access to alcohol and labelling, community and women's awareness, diagnosis, targeted education and quality care during pregnancy.[153]

3.141 The four-part prevention framework implemented by the Public Health Agency of Canada was widely recognised by inquiry participants as best practice.[154] It promotes:

- broad awareness-raising and health promotion through mass media;
- discussion about FASD/alcohol with all women of childbearing age and their families;
- antenatal support for pregnant women with alcohol and other social/health issues; and
- postnatal support for new mums and support for child assessment and development.[155]

3.142 Professor Doug Shelton of the Gold Coast Hospital and Health Service explained the strengths of the Canadian model:

> It's multifaceted and involves public health campaigns and the provision of direct services, particularly in midwifery and maternity care, so that prenatal alcohol exposure can be picked up very early, if not prior to the pregnancy, and services can be offered to encourage the woman to cease or decrease her alcohol consumption. Then really it goes the full circle to the

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150 Ms Caterina Giorgi, Chief Executive Officer, FARE, *Committee Hansard*, 10 March 2021, p. 1.

151 FARE, *Submission 50*, p. 20.

152 FARE, *Submission 50*, p. 20.

153 ACM, *Submission 31*, [p. 5].

154 See, for example, National Alliance for Action on Alcohol, *Submission 27*, [p. 3]; FARE, *Submission 50*, p. 20; Associate Professor Doug Shelton, Clinical Director, Women's, Newborn and Children's Services, Gold Coast Hospital and Health Service, *Committee Hansard*, 16 September 2020, p. 31.

155 FARE, *Submission 50*, p. 20.

> provision of care to women postnatally, including mental health and support with any other stressors and issues they may have in their lives.[156]

3.143 FARE commented that this model has been implemented in parts of Australia by clinicians and researchers but has not yet been adopted by the government as a national approach. It noted that:

> For a national prevention program to be effective, clear responsibilities are required between federal, state and regional level governments to be implemented within specified timeframes. Adequate funding needs to be provided for such a program, for which principles already exist.[157]

Committee view

National public education campaign

3.144 The committee heard overwhelming evidence of the need for a national public education campaign over the course of this inquiry. The Australian Government's announcement that it is funding a national campaign from July 2020 to June 2023 is welcome news. However, given the scale of the effort required to build public awareness and understanding of FASD and alcohol-related harms in the broader community, the committee is of the view that government must invest in this activity over the life of the *National Fetal Alcohol Spectrum Disorder (FASD) strategic action plan 2018–2028*.

Recommendation 5

3.145 The committee recommends that the Australian Government develop a broader strategy and budget for a national public education campaign over the life of the *National Fetal Alcohol Spectrum Disorder (FASD) strategic action plan 2018–2028*.

FASD education for schools

3.146 The committee considers that education about the risks of maternal alcohol consumption, and FASD, must be included in secondary school curriculums as a part of sex education. This activity should complement the efforts of a national public education campaign.

Recommendation 6

3.147 The committee recommends that the Department of Health fund the development of FASD education resources to be used in secondary school curriculums.

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156 Professor Doug Shelton, Clinical Director, Women's, Newborn and Children's Services, Gold Coast Hospital and Health Service, *Committee Hansard*, 16 September 2020, p. 31.

157 FARE, *Submission 50*, p. 20.

Overcoming barriers experienced by health professionals

3.148 The committee is deeply concerned by evidence suggesting that the risks of alcohol consumption during pregnancy are not routinely raised with pregnant women and women of child-bearing age by health professionals. The committee is also concerned that the 2020 *Australian guidelines to reduce health risks from drinking alcohol* are not reflected in current clinical guidance and not well understood by health professionals.

Recommendation 7

3.149 The committee recommends that the *Australian Clinical Practice Guidelines: Pregnancy care* are updated as a matter of priority to ensure consistency with the 2020 *Australian guidelines to reduce health risks from drinking alcohol*.

3.150 There is a clear need to further and more thoroughly teach FASD, and screening and brief intervention practices, in tertiary training programs at both undergraduate and postgraduate levels. The committee encourages partnerships between universities, training bodies, professional bodies, research bodies and service providers to identify and address the current gaps.

Recommendation 8

3.151 The committee recommends that the medical profession, including the various medical colleges, acknowledge the critical role they play in education and awareness-raising of the dangers of consumption of alcohol for both women and men, particularly as it relates to consumption in relation to pregnancy.

Routine screening

3.152 The committee commends the efforts to improve screening and brief intervention practices, including embedding standardised screening tools into health systems, like that being trialled in the Hunter New England study. Initiatives like this should be carefully evaluated, with a view to developing a universal and best-practice screening and brief intervention model for broader implementation.

3.153 The committee notes the Australian Government's recent funding allocation for the development of best-practice resources for health professionals, including screening tools for treating at-risk groups. Whilst this is a valuable activity, the committee considers further steps are needed to embed educational resources and screening tools into routine practice in antenatal care.

Recommendation 9

3.154 The committee recommends that the Australian Government provide funding for professional development training for all health professionals

involved in antenatal care, in order to embed routine FASD screening practices and tools, including AUDIT-C.

Reducing community-level alcohol consumption

3.155 The committee is of the view that prevention efforts must fundamentally aim to shift societal attitudes and behaviour around alcohol consumption in the broader Australian community. The long-awaited national alcohol strategy provides an opportunity for Australia to address alcohol-related harm in a meaningful way. At the Commonwealth level, marketing, pricing and taxation reforms should be considered as a priority to address the availability of cheap alcohol and reduce risky alcohol consumption.

Recommendation 10

3.156 The committee recommends that the Australian Government implement as a matter of priority marketing, pricing and taxation reforms as set out in the *National alcohol strategy 2019–2028*.

Mandatory pregnancy warning labels

3.157 The introduction of pregnancy warning labels represents a significant step forward in reducing alcohol-related harm, and specifically, the risk of FASD. The committee encourages the alcohol industry to respond quickly to mandatory labelling requirements ahead of the proposed introduction date. The committee is of the view that a specific awareness campaign is needed to promote and explain the new pregnancy warning labels to the community.

Recommendation 11

3.158 The committee recommends that the Australian Government run a specific public education campaign with respect to the roll-out of mandatory pregnancy warning labels.

A comprehensive national prevention strategy

3.159 The committee acknowledges the strengthened national priority on FASD prevention activities as outlined in both the *National alcohol strategy 2019–2028* and the *National FASD strategic action plan 2018–2028*. The committee commends recent funding announcements by the Australian Government, which have included several key preventative measures announced in the course of this inquiry, under both national strategies.

3.160 Despite this investment, the committee holds concerns that the national approach to FASD prevention will continue to be fragmented, piecemeal and underfunded into the future. This is an unacceptable risk, given the significant social and economic costs of FASD outlined in the previous chapter. Therefore, the committee is of the view that a single comprehensive national prevention

strategy and funding allocation must be implemented by the Australian Government.

3.161 The prevention strategy should provide the blueprint for a comprehensive and collaborative approach to FASD prevention by the Australian Government and state and territory governments. It should be consistent with, and build upon, the prevention objectives outlined in the *National alcohol strategy 2019–2028* and the *National FASD strategic action plan 2018–2028*. Importantly, it must be fully costed and funded, with responsibilities allocated between the Commonwealth, states and territories.

Recommendation 12

3.162 The committee recommends that the Australian Government fund a National Prevention Strategy to be developed and delivered in collaboration with State and Territory Governments.

Chapter 4
Diagnosis

> … early diagnosis of FASD can improve the overall life outcomes for the individual and enable families and carers to access disability support services otherwise unavailable to them.[1]

4.1 FASD is a complex disability, and diagnosis is difficult, time-consuming and expensive.[2] It involves a multidisciplinary assessment, health professionals with specialist skills, and regard for potentially complex family histories and a range of possible neurodevelopmental impairments.[3]

4.2 This chapter discusses some of the persistent obstacles to FASD diagnosis and early intervention and the consequences of failing, delaying or misdiagnosing a person. It also considers a range of initiatives and suggestions for improving access to diagnostic services.

Diagnosing FASD

Existing diagnostic guidelines

4.3 FASD diagnosis in Australia is guided by the *Australian guide to the diagnosis of FASD*. It contains the Australian FASD Diagnostic Instrument,[4] with diagnostic criteria intended to be used by clinicians,[5] and guidelines for its use.[6]

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1 Foundation for Alcohol Research and Education (FARE), *Submission 50*, Attachment 1, p. 28.

2 National Organisation for Fetal Alcohol Spectrum Disorder (NOFASD), *Submission 40*, pp. 7 and 11–15; Legal Aid Western Australia, *Submission 41*, p. 3; National Aboriginal Community Controlled Health Organisation (NACCHO), *Submission 56*, p. 5. The *Australian guide to the diagnosis of FASD* has been developed to assist clinicians in the diagnosis, referral and management of FASD.

3 NOFASD Australia, *Submission 40*, pp. 7 and 11–15; Legal Aid Western Australia, *Submission 41*, p. 3; National Aboriginal Community Controlled Health Organisation (NACCHO), *Submission 56*, p. 5.

4 Professor Carol Bower and Professor Elizabeth J Elliott AM, *Australian guide to the diagnosis of FASD*, 2016, Appendix A (Australian Fetal Alcohol Spectrum Disorder (FASD) Diagnostic Instrument), pp. 45–71.

5 Professor Carol Bower and Professor Elizabeth J Elliott AM, *Australian guide to the diagnosis of FASD*, 2016, p. 4. The Australian diagnostic criteria are similar to the Canadian guidelines, and the guide uses clinical aids developed in the United States.

6 Professor Carol Bower and Professor Elizabeth J Elliott AM, *Australian guide to the diagnosis of FASD*, 2016, pp. 4–39.

4.4 The *Australian guide to the diagnosis of FASD* requires evidence of prenatal exposure and severe impairment in three or more neurodevelopmental domains. There are two diagnostic sub-categories:

- FASD with three sentinel facial features; and
- FASD with less than three sentinel facial features.[7]

4.5 The University of Western Australia commented that there has been 'significant progress in Australia in regard to diagnostic rigor' since the guide's publication in 2016.[8]

What is involved in a diagnosis

4.6 Best practice in diagnosing FASD ideally requires a multidisciplinary team of clinicians to evaluate prenatal alcohol exposure, neurodevelopmental problems and facial abnormalities.[9]

4.7 The multidisciplinary team should include, but is not limited to:

- paediatricians or physicians;
- neuropsychologists;
- speech pathologists; and
- occupational therapists.[10]

4.8 According to the University of Western Australia, a FASD diagnosis typically involves multiple assessments, spread over one to two days, followed by a case conference with the multidisciplinary team.[11]

4.9 VicFAS told the committee that, in its clinics, each child is assessed by a multidisciplinary team using the *Australian guide to the diagnosis of FASD*, a process which can take between two and three days depending on the child and family needs.[12]

4.10 In rural and remote areas, the committee heard that the process for diagnosing FASD takes longer than two weeks and can require travel and additional support staff to facilitate appointments and contact with families.[13]

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7 Professor Carol Bower and Professor Elizabeth J Elliott AM, *Australian guide to the diagnosis of FASD*, 2016, p. 4; FASD Research Australia, *Submission 42*, p. 8.

8 University of Western Australia, *Submission 23*, p. 2.

9 Professor Carol Bower and Professor Elizabeth J Elliott AM, *Australian guide to the diagnosis of FASD*, 2016, p. 4.

10 University of Western Australia, *Submission 23*, p. 2.

11 University of Western Australia, *Submission 23*, p. 2.

12 VicFAS, *Submission 34*, p. 2.

13 Dr John Boffa, Chief Medical Officer Public Health, Central Australian Aboriginal Congress, *Committee Hansard*, 14 October 2020, p. 12.

4.11 Data from the national FASD register indicates that in over 80 per cent of cases diagnosis is made by a paediatrician in conjunction with a multi-disciplinary team, usually in one of several specialist FASD assessment services.[14]

Diagnosis and early intervention

4.12 The committee heard that early diagnosis of FASD is crucial, as it is for autism and other neurodevelopmental disorders, because it allows for early intervention to address specific areas of need.[15]

4.13 Early intervention in a FASD context is broad-ranging. It can include therapies like speech therapy and occupation therapy, as well as more holistic supports that are focused on behaviour management and educational participation.[16]

4.14 Dr Alison Crichton, VicFAS Clinical Coordinator, noted the value of a diagnosis for highlighting support needs at the earliest possible stage:

> A key though brief role that we play at diagnosis is communicating the FASD diagnosis and implications of this, articulating the child's support need and working with the school so the needs of the child will be met by the school or other community services.[17]

Barriers to diagnosis and early intervention

Difficulties diagnosing FASD

4.15 Despite the introduction of a range of initiatives to raise awareness, develop diagnostic guidelines and implement intervention programs, there are still a number of obstacles to diagnosis and early intervention.

4.16 The *Australian guide to the diagnosis of FASD* outlines some of the difficulties of diagnosing FASD, including that:

- health professionals are often unaware of the diagnostic criteria, how to diagnose FASD, or where to refer patients for diagnosis or treatment;
- many health professionals are unfamiliar with the national guidelines to reduce health risks from drinking alcohol;
- few discuss alcohol use in pregnancy with their patients;
- many are reluctant to raise the possibility of a FASD diagnosis because of concern about stigmatising families;

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[14] FASD Research Australia, answers to questions on notice 19 May 2020 (received 5 June 2020), [p. 3].

[15] See, for example, FASD Research Australia, *Submission 42*, p. 11; roundsquared, *Submission 11*, p. 4.

[16] Dr Alison Crichton, VicFAS Clinical Coordinator, Monash Health, *Committee Hansard*, 24 June 2020, pp. 23–24. Early intervention is discussed in further detail in Chapter 5.

[17] Dr Alison Crichton, VicFAS Clinical Coordinator, Monash Health, *Committee Hansard*, 24 June 2020, p. 19. Support and management for FASD is discussed further in the next chapter.

- there are limited training opportunities for health professionals and no nationally adopted diagnostic instrument; and
- there is confusion about diagnostic criteria and a perceived lack of evidence-based treatments.[18]

Lack of trained health professionals

4.17 The committee heard that one the reasons for the lack of FASD diagnostic services is a lack of appropriately trained clinicians to assess and diagnose FASD. Surveys continue to show evidence of a knowledge gap in clinicians and the general public regarding FASD.[19]

4.18 The Australian Medical Association told the committee that some of the key barriers to diagnosing FASD are the complex requirements of a best-practice FASD diagnosis and the lack of inclusion of FASD in mainstream training requirements for medical practice.[20]

Limited diagnostic services

4.19 There is a need for more multidisciplinary diagnostic centres across Australia, the committee heard.[21]

4.20 Although most states and territories now have diagnostic services, funding is often short-term, services are patchy in rural and remote settings, and access is limited by long waiting lists, the patient's age and the cost involved.[22]

4.21 In Western Australia, for example, there is no public health service delivering holistic and multidisciplinary FASD diagnostic and management services. The Western Australian (WA) Government told the committee that hospital and community paediatricians are currently providing 'limited and fragmented services' without appropriate or specific funding.[23]

4.22 In Queensland, despite a high population of people likely affected by FASD, there are only two clinics with specialist knowledge.[24]

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[18] Professor Carol Bower and Professor Elizabeth J Elliott AM, *Australian guide to the diagnosis of FASD*, 2016, p. 2.

[19] University of Western Australia, *Submission 23*, p. 2.

[20] Australian Medical Association (AMA), answer to question on notice (received 21 October 2020), p. 2.

[21] Dr Sharman Stone, *Submission 8*, p. 4.

[22] FASD Research Australia, *Submission 42*, p. 10; Gold Coast Hospital and Health Service, Child Development Service, *Submission 35*, p. 5.

[23] Western Australian Government, *Submission 65*, Attachment 1, p. 25.

[24] Queensland Advocacy Incorporated, *Submission 21*, [p. 4].

Funding issues

4.23 Professor Elizabeth Elliott, speaking for FASD Research Australia, told the committee that the state of diagnostic and treatment services in Australia is a product of a short-term and fragmented funding model:

> Funding is very variable. Clinics are funded by states and territories, by the Australian government or by private enterprise, and it's often short term.[25]

4.24 The Royal Australasian College of Physicians submitted that current funding and availability of diagnostic and treatment services, including wraparound medical care, is unsatisfactory.[26]

4.25 It recommended that all children in Australia should have access to multidisciplinary child development services to diagnose FASD and other neurodevelopmental conditions.[27]

4.26 In September 2020, the Minister for Health announced additional funding of $24 million over four years from 2020–21 for FASD diagnostic and support services. The Department of Health told the committee:

> This initiative will reduce waiting times for FASD diagnostic services and support people who have been diagnosed with FASD, their families and carers.[28]

4.27 The Department of Health, at a public hearing in March 2021, advised that the funding will be used to continue some existing FASD services and initiatives, and a portion of the budget ($9.8 million) will be used to expand diagnostic services across Australia through a competitive open-market process.[29]

4.28 Professor Elizabeth Elliott noted that the funding should be used to bolster public health services, including child development services, community and general paediatric services, and multidisciplinary FASD assessment services.[30]

4.29 She noted that, whilst the funding is welcome, consideration must be given to its equitable distribution and to ensure that remote and rural communities are

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[25] Professor Elizabeth Elliott, Co-Director, FASD Research Australia Centre of Research Excellence, Telethon Kids Institute, *Committee Hansard*, 19 May 2020, p. 27.

[26] Royal Australian College of College of Physicians, *Submission 64*, p. 5.

[27] Royal Australian College of College of Physicians, *Submission 64*, p. 5.

[28] Department of Health, answer to question on notice IQ20-000672 19 May 2020 (received 16 October 2020), [p. 2].

[29] Mr David Laffan, Acting First Assistant Secretary, Population Health Division, Department of Health, *Committee Hansard*, 10 March 2021, pp. 18–19.

[30] Professor Elizabeth Elliott, Fellow, Royal Australasian College of Physicians, *Committee Hansard*, 16 September 2020, p. 9.

being appropriately serviced. In addition, she suggested that Telecare can be better utilised to increase accessibility.[31]

4.30 The committee heard that an audit of diagnostic services and funding sources is needed. This should include consideration of new diagnostic models and trials in order to evaluate their efficacy and cost-effectiveness if they were to be implemented more broadly in Australia.[32]

Cost and accessibility

4.31 According to FASD Research Australia, access to diagnostic services is 'problematic and inequitable', as some clinics provide a free service open to any child and others charge a significant fee, restricting access for some families.[33]

4.32 For families in rural, regional and remote areas, on low incomes or with language or literacy challenges, access to screening or diagnostic services can be especially difficult and costly.[34]

Access to services in rural and remote areas

4.33 Inquiry participants noted that most diagnostic and treatment services are located in metropolitan areas and that, although telehealth is sometimes provided, rural and remote areas are insufficiently supported.[35]

4.34 The Gold Coast Hospital and Health Service, Child Development Service, argued that the best-practice model for diagnosis, which involves a full multidisciplinary team, is only accessible to a small percentage of the population, is time-consuming and is not scalable.[36]

4.35 It was further noted that access to allied health clinicians to complete the recommended assessment poses a real challenge in many regions, creating a 'diagnostic burden' unlikely to be overcome in rural and remote areas:

> Establishing more diagnostic capable services throughout Australia will contribute to improved community awareness, understanding and access

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31 Professor Elizabeth Elliott, Fellow, Royal Australasian College of Physicians, *Committee Hansard*, 16 September 2020, p. 9.

32 Professor Elizabeth Elliott, Co-Director, FASD Research Australia Centre of Research Excellence, Telethon Kids Institute, *Committee Hansard*, 19 May 2020, pp. 27–28.

33 FASD Research Australia, *Submission 42*, p. 10.

34 roundsquared, *Submission 11*, pp. 3–4.

35 See, for example, roundsquared, *Submission 11*, p. 4; Royal Australian College of General Practitioners, *Submission 53*, p. 1; Gold Coast Hospital and Health Service, answer to written question on notice 29 September 2020 (received 13 October 2020) pp. 2–3; NOFASD Australia, *Submission 40.2*, [p. 3]; FASD Research Australia, *Submission 42*, pp. 10–11.

36 Gold Coast Hospital and Health Service, Child Development Service, *Submission 35*, p. 5.

> to diagnostic assessments. However, such services will likely only develop in major regional areas, leaving rural and remote areas unsupported.[37]

4.36 The committee heard that, while telehealth has been helpful in bridging certain gaps in regional and remote areas, such as progressing parts of the diagnostic assessment process, inquiry participants felt it was not a substitute for face-to-face service delivery and support.[38]

4.37 It was suggested that outreach services such as fly-in fly-out clinicians were also useful as a temporary solution, but ultimately an unsustainable model.[39]

Medicare rebates

4.38 Several inquiry participants suggested the need to reform Medicare rebates to support increased diagnostic and treatment activity.[40]

4.39 Mrs Katherine Burchfield, Health Director at the Royal Far West, told the committee that current Medicare rebates are too low to support services and cover the cost of assessment and therapeutic responses:

> I appreciate that Medicare is not the only funding mechanism through which that could be done, but it would be, in our view, the most effective way of providing appropriate resources into the system to allow this better response around FASD from our clinical staff.[41]

4.40 It was also suggested the list of items on the Medicare Benefits Scheme (MBS) be reviewed to enable better access to telehealth. Royal Far West noted that telehealth can be used to increase access to therapeutic support in rural and remote regions, by using case conferences between urban specialist units and rural care teams to support best practice wraparound support.[42]

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37 Gold Coast Hospital and Health Service, Child Development Service, *Submission 35*, p. 5.

38 Danila Dilba Health Services, answer to written questions on notice 20 October 2020 (received 3 November 2020), p. 3. For example, PATCHES relied on telehealth from March to June 2020 and was able to offer standardised assessments to clients in the NT, but practitioners found difficulty in assessing functional communication within the child's natural setting and picking up on subtle non-verbal information that comes with face-to-face contact.

39 Gold Coast Hospital and Health Service, Child Development Service, *Submission 35*, p. 5.

40 See, for example, FASD Research Australia *Submission 42*, p. 23; Gold Coast Hospital and Health Service, Child Development Service, *Submission 35*, p. 12; Professor Harry Blagg, Mrs Suzie May, Clinical Associate Professor Raewyn Mutch, Dr Tamara Tulich and Dr Robyn Williams, *Submission 22*, p. 2. See also, Parliament of Australia, *FASD: The hidden harm: Inquiry into the prevention, diagnosis and management of Fetal Alcohol Spectrum Disorders*, House of Representatives Standing Committee on Social Policy and Legal Affairs, November 2012. The Hidden Harm report recommended that the Commonwealth Government include FASD in the List of Recognised Disabilities and the Better Start for Children with a Disability Initiative (Recommendation 1).

41 Mrs Katherine Burchfield, Health Director, Royal Far West, *Committee Hansard*, 14 October 2020, p. 37.

42 Royal Far West, *Submission 68,* p. 3.

4.41 Professor Doug Shelton of the Gold Coast Hospital and Health Service, Child Development Service, noted that there are currently no Medicare item codes specific to FASD, although there are some for other neurodevelopmental conditions, such as autism spectrum disorder:

> We would suggest that perhaps these particular item numbers should be more broadly applicable to neurodevelopmental presentations rather than linked to particular diagnoses, which would allow primary care and private paediatricians to become involved in the diagnosis and assessment of children potentially with FASD or indeed any complex neurodevelopmental presentation.[43]

4.42 The Department of Health told the committee that the MBS Review Taskforce is considering recommendations that FASD be included on the list of neurodevelopmental disorders under Medicare Item 135.[44]

4.43 The department noted that the MBS Review Taskforce is also considering ways to improve access to paediatric allied health assessments, including by amending the list of eligible disabilities by M10 items to include FASD:

> These recommendations would support an increase in screening and diagnosis for FASD … the MBS task force is considering stakeholder feedback. … It's then up to government to carefully consider the taskforce's recommendations before making a response.[45]

Long wait times

4.44 Inquiry participants told the committee that many clinics have limited resources to cope with demand, creating long wait times.[46] For example, the current waiting period for diagnosis in NSW is in excess of eight months.[47]

4.45 According to FASD Research Australia, researchers have found that in a study of 42 families of children with FASD, the average wait time between symptoms and diagnosis was four years, and 75 per cent of families had seen at least three doctors during that time.[48]

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43 Associate Professor Doug Shelton, Clinical Director, Women's, Newborn and Children's Services, Gold Coast Hospital and Health Service, *Committee Hansard,* 16 September 2020, p. 28.

44 Ms Sharon Appleyard, First Assistant Secretary, Population Health and Sport Division, Department of Health, *Committee Hansard*, 19 May 2020, p. 6. See also AMA, answer to written questions on notice 29 September 2020 (received 21 October 2020), p. 1.

45 Ms Sharon Appleyard, First Assistant Secretary, Population Health and Sport Division, Department of Health, *Committee Hansard*, 19 May 2020, p. 6. See also AMA, answers to written questions on notice 29 September 2020 (received 21 October 2020), p. 1.

46 FASD Research Australia, *Submission 42*, pp. 10–11.

47 roundsquared, *Submission 11*, p. 4. See also FARE, *Submission 50*, Attachment 1, p. 25; Gold Coast Hospital and Health Service, answers to written questions on notice 29 September 2020 (received 13 October 2020), pp. 1–2; NOFASD Australia, *Submission 40.2*, [pp. 3–4].

48 FASD Research Australia, *Submission 42*, pp. 10–11.

4.46 The Child and Youth Assessment and Treatment Service in Central Australia faces considerable wait times. According to Dr John Boffa, Chief Medical Officer,Public Health at the Central Australian Aboriginal Congress:

> … we can complete the assessment on about two children a week. But that still leaves a waiting list of more than 100 children, mostly from town—we're not even going out bush.[49]

4.47 The committee heard that these barriers demonstrate the need for a sustainable national funding strategy for FASD diagnostic services to ensure equitable access and timely and comprehensive assessments for all young people at risk of FASD.[50]

Culturally safe and language-appropriate diagnostic services

4.48 Culturally appropriate, practical and psychological supports are needed for the individual, their caregiver and family, during what may be a confronting process.[51] For example, VicFAS uses First Nations health workers as support for families during the diagnostic process.[52]

4.49 Inquiry participants also suggested that the FASD diagnostic guidelines should be revised to include specific cultural competencies for ensuring culturally safe therapeutic responses. In addition, it was suggested that the guidelines should specifically reference the effects of intergenerational trauma on neurocognitive development.[53]

Screening and diagnosis in a youth justice/child protection setting

4.50 Getting a diagnosis is particularly difficult for children or young adults in the justice system, with lengthy delays in accessing diagnostic assessments even where there is clear evidence of a disability or impairment.[54]

4.51 In addition, in the child protection setting, the committee heard that there is less likely to be information available about the mother's alcohol consumption, creating a further barrier to FASD diagnosis.[55]

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[49] Dr John Boffa, Chief Medical Officer Public Health, Central Australian Aboriginal Congress, *Committee Hansard*, 14 October 2020, p. 13.

[50] FASD Research Australia, *Submission 42*, p. 11.

[51] AMA, *Submission 5*, Position statement, p. 1; Australian Human Rights Commission, *Submission 17*, pp. 16 and 18.

[52] Ms Prue Walker, Private capacity, *Committee Hansard*, 24 June 2020, p. 23.

[53] Professor Harry Blagg, Mrs Suzie May, Clinical Associate Professor Raewyn Mutch, Dr Tamara Tulich and Dr Robyn Williams, *Submission 22*, p. 13.

[54] See, for example, Dr Andrew Webster, Head of Clinical Governance, Danila Dilba Health Service, *Committee Hansard*, 14 October 2020, p. 2; NOFASD, *Submission 40*, p. 10; Legal Aid WA, *Submission 41*, p. 4.

[55] Ms Sarah Ward, Acting Head, Health Promotion, FARE, *Committee Hansard*, 24 June 2020, p. 7.

4.52 The Gold Coast Hospital and Health Service noted that it has seen increasing referrals to its Child Development Service as a result of greater awareness of FASD in the Department of Child Safety. It noted that half of the children seen by the service are listed as being in child protection.[56]

4.53 The committee heard that there must be mandatory training for all Department of Child Safety networks in Australia and a close relationship with local child health services that assess for FASD.[57]

4.54 Inquiry participants were also supportive of routine screening for FASD in the child protection system, including adolescents in out-of-home care.[58]

Misdiagnosis and delayed diagnosis

Misdiagnosis

4.55 The committee heard that as many as 80 per cent of people diagnosed with FASD were previously misdiagnosed with another disability or disorder.[59]

4.56 Misdiagnosis occurs for a range of reasons, including the prevalence of co-occurring conditions such as Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder, or other behavioural learning problems.[60]

4.57 Additionally, as facial anomalies become less distinctive with puberty and behavioural and cognitive impairments become more pronounced, there is a greater risk of misdiagnosis because the underlying neurological abnormalities are not understood.[61]

4.58 One carer explained the consequence of misdiagnosis of autism spectrum disorder for her son with FASD:

> As our state offered no assistance related to FASD for our son or our family, we just continued using strategies for autism, just as we had been

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[56] Gold Coast Hospital and Health Service, Child Development Service, *Submission 35*, p. 13.

[57] Gold Coast Hospital and Health Service, Child Development Service, *Submission 35*, p. 13.

[58] See, for example, Victorian FASD Special Interest Group, *Submission 29*, p. 3; NOFASD, answers to questions on notice 24 June 2020 (received 21 July 2020), pp. 5–6.

[59] NOFASD Australia, *Submission 40*, p. 7.

[60] See, for example, AMA, *Submission 5*, Position statement, p. 3; AMA, answers to written questions on notice 29 September 2020 (received 21 October 2020), p. 2; Australian College of Midwives, *Submission 31*, [p. 4]; Joint submission Drug ARM and Queensland Coalition for Action on Alcohol, *Submission 45*, p. 4; Catholic Women's League Australia, *Submission 26*, p. 6.

[61] roundquared, *Submission 11*, p. 6. People affected by FASD may not display the characteristic physical features associated with the condition and may go undiagnosed or misdiagnosed as a result.

> advised to do. We didn't know what else to do. Our son's behavioural problems intensified.[62]

Delayed diagnosis

4.59 In many cases, a FASD diagnosis is often not made until children start school, when their functional impairments are more evident.[63] Since not all neurodevelopmental domains can be assessed in early childhood, assessment can require a longitudinal approach.[64]

4.60 Inquiry participants told the committee that delayed diagnosis is stressful for families, and that their child's behaviour and health may deteriorate as a result.[65]

4.61 VicFAS told the committee that the delays in diagnosing FASD can also have serious impacts on the stability of placements of children in care and can lead to placement breakdown.[66]

4.62 Due to the difficulty in getting a FASD diagnosis, some inquiry participants raised concerns that a FASD diagnosis may not occur until an individual reaches adolescence or adulthood, by which time they may already be in the justice system.[67]

Concerns about over-diagnosis

4.63 The WA Government raised concerns about possible over-diagnosis of FASD because, under the current guidelines, any reported in-utero exposure to alcohol can be enough to warrant exploration of FASD:

> In addition, there is no clear neurocognitive phenotype of FASD, which can lead to over and mis-diagnosis. Observed cognitive impairment may be due to other factors that are labelled as FASD because there is not a specific pattern of deficits.[68]

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62 Cheryl, Private capacity, *Committee Hansard*, 24 June 2020, p. 12.

63 Professor Carol Bower, Co-Director, FASD Research Australia Centre of Research Excellence, Telethon Kids Institute, *Committee Hansard*, 19 May 2020, p. 28.

64 NT Government, *Submission 2*, p. 19; Professor Carol Bower, Co-Director, FASD Research Australia Centre of Research Excellence, Telethon Kids Institute, *Committee Hansard*, 19 May 2020, p. 28.

65 FASD Research Australia, *Submission 42*, p. 11. Researchers found that, of 42 families studied, the average wait time between symptoms and diagnosis was four years, and three quarters had seen at least three doctors during that time.

66 VicFAS, *Submission 34*, p. 7.

67 Professor Harry Blagg, Mrs Suzie May, Clinical Associate Professor Raewyn Mutch, Dr Tamara Tulich and Dr Robyn Williams, *Submission 22*, p. 3.

68 Western Australian (WA) Government, *Submission 65*, p. 26.

4.64 The WA Government submitted that further research is needed to support the reliable identification of impairments directly attributable to prenatal alcohol exposure.[69]

4.65 The Catholic Women's League Australia (CWLA) told the committee that in the absence of a 'universally agreed diagnostic criteria for FASD', there is the capacity for over-diagnosis. However, the CWLA noted that the current evidence suggests under-diagnosis is the 'more common problem'.[70]

Secondary disabilities and co-occurring conditions

Co-occurring conditions

4.66 Individuals with FASD experience a high prevalence of co-occurring conditions, the committee heard.[71]

4.67 At least 428 comorbid conditions have been identified to date, although further research is needed to fully understand the range and impact of co-occurring conditions.[72]

4.68 FASD Research Australia noted that some of the most common co-occurring conditions are hearing and vision impairment, conduct and language disorders and chronic serious otitis media (ear infections).[73]

4.69 The University of Queensland suggested that routine screening for comorbid conditions, as well as a more holistic and integrated approach to clinical care, is needed for individuals with FASD.[74]

Diagnosing secondary disabilities

4.70 The committee heard that secondary disabilities are common with FASD—that is, consequential conditions arising from the FASD but not directly linked to the organic basis of the disorder.[75]

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69 WA Government, *Submission 65*, p. 15.

70 Catholic Women's League Australia, *Submission 26*, pp. 5–6.

71 University of Queensland, *Submission 36*, p. 9.

72 University of Queensland, *Submission 36*, p. 9; FASD Research Australia, *Submission 42*, p. 12; NOFASD, *Submission 40*, p. 7.

73 FASD Research Australia, *Submission 42*, p. 12, citing Svetlana Popova et. al., 'Comorbidity of fetal alcohol spectrum disorder: A systematic review and meta-analysis', *Lancet*, 387(10022): 978–987, 2016, doi.org/10.1016/s0140-6736(15)01345-8.

74 University of Queensland, *Submission 36*, p. 9; Gold Coast Hospital and Health Service, Child Development Service, answers to written questions on notice 29 September 2020 (received 13 October 2020), p. 6.

75 Gold Coast Hospital and Health Service, Child Development Service, *Submission 35*, p. 17.

4.71 Secondary disabilities can include, for example, mood disorders such as anxiety and depression, and behavioural issues, like aggression, which can arise in FASD-affected individuals because of an awareness of their cognitive inadequacies compared to their peers.[76]

4.72 According to the Gold Coast Hospital and Health Service, Child Development Service, the secondary disabilities associated with FASD have a heavy treatment burden:

> Secondary disabilities potentially afflict every aspect of the individual typically are well established by the time the individual reaches a tertiary service for assessment and diagnosis. As such, the treatment burden (both financially and effort based) is high, which results in many treatment services being either incapable of or unwilling to engage with the client.[77]

Limitations of current diagnostic guidelines

Issues with the current diagnostic guidelines

4.73 The committee heard that the current Australian diagnostic guidelines are too rigid and 'at odds with other diagnostic classifications'.[78]

4.74 Associate Professor Doug Shelton of the Gold Coast Hospital and Health Service gave evidence that the current guidelines set the bar too high:

> At the moment the guidelines hinge upon having a severe neurodevelopmental impairment in at least three brain domains. The definition of 'severe' is that you have to be functioning at less than the second percentile or two standard deviations below the mean. That's a very strict criteria …[79]

4.75 The complex nature of FASD diagnosis as provided in the current diagnostic guidelines also means that children and families need more time than current funding provisions allow, and that the demand for diagnosis is likely to increase over time.[80]

4.76 The WA Government also raised concerns that the current diagnostic guidelines 'lack specificity and clear guidelines for differential diagnosis'.[81]

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[76] Gold Coast Hospital and Health Service, Child Development Service, *Submission 35*, p. 17.

[77] Gold Coast Hospital and Health Service, Child Development Service, *Submission 35*, p. 17.

[78] Gold Coast Hospital and Health Service, Child Development Service, *Submission 35*, p. 6.

[79] Associate Professor Doug Shelton, Clinical Director, Women's, Newborn and Children's Services, Gold Coast Hospital and Health Service, *Committee Hansard*, 16 September 2020, p. 30.

[80] Gold Coast Hospital and Health Service, answers to written questions on notice 29 September 2020 (received 13 October 2020), p. 2.

[81] WA Government, *Submission 65*, [p. 7].

Updates to the current guidance and diagnostic instrument

4.77 The *Australian guide to the diagnosis of FASD* was published in 2016 and has not been updated since 2016.[82]

4.78 FASD Research Australia told the committee that, to 'remain current and evidence-based', there must be a review and revision of the *Australian guide to the diagnosis of FASD*.[83]

4.79 The Department of Health (the department) advised the committee that the University of Queensland has been funded to undertake a comprehensive review and update of the Australian FASD guidelines between 2019–20 and 2022–23.[84] The committee heard that, once completed, the revised diagnostic tool will be considered by the National Health and Medical Research Council for approval as a national Clinical Practice Guideline.[85]

4.80 According to the department, the funding will enable the review and update of the *Australian guide to the diagnosis of FASD* to ensure that it aligns with international and clinical best practice for the diagnosis of FASD, as well as facilitating dissemination activities amongst clinicians.[86]

4.81 The committee heard that the review should consider expanding the criteria for a FASD diagnosis to include children with moderate to severe functional impairment who currently do not meet the diagnostic guidelines.[87]

Initiatives aimed at improving access to diagnostic services

Tiered models using primary health care providers

4.82 The committee heard that, in addition to strengthening the specialised end of diagnostic service provision, there needs to be a greater focus on the role of primary health care providers.[88]

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82 FASD Research Australia, *Submission 42*, p. 8. See also FASD Hub, *FASD diagnosis: Australian guide to the diagnosis of FASD* (accessed 13 February 2021). The *Australian guide to the diagnosis of FASD* was released on 5 May 2016 and updated on 13 May 2016. Updates were made in February 2020 to some links, and pages were reformatted; however, there have been no amendments to the diagnostic instrument and how to use it.

83 FASD Research Australia, *Submission 42*, p. 11.

84 Mr David Laffan, Acting First Assistant Secretary, Population Health Division, Department of Health, *Committee Hansard*, 10 March 2021, pp. 15 and 19; Department of Health, *Submission 25*, p. 6; Department of Health, answer to question on notice IQ20-000262 (received 12 June 2020).

85 Mr David Laffan, Acting First Assistant Secretary, Population Health Division, Department of Health, *Committee Hansard*, 10 March 2021, p. 19; Dr Natasha Reid, Private capacity, *Committee Hansard*, 16 September 2020, p. 39.

86 Department of Health, *Submission 25*, p. 6.

87 Gold Coast Hospital and Health Service, answers to written questions on notice 29 September 2020 (received 13 October 2020), p. 3.

4.83 The *National Fetal Alcohol Spectrum Disorder (FASD) strategic action plan 2018–2028* already recognises that 'primary health care providers in remote locations can play a key role in the coordination of screening services'.[89]

Reserving specialist FASD clinics for complex cases

4.84 It was suggested to the committee that assessment and diagnostic services need to extend beyond specialist clinics and become 'part of routine practice' across a range of primary health care settings, reserving specialist services for the most complex cases.[90]

4.85 VicFAS told the committee that it was supportive of a multi-tier model of FASD diagnosis. It suggested that there could be a network of practitioners equipped to provide individual diagnosis and referral pathways, so that the most complex cases are done by diagnostic clinics, and more straightforward assessments can be conducted in the community.[91]

4.86 VicFAS also suggested that a paediatric FASD consultation service could be established to facilitate local diagnosis which could utilise technologies such as telehealth:

> This may include reviewing clinical photos for FASD phenotype, discussing clinical cases by telehealth/ phone/ and email, reviewing and interpreting assessments, using the Australian FASD Diagnostic Guidelines. In the short term this aims to increase the capacity for FASD diagnosis in Victoria with little increased resourcing. In the longer term the consultation service will empower community paediatricians to assess and mange children with FASD locally and independently.[92]

4.87 roundsquared told the committee that it supported the development and trial of a FASD pre-screening tool that could be used by a wider range of health services, including general practitioners (GPs), child and maternal welfare services and adolescent health services.[93]

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88 Associate Professor Doug Shelton, Clinical Director, Women's, Newborn and Children's Services, Gold Coast Hospital and Health Service, *Committee Hansard*, 16 September 2020, p, 28.

89 *National Fetal Alcohol Spectrum Disorder (FASD) strategic action plan 2018–2028 (National FASD strategic action plan)*, p. 22, www.health.gov.au/sites/default/files/national-fasd-strategic-action-plan-2018-2028.pdf (accessed 15 March 2021).

90 University of Queensland, *Submission 36*, p. 8.

91 VicFAS, *Submission 34*, p. 9.

92 VicFAS, *Submission 34*, p. 14.

93 roundsquared, *Submission 11*, pp. 8 and 11; *National FASD strategic action plan*, p. 22. The development and trial of a possible FASD pre-screening tool that could be used by a wider range of health services was also flagged in the *National FASD strategic action plan*.

Queensland tiered assessment model

4.88 The Gold Coast Hospital and Health Service, Child Development Service, has developed a primary care model that uses a tiered assessment approach to diagnose FASD.[94]

4.89 The model was developed in response to the waitlist burden for diagnostic services, and the large number of 'at risk' individuals not seeking or unable to access diagnostic services.[95]

4.90 The committee heard that the tiered assessment model is equivalent to a full comprehensive assessment under the *Australian guide to the diagnosis of FASD*. The assessment process is broken into six 'manageable' tiers, through which a child progresses, and the information collected from each stage forms the basis of a diagnostic decision.[96]

4.91 Through the model, primary care and specialist services collaborate to ensure that practitioners and GPs in rural and remote areas receive support from specialists.[97]

4.92 According to Professor Doug Shelton of the Gold Coast Hospital and Health Service, Child Development Service:

> We strongly believe that to democratise the diagnostic process it needs to be widely available, particularly in rural and regional areas. The only way to do that logically and cost-effectively is to provide it through primary care. This tiered assessment model is evidence based and proven to be effective.[98]

Use of technology and telehealth

Telehealth

4.93 The University of Queensland suggested there need to be more innovative and creative ways to assess and diagnosis FASD in a range of settings, including by telehealth. It noted the use of telehealth to undertake assessments in Canada for approximately 10 years, facilitating increased access to services in rural and remote areas.[99]

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94 Gold Coast Hospital and Health Service, Child Development Service, *Submission 35*, p. 5.

95 Gold Coast Hospital and Health Service, Child Development Service, *Submission 35*, p. 5.

96 Gold Coast Hospital and Health Service, Child Development Service, *Submission 35*, p. 5.

97 Gold Coast Hospital and Health Service, Child Development Service, *Submission 35*, p. 5.

98 Associate Professor Doug Shelton, Clinical Director, Women's, Newborn and Children's Services, Gold Coast Hospital and Health Service, *Committee Hansard*, 16 September 2020, p. 28.

99 University of Queensland, *Submission 36*, p. 10.

4.94 The committee heard from several health services using telehealth as a part of its FASD diagnosis and treatment service.[100] For example, VicFAS advised that it uses a model of face-to-face and telehealth services, with feedback on appointments provided through telehealth, and family and carer feedback occurring face-to-face with clinicians.[101]

4.95 The Gold Coast Hospital and Health Service said that its Child Development Service is increasingly using telehealth for its FASD diagnostic assessment and follow-up supports:

> Our experience to date suggests that the early stages of the diagnostic process, along with some basic response to early intervention- support the family whilst they are progressing through the diagnostic process, and addressing immediate 'quick win' clinical issues, is both effective and successful through a telehealth model of care.[102]

4.96 Royal Far West said telehealth has become a central tool for FASD diagnosis and treatment during the COVID-19 pandemic, although it noted that it still has limitations:

> Prior to COVID-19, Royal Far West completed almost all assessments face to face. Since COVID-19, Royal Far West has relied solely on telehealth for assessments, reviews and therapy. Where possible, we have completed assessments and diagnoses, but in many cases children are still waiting for completion of assessments face to face.[103]

4.97 The Gold Coast Hospital and Health Service, Child Development Service, explained that complex cognitive functions still require specialised equipment or face-to-face assessment. Although there are solutions being explored by clinics: 'these have start-up costs that in the current financial environment become inhibitive'.[104]

Northern Territory virtual diagnostic model

4.98 NT Health has developed a model of case management with Aboriginal Community Controlled Health Services (ACCHSs) in Darwin and Alice Springs to assess children for neurodevelopmental disorders, including FASD, through a single virtual setting, and connect them with appropriate services.[105]

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[100] VicFAS, *Submission 34,* p. 3.

[101] VicFAS, *Submission 34*, pp. 3–4.

[102] Gold Coast Hospital and Health Service, Child Development Service, answer to questions on notice 29 September 2020 (received 13 October 2020), p. 3.

[103] Royal Far West, answers to written questions on notice 20 October 2020 (received 6 November 2020), p. 2.

[104] Gold Coast Hospital and Health Service, Child Development Service, answer to questions on notice 29 September 2020 (received 13 October 2020), p. 3.

[105] NT Government, *Submission 2*, p. 19. Consumption of alcohol during pregnancy is routinely recorded on maternal records during antenatal visits in the Northern Territory.

4.99 Through this model, the ACCHS is able to maintain contact with the child and their family 'regardless of the diagnosis, to ensure that effective care coordination occurs'.[106]

4.100 Dr Andrew Webster, Head of Clinical Governance, Danila Dilba Health Service told the committee that ACCHSs can provide a 'one-stop shop' within a trusted service rather than families having to go through the process of diagnosis with multiple providers.[107]

3D facial imaging and epigenetic studies

4.101 Researchers are currently contributing to the development of 3D facial imaging as a potential diagnostic tool and to genetic research in children with prenatal alcohol exposure and/or FASD to enable earlier and more accurate diagnosis of FASD.[108]

4.102 Royal Far West suggested that further research is needed to investigate the use of other technologies such as 2D/3D facial photography, to facilitate best practice FASD assessment and care at a distance.[109]

Addressing workforce capacity

4.103 The committee heard that FASD diagnostic training needs to be embedded in training for a range of health professionals including medical practitioners, paediatricians, and allied health and social work professions.[110]

4.104 According to VicFAS, medical and allied health professionals also require more information about diagnostic pathways, for example, whether a child can be assessed and diagnosed appropriately within the community or if referral to a multidisciplinary team is required.[111]

Targeted training for health professionals

4.105 A range of training packages have been developed for clinicians to support diagnostic activity.[112] This includes an e-learning package to complement the *Australian guide to the diagnosis of FASD*.[113]

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106 NT Government, *Submission 2*, p. 19.

107 Dr Andrew Webster, Head of Clinical Governance, Danila Dilba Health Service, *Committee Hansard*, 14 October 2020, p. 4.

108 FASD Research Australia, *Submission 42*, p. 10.

109 Royal Far West, *Submission 68*, [p.] 4.

110 VicFAS, *Submission 34*, p. 8.

111 VicFAS, *Submission 34*, p. 8.

112 See, for example, FASD Research Australia, *Submission 42*, p. 9.

113 FASD Research Australia, *Submission 42*, p. 5. AMA, *Submission 5*, Position statement, p. 3.

4.106 The committee heard, however, that interested practitioners may need to travel interstate to undertake more extensive training in diagnosis using the *Australian guide to the diagnosis of FASD*.[114]

4.107 The Gold Coast Hospital and Health Service has trained over 270 health professionals through a three-day practical training course. Those who complete the course are encouraged to promote themselves as 'FASD skilled' and register their service on FASD Hub:

> … we try to make it as practicable as possible, because, when they walk out the door, we want them to have the confidence to be able to go and diagnose children in their own patch immediately.[115]

FASD Models of Care project

4.108 The Fetal Alcohol Spectrum Disorder Models of Care project aims to develop and implement local models of care and expand sustainably funded FASD diagnosis and therapy service models across the country.[116]

4.109 The project includes an online Graduate Certificate in the Diagnosis and Assessment of Fetal Alcohol Spectrum Disorders (FASD) to provide multidisciplinary clinicians with the specialist knowledge and clinical skills required to participate in team-based diagnosis and assessment of FASD.[117]

4.110 The course is delivered to a range of disciplines including nursing, occupational therapy, paediatrics, psychology, speech pathology and social work.[118]

4.111 The University of WA reported significant interest in the course, although it suggested that a key barrier for clinicians engaging in further training and education is accessibility and cost. The course has not been HECS/HELP supported and limited scholarships have been available; however, some Commonwealth Supported Places have recently become available.[119]

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[114] Office of the Children's Guardian (NT), *Submission 4*, [p. 3].

[115] Associate Professor Doug Shelton, Clinical Director, Women's, Newborn and Children's Services, Gold Coast Hospital and Health Service, *Committee Hansard,* 16 September 2020, p. 32.

[116] The University of WA, *Submission 23*, p. 1. The project includes parties from across Australia, with eight services and organisations in WA, NT, Victoria, Tasmania and South Australia participating.

[117] The University of WA, *Submission 23*, p. 1.

[118] The University of WA, *Submission 23*, p. 4.

[119] The University of WA, *Submission 23*, p. 4; The University of Western Australia, *Postgraduate Graduate Certificate in the Diagnosis and Assessment of Fetal Alcohol Spectrum Disorders (FASD)* (accessed 15 March 2021).

Committee view

Availability of diagnostic services

4.112 Despite a growth in diagnostic and early intervention activity in recent years, access to FASD diagnostic services remains fragmented, poorly funded and lacking in a whole-of-government approach. The committee is of the view that this is an unacceptable situation, particularly noting the significant consequences of a delayed diagnosis or misdiagnosis, and the risk of secondary disabilities.

4.113 The committee welcomes the additional funding for diagnostic services, announced by the federal government during the inquiry. It is paramount that the funding address inequalities in access to diagnostic services, particularly in rural and remote areas.

Recommendation 13

4.114 The committee recommends that the Australian Government undertake a national audit of current FASD diagnostic services and funding to identify priority areas and inform a longer-term and sustainable funding model.

4.115 The committee is also supportive of measures to review Medicare rebates to better cover the costs of the range of assessment practices and therapeutic responses to FASD, including the increased use of telehealth.

Recommendation 14

4.116 The committee recommends that the Medicare Benefits Schedule (MBS) Review Taskforce recommends including MBS Items that cover the range of clinical practices involved in FASD assessments, diagnoses and treatments.

Exploring alternative models of assessment

4.117 The committee is of the view that FASD diagnosis must be made more widely available within the community, particularly in rural and remote areas. Therefore, alternative models of assessment must be pursued, and primary health care better utilised, in the assessment and diagnosis of FASD.

4.118 Evidence of tiered assessment models, such as that trialled in Queensland, were of particular interest to the committee and may have broader application. The committee also notes that there is scope for further innovation to support the increased role of primary health care in FASD assessment and diagnosis, including through telehealth.

Recommendation 15

4.119 The committee recommends that the Australian Government fund:

- **an evaluation of tiered models of assessment and use of technology to improve accessibility to diagnostic services, including in rural and remote communities; and**
- **the implementation of a trial for a model of tiered FASD assessment utilising primary health care services.**

Building workforce capacity

4.120 To meet future workforce needs, the committee considers that there must be increased diagnostic training across disciplines. The committee notes that there are well regarded existing programs that warrant further investment, including practical training courses offered by clinical services, as well as tertiary courses.

Recommendation 16

4.121 The committee recommends that the Australian Government allocate funding for FASD diagnostic training, including:

- **for the expansion of the delivery of practical training courses provided by clinical services; and**
- **for scholarships and/or subsidies to increase the number of practitioners with a Graduate Certificate in the Diagnosis and Assessment of Fetal Alcohol Spectrum Disorders (FASD).**

Recommendation 17

4.122 The committee recommends that Australian universities ensure that FASD modules are included in university curriculums for relevant occupations, including those for education and teaching, medicine, midwifery, psychology, social work, occupational therapy, speech and language pathology.

4.123 The review of the *Australian guide to the diagnosis of FASD* also presents an opportunity to strengthen diagnostic workforce capacity and primary health care involvement in assessments and referrals. The committee is of the view that the revised guide and diagnostic tool, once finalised, must be broadly disseminated and training provided to specialists and primary health care workers.

Recommendation 18

4.124 The committee recommends that the Australian Government allocate funding for a project to disseminate the *Australian guide to the diagnosis of FASD* immediately following its revision and to train health professionals in its use.

Chapter 5
Management and support services

> … [P]revention really must be the future. But in the meantime we must provide adequate diagnostic and treatment services, we must support children, families and adults living with FASD …[1]

5.1 FASD is a lifelong condition with no cure; however, early intervention can improve a child's development. The neuropsychological and behavioural issues associated with FASD can result in disabilities that can prevent independent living and require ongoing support throughout a person's life. Early individualised interventions, and support for carers and families, can improve a person's quality-of-life outcomes.[2]

5.2 This chapter explores the range of management and support services needed for individuals with FASD as well as their families, and what makes a difference in the education and justice systems. It also explores current barriers to accessing support services, including issues accessing the National Disability Insurance Scheme (NDIS) and social security payments.

Supporting individuals with FASD

Early intervention

5.3 Although there is no cure for FASD, inquiry participants stressed the importance of early diagnosis and early intervention treatment services in order to improve an individual's quality-of-life outcomes.[3]

5.4 In its submission to this inquiry, roundsquared noted that the earlier the diagnosis and intervention, the better the outcome for individuals with FASD:

> Diagnosis before the age of 6 year[s]; a loving, nurturing, and stable home environment during the school years; the absence of violence and involvement in special education and social service can help reduce the effects of FASDs and help people with these conditions reach their full potential.[4]

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1 Professor Elizabeth Elliott, Fellow, Royal Australasian College of Physicians (RACP), *Committee Hansard*, 16 September 2020, p. 3.

2 Department of Health, *National Fetal Alcohol Spectrum Disorder (FASD) strategic action plan 2018–2028*, p. 4, www.health.gov.au/resources/publications/national-fetal-alcohol-spectrum-disorder-fasd-strategic-action-plan-2018-2028 (accessed 11 March 2021).

3 Northern Territory (NT) Government, *Submission 2*, p. 22; Australian Medical Association (AMA), *Submission 5*, Position statement, p. 3.

4 roundsquared, *Submission 11*, p. 7.

5.5 The Aboriginal Medical Services Alliance of the Northern Territory submitted that interventions during early childhood are cost-effective and have positive long-term effects:

> Early intervention, and specifically intervention in early childhood, is the most cost-effective intervention to break cycles of intergenerational disadvantage and trauma and improve long-term outcomes across a range of health and wellbeing measures.[5]

Types of supports

5.6 Because the nature and type of disability experienced by an individual with FASD will vary, best-practice support involves a personalised care program, delivered through a multidisciplinary model of care.[6]

5.7 Children with FASD often require strategies and environmental accommodations to address challenging behaviours.[7] At school, children with FASD can experience challenges that require specialised programs which recognise and address their complex needs.[8]

5.8 Programs which develop social and emotional skills can help children with FASD to manage their behaviours and build resilience and connection to community. These protective factors help lessen the risks of mental health issues, antisocial and criminal behaviour, and substance misuse later in life.[9]

5.9 Although behaviour management is commonly the focus of supports, children with FASD also need help to develop life and education skills, particularly in the context of challenges in daily activities including learning, attending, sitting still, self-regulation and impulse management.[10]

5.10 The family and carers of children with FASD also need education and capacity building to help them understand the disability and assist them to support their child's education, self-regulation, behaviour and social skills.[11]

5.11 The *National Fetal Alcohol Spectrum Disorder (FASD) strategic action plan 2018–2028* acknowledges that support and management for an individual with

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5 Aboriginal Medical Services Alliance of the Northern Territory (AMSANT), *Submission 62*, p. 8.

6 Department of Health, *National Fetal Alcohol Spectrum Disorder strategic action plan 2018–2028 (National FASD strategic action plan)*, p. 24; Australian Human Rights Commission (AHRC), *Submission 17*, p. 26.

7 VicFAS, *Submission 34,* p. 11.

8 Department of Health, *National FASD strategic action plan*, p. 26.

9 NT Government, *Submission 2*, p. 22.

10 Danila Dilba Health Service, *Submission 61*, pp. 17–18.

11 Danila Dilba Health Service, *Submission 61*, p. 18.

FASD will also require consideration of any secondary disabilities and vulnerabilities, including childhood trauma.[12]

Adults with FASD

5.12 FASD is often not identified until relatively late in life, or not identified at all.[13]

5.13 If FASD is left undiagnosed into adulthood, individuals face significant challenges including the risk of developing secondary disabilities:

> Unsupported, as arguably most adults with FASD in Australia are, they may face a life of poor education outcomes, unsuccessful employment, increased risk of substance use disorders, increased involvement in risk-taking behaviours, challenges forming relationships, risk of homelessness, risk of being a victim of violent behaviour or perpetrating violence and contacts with justice systems.[14]

Support for adults with FASD

5.14 The committee heard that the type and level of support required for adults with FASD differs compared to children and young people, and there must be regard for an individual's functional capacity and longer-term support needs.[15]

5.15 Inquiry participants outlined a range of possible supports for adults with FASD. These could include assistance with financial management, interpersonal relationships or legal situations.[16] Additionally, they may need support for living arrangements, personalised workforce training and vocational support.[17]

5.16 Specific supports may also be necessary for adults with FASD who are also parents. This can include strategies such as modelling and rehearsal, concrete instructions, physical demonstrations and guidance, breaking tasks into smaller steps, overlearning routines and using pictorial aids.[18]

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[12] Department of Health, *National FASD strategic action plan*, p. 24.

[13] Department of Health, *National FASD strategic action plan*, p. 24.

[14] National Organisation for Fetal Alcohol Spectrum Disorder (NOFASD), answer to questions on notice 24 June 2020 (received 21 July 2020), p. 14. See also, for example, Department of Health, *National FASD strategic action plan*, p. 24.

[15] NT Government, *Submission 2*, p. 22; Newcastle Local Drug Action Team, *Submission 69*, Attachment 1, p. 13.

[16] AMA, *Submission 5*, Position statement, p. 3.

[17] Royal Australian College of General Practitioners (RACGP), *Submission 53*, [p. 5].

[18] Emerging Minds, *Submission 15,* [p. 13].

Availability of support services

5.17 An Australian study has found that caregivers struggle to find support and relevant services following the diagnosis of FASD.[19]

5.18 The study concluded that this is due in part to the structure of the Australian health system, the different levels of support provided depending on a child's diagnosis, and the lack of recognition for FASD and its associated impairments.[20]

5.19 According to one witness, after a difficult journey to a FASD diagnosis, she faced further barriers accessing services for her son with FASD:

> It should have been a simple matter of finding services and organisations that would be able to support us with therapies and services. However, we were soon left in despair. Any searches or leads we found mostly ended with allied health professionals who didn't have either the qualifications, training, awareness or knowledge to provide what was needed for our son.[21]

5.20 The Royal Australian College of General Practitioners told the committee that there are mainstream therapy programs available to assist with domain-specific impairments commonly seen in FASD; however, there are not many FASD-specific therapy programs or providers.[22]

5.21 The Royal Australian and New Zealand College of Psychiatrists also expressed concerns about gaps in specialist mental health services needed to meet the needs of individuals with FASD with complex and challenging behaviours.[23]

5.22 The committee heard child health services in some remote communities, where there are high rates of FASD and early life trauma, are inadequate to address the chronic, complex needs of children with FASD.[24]

5.23 However, some supports, such as family-led therapy, have been delivered remotely through telehealth with good results. There are additional challenges

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19 VicFAS, *Submission 34,* p. 11 citing Chamberlain, K., Reid, N., Warner, J., Shelton, D. and Dawe, S. (2017), 'A qualitative evaluation of caregivers' experiences, understanding and outcomes following diagnosis of FASD', *Research in Developmental Disabilities*, vol. 63, 99–106, https://doi.org/10.1016/j.ridd.2016.06.007.

20 VicFAS, *Submission 34,* p. 11 citing Chamberlain, K., Reid, N., Warner, J., Shelton, D. and Dawe, S. (2017), 'A qualitative evaluation of caregivers' experiences, understanding and outcomes following diagnosis of FASD', *Research in Developmental Disabilities*, vol. 63, 99–106 at 105, https://doi.org/10.1016/j.ridd.2016.06.007.

21 Sophie, Private capacity, *Committee Hansard,* 24 June 2020, p. 12.

22 RACGP, *Submission 53*, [p. 5].

23 Royal Australian and New Zealand College of Psychiatrists, answers to written questions on notice, 29 September 2020 (received 13 October 2020), [p. 2].

24 FASD Research Australia, *Submission 42*, p. 15.

to using telehealth, such as building rapport with families and the need for additional coordination, but these were not considered insurmountable.[25]

Meeting the cost of management and support services

5.24 The costs associated with FASD management and accessing support services can be prohibitive, the committee heard.[26]

5.25 Other than the funding available through the NDIS, discussed further below, there are limited other avenues to meet the costs of FASD supports:

> The only options for families would be either through current Medicare Funding Schemes via GP, which has prohibitive gap payments or paying completely for private services.[27]

5.26 The Royal Australian College of General Practitioners observed that patients with intellectual disability and socioeconomic disadvantage may be unable to pay Medicare gaps for consultations and services:

> Financial barriers to seeing specialists or allied health can occur regardless of geographic location. Many State public hospital systems have limited availability in outpatient services such as allied health.[28]

5.27 According to the Gold Coast Hospital and Health Service, its Child Development Service and others like it are not funded to provide longer term intervention and therapy supports for children in care. As a result these children risk being further disadvantaged where the relevant Department of Child Safety is reluctant to subsidise additional costs.[29]

Supporting parents and carers

The impact on parents and carers

5.28 It is clear from the evidence before this committee that caring for a child with FASD impacts greatly on parents and carers, who experience stress, the burden of care, unmet needs and impacts on quality of life.[30]

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[25] Danila Dilba Health Service, answers to written questions on notice, 20 October 2020 (received 3 November 2020), pp. 3–4.

[26] Gold Coast Hospital and Health Service, Child Development Service, answers to written questions on notice, 29 September 2020 (received 13 October 2020), p. 3.

[27] Gold Coast Hospital and Health Service, Child Development Service, answers to written questions on notice, 29 September 2020 (received 13 October 2020), p. 4. Funding for supports through the National Disability Insurance Scheme is discussed further below.

[28] RACGP, answers to written questions on notice, 29 September 2020 (received 16 October 2020), [p. 4].

[29] Gold Coast Hospital and Health Service, Child Development Service, answers to questions on notice 29 September 2020 (received 13 October 2020), p. 4.

[30] University of Queensland, *Submission 36,* p. 15.

5.29 The mother of a child with FASD described to the committee the personal impact of caring for her son with FASD:

> Not only am I our son's full-time carer but, for the last nine years, I've also been his educator. We had no alternative but to home educate our son after an initial six weeks of school life during which he was unable to cope with the anxiety and the daily sensory distress. It is not easy but this has also given me an opportunity to tailor an educational program to his strengths and interests. My personal story of having no FASD supports, fighting for funding and fighting for support for me so that I can support our son has taken its toll—but this should not be the case.[31]

5.30 The committee heard that the stress experienced by caregivers has been partly attributed to the lack of understanding of FASD in the community and the need for caregivers to constantly explain their child's behaviour and advocate for their child's needs.[32]

5.31 This view was supported by evidence received by the committee from a carer of a child with FASD, who described the personal impact of the lack of support from the state's child protection system:

> There is a great reluctance to put a label on the behaviour or to acknowledge FASD's existence. This denial means that not only do I not get support, I am undermined and blamed. An example of the disrespect I feel was when I expressed my despair and frustration, the answer was to try to remove him, without any discussion with me. They have no understanding of the importance of stability for a FASD child. The threat of removal caused me to conceal from them the behaviours I am dealing with.[33]

Capacity of parents/carers to engage supports

5.32 Parents and carers face challenges attempting to follow up with the recommendations of a FASD diagnosis and engage the supports needed for their child.[34]

5.33 VicFAS explained that the barriers faced by parents and carers include difficulty completing paperwork, unfamiliarity with the service system, competing demands of raising other children, and general carer stress.[35]

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31 Cheryl, Private capacity, *Committee Hansard*, 24 June 2020, p. 13.

32 University of Queensland, *Submission 36*, p. 15.

33 Ms Nikki Mortier, answers to written questions on notice 29 September 2020 (received 1 October 2020), [p. 2].

34 VicFAS, *Submission 34*, p. 11; Gold Coast Hospital and Health Service, Child Development Service, *Submission 35*, p. 14.

35 VicFAS, *Submission 34*, p. 7.

5.34 This issue is particularly pronounced in the child protection context, where carers may not know the extent and complexity of a child's history and care needs:

> Navigating systems that they are not familiar with represents a significant contribution to this difficulty. Even if there is agreement from the Department of Child Safety to provide support, foster carers report that it is often left to them to find these services, with no adjustment in funding to compensate for this expense.[36]

Types of supports for parents/carers

5.35 The University of Queensland submitted that the health and wellbeing of caregivers and families is of clinical importance to achieving positive outcomes for children with FASD and that supports must be practical:

> Access to practical supports such as regular respite and also access to interventions that can support caregiver mental wellbeing and family functioning are important areas for consideration.[37]

5.36 Witnesses who care for children with FASD described for the committee the types of practical supports that parents and carers need.[38] For example, they need respite and support with household duties:

> Support for those living with FASD, must include support for those who care for them, such as house keeping assistance, some-one to run errands and general household maintenance would make a HUGE difference to carers/parents ability to continue to provide the care needed.[39]

5.37 The Australian Government funds NOFASD to provide a national carer helpline service.[40] Support groups, such as those delivered by NOFASD and the Russell Family Fetal Alcohol Disorders Association, also provide online support for parents and carers of children with FASD.[41] These supports have been well received by parents and carers. However, the committee heard that there are limited face-to-face support groups available to complement online services.[42]

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36 Gold Coast Hospital and Health Service, Child Development Service, *Submission 35,* p. 14.

37 University of Queensland, *Submission 36,* p. 15.

38 See, for example, Cheryl, Private capacity, *Committee Hansard*, 24 June 2020, p. 13; Ms Nikki Mortier, answers to questions on notice 29 September 2020 (received 1 October 2020), [p. 2].

39 Name withheld, *Submission 24*, p. 5.

40 NOFASD, *Submission 40*, p. 16.

41 FASD Research Australia, *Submission 42,* p. 21.

42 See, for example, VicFAS, *Submission 34*, p. 12; NOFASD, *Submission 40*, Attachment 2, [pp. 10–11]; Name withheld, *Submission 24*, p. 2; Cheryl, Private capacity, *Committee Hansard,* 24 June 2020, p. 12.

5.38 In Western Australia, the community-initiated and community-led Triple P Positive Parenting Program Jandu Yani U ('for all families') has trained 'parent coaches' to deliver informal skills training to hundreds of community members within the Fitzroy Valley.[43] Inquiry participants suggested the model has had significant outcomes for families and they were supportive of further expansion in appropriate settings.[44]

Wraparound support services

5.39 Inquiry participants outlined the need for 'wraparound' support services as well as diagnostic services.[45] According to Dr Andrew Webster, Head of Clinical Governance at Danila Dilba Health Service (NT):

> If you just focus on diagnosis, the child has sometimes a year, maybe two years, of undergoing a diagnostic process without any therapy happening. So we've also looked at employing a social worker, NDIS connectors and other sorts of people who can work in the team to really support that family and that child as they go through this process.[46]

5.40 In the US and Canada, diagnostic clinics use case coordinators and volunteer 'parent navigators' to work with families to provide post-diagnosis support including counselling and assisting with paperwork, and help obtaining funding to implement recommendations.[47]

5.41 Several inquiry participants were supportive of support/case coordination models which assist those with FASD and their families to navigate diagnostic and support services:

> FASD is a lifelong condition that is characterised by contact with multiple services and professionals. Therefore, support/case coordination (along the lines of the key worker model) may be the most appropriate model of post-diagnostic support. This kind of role should be supported under the NDIS.[48]

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43 FASD Research Australia, *Submission 42*, p. 15. The Jandu Yani U program is discussed in further detail in Chapter 6.

44 See, for example, FASD Research Australia, *Submission 42*, p. 15; Victorian Alcohol and Drug Association, *Submission 60*, p. 6.

45 Jandu Yani U Project Team, *Submission 49*, p. 7; RACP, *Submission 64*, p. 6.

46 Dr Andrew Webster, Head of Clinical Governance, Danila Dilba Health Service, *Committee Hansard*, 14 October 2020, pp. 4–5.

47 VicFAS, *Submission 34*, pp. 12–13.

48 Emerging Minds, *Submission 15*, [p. 12]. See also VicFAS, *Submission 34*, pp. 12–13.

Accessing the NDIS

5.42 To access funding under the NDIS, a person must meet disability and early intervention requirements as set out in the *National Disability Insurance Scheme Act 2013* (NDIS Act).[49]

5.43 The National Disability Insurance Agency (NDIA) told the committee that FASD is not on the Australian Government's List of Recognised Disabilities. However, it noted that access to the NDIS can be met by demonstrating that a person has a permanent and significant disability.[50]

5.44 As at 30 September 2020, the NDIA reported that there were 1,606 NDIS applicants with a primary or secondary diagnosis of FASD.[51]

Evidence of a permanent and significant disability

5.45 Children aged over seven years of age must have a permanent and significant disability to access support through the NDIS.[52]

5.46 Of the range of impairments that people with FASD may experience, only Fetal Alcohol Syndrome (FAS) is recognised as a permanent and significant disability by the NDIS.[53]

5.47 According to roundsquared, without a FASD diagnosis, evidence of permanent and significant disability or developmental delay resulting in functional impairment can be difficult to provide, resulting in FASD not being recorded as the primary disability with the NDIS.[54]

5.48 The committee heard concerns that medical professionals are often unable to adequately describe the functional impact of FASD and have a limited understanding of the NDIS. This contributes to the difficulties that individuals face gaining access to NDIS supports.[55]

NDIS funding for early childhood intervention

5.49 Children under seven years of age with developmental delay or disability can access Early Childhood Early Intervention (ECEI) funding through the NDIS.[56]

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49 National Disability Insurance Agency (NDIA), *Submission 67,* p. 3.

50 NDIA, answer to question on notice SQ20-000216, 25 June 2020 (received 22 July 2020).

51 NDIA, answer to question on notice SQ21-000010, 4 December 2020 (received 14 January 2021).

52 roundsquared, *Submission 11*, p. 7.

53 roundsquared, *Submission 11*, p. 7.

54 roundsquared, *Submission 11*, p. 7.

55 See, for example, Victorian FASD Special Interest Group, *Submission 29*, p. 4; VicFAS, *Submission 34*, p. 12.

56 NDIA, answer to question on notice SQ20-000216, 25 June 2020 (received 22 July 2020), [p. 2].

5.50 The NDIA told the committee that the aim of ECEI funding is for the child, through quality early childhood intervention, to need fewer funded supports in the long run:

> The reason we do early childhood intervention is to help the child to be as developed and ready, and the environment the child is moving to in the next stage of life is ready for that person to continue life's journey.[57]

5.51 The NDIA reported that in December 2019, just over a third of all NDIS participants were aged zero to six years. The NDIA also reported that since July 2019, there were 19,636 participants aged zero to six years that had gained access to NDIS.[58]

5.52 The Gold Coast Hospital and Health Service, Child Development Service, told the committee that the ECEI funding has been used to provide access to vital early intervention support.[59]

5.53 It noted that the process has been 'very positive' for its service, and reduced the number of children 'inappropriately "labelled" with an alternative diagnosis', such as autism spectrum disorder, 'purely to obtain disability supports'.[60]

5.54 The Northern Territory Government noted that it is working with the NDIA to access early intervention funding using the results of the Ages and Stages Questionnaire (ASQ-TRAK).[61] It is proposed that the NDIA allow ASQ-TRAK results to be regarded as adequate documentation for NDIS ECEI funding.[62]

5.55 The NDIA told the committee that it is currently consulting the community in relation to an ECEI Reset, which will consider how best to support young children and their families and will inform the final design of the ECEI pathway for the younger cohort.[63]

Difficulty navigating access pathways

5.56 Inquiry participants expressed frustration at the difficulty navigating access to the NDIS:

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[57] Mr Peter De Natris, Strategic Advisor, Early Childhood Intervention and Autism, NDIA, *Committee Hansard*, 4 December 2020, p. 12.

[58] NDIA, *Submission 67*, p. 8.

[59] Gold Coast Hospital and Health Service, Child Development Service, answers to written questions on notice 29 September 2020 (received 13 October 2020), p. 3.

[60] Gold Coast Hospital and Health Service, Child Development Service, answers to written questions on notice 29 September 2020 (received 13 October 2020), p. 3.

[61] NT Government, *Submission 2*, p. 19. ASQ-TRAK is a developmental screening tool that is used for monitoring and observing First Nations children's developmental progress until two years of age.

[62] NT Government, *Submission 2*, p. 19.

[63] NDIA, answer to question on notice SQ21-000022, 4 December 2020 (received 4 January 2021).

> … most individuals and their families affected by FASD or at risk of the disorder remain unaware that they can approach NDIS for support, let alone understand the nature and level of evidence necessary to demonstrate the functional need.[64]

5.57 One witness trying to get supports for her adopted son with FASD described the NDIS journey as 'horrendous'. She explained:

> Trying to obtain the services that we needed was painful. What we needed was help so that we could provide our son with the one-on-one care that is needed all of the time. It's a level of supervision which I relate to as poolside supervision at all times. Imagine the toll this takes on you when you're trying to do all the other daily tasks that need to be done.[65]

5.58 The Australian Human Rights Commission noted the challenge of documenting evidence of functional impairment—a requirement to gain access to the NDIS—for people with additional social, cultural, educational and literacy barriers.[66]

5.59 The NDIA told the committee that it is working with general practitioners to improve their ability to support patients applying to the NDIS. It also noted that NDIS supports are being coordinated with mainstream services through NDIA staff, Local Area Coordinators, Early Childhood Partners and NDIS-funded support coordinators.[67]

Adequacy of support plans

5.60 When an individual with FASD becomes an NDIS participant, a participant support plan is provided in order to meet their reasonable and necessary disability needs.[68]

5.61 However, inquiry participants expressed concerns that those responsible for developing participant support plans lack the skills, experience and resources needed to adequately assess and advise families on appropriate supports and services for children with FASD.[69]

5.62 The National Organisation for FASD (NOFASD) conducted a survey of parents and carers of children with FASD, and found that the vast majority (over 80 per cent) experienced difficulties with the application process and felt that

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[64] Gold Coast Hospital and Health Service, Child Development Service, *Submission 35,* p. 19. See also, for example, roundsquared, *Submission 11*, pp. 8–9; Dr Vanessa Spiller, *Submission 16,* [p. 3]; AHRC, *Submission 17,* p. 10.

[65] Cheryl, Private capacity, *Committee Hansard*, 24 June 2020, pp. 12–13.

[66] AHRC, *Submission 17,* p. 10.

[67] NDIA, answer to question on notice SQ21-000018, 4 December 2020 (received 14 January 2021).

[68] NSW Government, *Submission 57*, p. 8.

[69] Emerging Minds, *Submission 15,* [p. 12]; University of Queensland, *Submission 36,* p. 14.

NDIS planners did not have a good understanding of FASD. According to one participant:

> The NDIS is extremely difficult to develop an adequate plan with. I needed to educate the planner/s on FASD and even with an enormous amount of information provided and verbally provided, little of the information was used to develop a plan. There did not appear to be a desire to learn about FASD, particularly with our initial planner.[70]

5.63 The committee heard that the pathway to access the NDIS for a person with psychosocial disabilities is particularly difficult due to the episodic nature of mental health conditions and poor understanding amongst NDIS planners.[71]

5.64 Queensland Advocacy Incorporated expressed concerns about the NDIA's use of Typical Support Packages (TSPs), stating that they do not result in adequate supports for people with FASD. It noted that getting the right support plan is like 'winning the lottery' and that TSPs do not recognise the diversity of supports needs.[72]

Availability of service providers

5.65 The availability of providers to deliver services according to participant plans is also problematic, the committee heard. Several inquiry participants cited issues with 'thin markets' in parts of Australia where there are limited or no providers available to deliver therapeutic and allied health services.[73]

5.66 According to Dr Lauren Rice, Research Fellow with the University of Sydney Brain and Mind Centre, the lack of support services for rural and remote communities, like Fitzroy Valley in Western Australia, means that NDIS funding is not being used:

> What's happening is we have kids who are zero to seven who would easily meet the criteria for an NDIS plan, but why put them on a plan when the service isn't here …[74]

5.67 The NDIA told the committee that the average utilisation rate for people with FASD is between 65 and 70 per cent of their plan, depending on whether it is the person's first plan or a subsequent plan:

> We know across the whole scheme that participants tend to use more of their plans the longer they've been in the scheme … When you look at it by

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70 NOFASD, *Submission 40*, Attachment 2, [p. 14].

71 roundsquared, *Submission 11*, p. 9.

72 Queensland Advocacy Incorporated, *Submission 21*, [p. 7–8].

73 See, for example, Neurodevelopmental and Behavioural Paediatric Society of Australasia, *Submission 54*, p. 6; AMSANT, *Submission 62*, p. 8.

74 Dr Lauren Rice, Research Fellow with the University of Sydney Brain and Mind Centre, *Committee Hansard*, 14 October 2020, p. 39.

> some of the different age groups, generally speaking it's a fairly similar utilisation rate for FASD as it is for the scheme as a whole.[75]

Accessing the NDIS in the child protection system

5.68 The committee heard that young people in care are often unable to access services in their NDIS plan because the people responsible for their care are unfamiliar with the operation of the NDIS and how to maximise its effectiveness.[76]

5.69 In addition, administrative delays and a lack of specialist service providers create barriers to accessing the NDIS for children in care. According to the Gold Coast Hospital and Health Service, Child Development Service:

> It is our experience that children under the care of the department, tend to wait longer to access NDIS plans than other children, often due to delays in submitting Application Request Form. Concurrently when [the] plan has been established, children known to the Department are disadvantaged, as they must choose a NDIS managed plan, this in turn significantly reduces the options for eligible providers. FASD intervention, especially in the context of trauma, is a specialist service and unless these clinicians are registered with NDIS, they cannot provide services to this client group.[77]

FASD and the education system

Current challenges

5.70 Evidence before the committee indicated the education system is not well equipped to support children with FASD.[78]

5.71 Witnesses suggested there is a need for greater awareness of FASD within the education system, more teaching and support staff, and more training on FASD-specific strategies and non-punitive behaviour management.[79]

5.72 The committee heard from a foster carer who has had to put her child with FASD in private school in order to access an appropriate level of support:

> I think the big problem for the department of education is that teachers are not well trained in dealing not just with FASD but with all the behavioural disabilities and problems the kids have. They have a single approach—we

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75 Ms Sarah Johnson, Scheme Actuary, NDIA, *Committee Hansard*, 4 December 2020, p. 5.

76 Office of the Children's Commissioner (NT), *Submission 32*, [p. 3].

77 Gold Coast Hospital and Health Service, Child Development Service, *Submission 35*, p. 14.

78 See, for example, Ms Nikki Mortier, Private capacity, *Committee Hansard,* 16 September 2020, p. 36; Sophie, Private capacity, *Committee Hansard,* 24 June 2020, p. 15; Cheryl, Private capacity, *Committee Hansard,* 24 June 2020, p. 16.

79 Ms Nikki Mortier, Private capacity, *Committee Hansard,* 16 September 2020, p. 36; Sophie, Private capacity, *Committee Hansard,* 24 June 2020, p. 15; Cheryl, Private capacity, *Committee Hansard,* 24 June 2020, p. 16.

> found this time after time in his state school—and that is a punitive approach.[80]

Funding for educational supports

5.73 Inquiry participants expressed frustration with definitional barriers that restrict access to necessary funding for supports for children with FASD in schools.[81]

5.74 The Child Development Service on Queensland's Gold Coast reported being told that their diagnosis and functional characterisation of a FASD child is not applicable to the education context.[82] Similar examples were cited in Western Australia.[83]

5.75 It was suggested to the committee that a review of state and territory education policies should be undertaken to ensure that students with FASD are not precluded from having their disability recognised and obtaining the support they need.[84]

5.76 The committee also heard concerns about the poor interface between the NDIS and the education system, and the need for further NDIS funding for resources and support workers for children with FASD in schools.[85]

Teacher training and resources

5.77 The *National FASD strategic action plan 2018–2028* acknowledges that teachers require training in understanding the learning and behavioural characteristics of children with FASD and delivering evidence-based FASD education practices and strategies. It also notes the need for assessment and individualised education plans developed by a multidisciplinary team.[86]

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80 Ms Nikki Mortier, Private capacity, *Committee Hansard,* 16 September 2020, p. 36.

81 Gold Coast Hospital and Health Service, Child Development Service, *Submission 35*, p. 11.

82 Gold Coast Hospital and Health Service, Child Development Service, *Submission 35*, p. 11.

83 Western Australian (WA) Government, *Submission 65,* p. 22; Gilbert and Tobin, *Submission 63*, p. 12. In WA, for example, under the Individual Disability Allowance, students with neurodevelopmental impairments, including FASD, can access funding where their disability aligns with an eligible category such as global developmental delay or intellectual disability. However, Gilbert and Tobin submitted that where a child can demonstrate they fit within an eligible category, such as global development delay, they can only get the Individual Disability Allowance if no other pre-diagnosed condition could better account for the delay on which the diagnosis is based. Therefore, a child who has already been diagnosed with FASD would be ineligible.

84 Gilbert and Tobin, *Submission 63*, p. 15.

85 Dr John Boffa, Chief Medical Officer Public Health, Central Australian Aboriginal Congress, *Committee Hansard*, 14 October 2020, pp. 12–13 and p. 16.

86 Department of Health, *National FASD strategic action plan*, p. 26.

5.78 In Western Australia, the Marninwarntikura Women's Resource Centre has developed a nationally available resource for educators which encourages:

- screening of children at school, and where necessary, referral for multidisciplinary assessment;
- therapeutic supports implemented within the school and focused on building the capacity of families; and
- collaboration between teachers and multidisciplinary teams to develop care plans that take into account individual students learning needs.[87]

5.79 State governments reported to the committee that they have implemented initiatives aimed at building the capacity of support staff and teachers working with students with FASD, and putting in place individualised supports including personalised learning plans, case managers and access to specialist like psychologists.[88]

5.80 The Department of Health told the committee that it has committed funding for a suite of teacher and education setting resources to be developed from 2019–20 to 2022–23. The suite is intended to be a national resource, although the department acknowledged that it will be the responsibility of states and territories to utilise it 'in the most effective way for them'.[89]

Connecting families with screening and support services

5.81 Inquiry participants suggested the education system presents an opportunity to assess a child's developmental trajectory and support the family to access referral and support services for FASD as necessary and as the child grows.[90]

5.82 For example, entry to pre-school, to preparatory year/primary school and to high school are developmental change points where healthcare providers could be linked directly into the education system to support improved learning outcomes for individuals with FASD.[91]

5.83 In the Northern Territory, the health and education departments have implemented a joint program to screen school-aged children in remote

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87 Marninwarntikura Women's Resource Centre, *Fetal Alcohol Spectrum Disorder (FASD) and complex trauma: A resource for educators*, 2018, pp. 30–31, https://mwrc.com.au/blogs/news/fasd-and-complex-trauma-a-resource-for-educators-2nd-edition (accessed 12 March 2021); see also discussion in Gilbert and Tobin, *Submission 63*, pp. 22–23.

88 See, for example, WA Government, *Submission 65*, pp. 21–22; NT Government, *Submission 2*, p. 23.

89 Department of Health, answer to written question on notice IQ20-000381, 19 May 2020 (received 20 July 2020).

90 Gilbert and Tobin, *Submission 63*, p. 21; Gold Coast Hospital and Health Service, Child Development Service, *Submission 35*, p. 11.

91 Gold Coast Hospital and Health Service, Child Development Service, *Submission 35*, p. 11.

communities. The screening supports early intervention, health promotion and integrates programs and services to coordinate care for the individual.[92]

FASD and the justice system

5.84 Inquiry participants expressed concern over the lack of recognition and support for young people with FASD in the justice system.[93]

Impact on legal proceedings

5.85 In its submission to the inquiry, the Australian Human Rights Commission outlined a range of problems encountered in the justice system for people with FASD:

> There is increasing concern regarding the forensic implications of FASD in Australia, as the neuropsychological sequelae can affect all aspects of the legal proceedings, including the person understanding the expectations and providing credible evidence in forensic interviews, fitness to plead, capacity to stand trial and the process of sentencing.[94]

5.86 The committee heard that FASD assessments are generally obtained after conviction, for sentencing purposes. Therefore, without a diagnosis of FASD *before* sentencing, the court will not consider the impacts of FASD on a person's level of understanding and ability to comply with orders.[95]

5.87 The committee also heard that, while FASD can be considered a mitigating factor by the courts, it can also be considered a risk factor leading to a more punitive sentence being imposed. In addition, where mandatory sentencing applies to an offence, FASD cannot be taken into account to mitigate a sentence.[96]

5.88 The Australian Human Rights Commission noted that, to address some of these problems, nationally consistent disability justice plans across jurisdictions have been recommended to ensure that people with disability are supported in accessing the same legal protections and redress as the rest of the community.[97]

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92 NT Government, *Submission 2*, p. 18.

93 Dr Andrew Webster, Danila Dilba Health Service, *Committee Hansard*, 14 October 2020, p. 2; AHRC, *Submission 17*, pp. 13–15.

94 AHRC, *Submission 17*, p. 14 citing Australian Human Rights Commission, *Submission to the Australian Law Reform Commission inquiry into incarceration rates of Aboriginal and Torres Strait Islander peoples*, 4 September 2017, www.alrc.gov.au/wp-content/uploads/2019/08/43._ahrc.pdf (accessed 12 March 2021).

95 Aboriginal Legal Service of Western Australia, *Submission 46*, p. 6.

96 Aboriginal Legal Service of Western Australia, *Submission 46*, p. 6.

97 AHRC, *Submission 17*, p. 14.

Screening for FASD

5.89 The Australian Medical Association noted that most children who enter the justice system have previously been recognised by child protection authorities, and should be assessed for signs of FASD and afforded any necessary supports.[98]

5.90 The Aboriginal Legal Service of Western Australia observed that although there have been improvements in the availability of FASD assessments for youth offenders there is a 'black spot' in relation to adults.[99]

5.91 The Royal Commission into the Protection and Detention of Children in the Northern Territory found that screening for FASD among children and young people in detention is not occurring, and recommended routine screening.[100]

Access to the NDIS in the justice system

5.92 While an NDIS participant is incarcerated, the relevant state or territory justice system is responsible for most disability-related supports.[101] This includes reasonable adjustments and other supports, such as allied health and other therapies directly relating to a person's disability.[102]

5.93 The Aboriginal Legal Service of Western Australia suggested that prison may be the best environment to commence engagement with FASD clients, whilst they are in a drug and alcohol free environment. Further, the absence of appropriate support could increase the risk of further reoffending by the individual.[103]

5.94 However, the committee heard that young people with FASD have little support available to assist them to access the NDIS whilst in prison.[104] One witness noted that access to the NDIS is 'sporadic and uncoordinated' and is 'provided with limited input from the primary health care team who knows these children and their needs'.[105]

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98 AMA, *Submission 5*, Position statement, p. 3.

99 Aboriginal Legal Service of Western Australia, *Submission 46*, p. 5.

100 Office of the Children's Commissioner (NT), *Submission 32*, [p. 2].

101 NDIA, answer to written question on notice SQ21-000015, 4 December 2020 (received 14 January 2021).

102 NDIA, answer to written question on notice SQ20-000223, 25 June 2020 (received 22 July 2020).

103 Aboriginal Legal Service of Western Australia, *Submission 46*, p. 8.

104 Aboriginal Legal Service of Western Australia, *Submission 46*, p. 8.

105 Dr Andrew Webster, Head of Clinical Governance, Danila Dilba Health Service, *Committee Hansard*, 14 October 2020, p. 2.

Training and support for judicial and custodial officers

5.95 The committee heard that, although there has been an increase in awareness of FASD in the criminal justice system, judicial officers and the custodial workforce would benefit from further training in FASD underpinned by a therapeutic approach.[106]

5.96 Dr Andrew Webster of the Danila Dilba Health Service (NT) described the inadequacy of the treatment of children at the Don Dale Youth Detention Centre in Darwin and the need for a better approach:

> In particular, we note that the children involved in significant incidents in Don Dale, whose freedom of movement and association in the facility is restricted to manage their behaviour, have diagnosed FASD or are currently being assessed for this. It is our assessment that many existing responses to challenging behaviours at Don Dale may be counterproductive and even lead to further escalation of some of the situations.[107]

5.97 Dr Webster noted that training should not only raise awareness of FASD but also help custodial and justice staff to understand the behavioural implications of FASD, and to change their approach to working and communicating with children with FASD.[108]

Alternative rehabilitative and therapeutic facilities

5.98 Several inquiry participants outlined the inappropriateness of current detention facilities for children with FASD and advocated for alternative and rehabilitative facilities.[109]

5.99 Dr Webster told the committee that it is 'absolutely clear to our staff that several of the children within Don Dale today should be in a therapeutic facility, not a detention centre'.[110]

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[106] Aboriginal Legal Service of Western Australia, *Submission 46*, p. 5; Ms Tess Kelly, Senior Policy Officer, Danila Dilba Health Service, *Committee Hansard*, 14 October 2020, p. 5; Queensland Family and Child Commission, *Submission 14*, p. 5.

[107] Dr Andrew Webster, Head of Clinical Governance, Danila Dilba Health Service, *Committee Hansard*, 14 October 2020, p. 2.

[108] Dr Andrew Webster, Head of Clinical Governance, Danila Dilba Health Service, *Committee Hansard*, 14 October 2020, p. 2.

[109] See, for example, Dr Andrew Webster, Head of Clinical Governance, Danila Dilba Health Service, *Committee Hansard*, 14 October 2020, p. 2; Dr Raewyn Mutch, *Committee Hansard*, 25 June 2020, p. 11; Danila Dilba Health Service, *Submission 61*, pp. 23–24; North Australian Aboriginal Justice Agency, *Submission 66*, pp. 13–14; Joint submission Professor Harry Blagg, Mrs Suzie May, Dr Tamara Tulich and Dr Robyn Williams, *Submission 22*, p. 8.

[110] Dr Andrew Webster, Head of Clinical Governance, Danila Dilba Health Service, *Committee Hansard*, 14 October 2020, p. 2.

5.100 Professor Harry Blagg of the University of Western Australia argued that severe levels of cognitive disability, like those experienced by some people with FASD, require a different approach by the justice system:

> … for most of the kinds of conditions that we place on young people even as part of diversion, restorative justice and the courts, they are able to participate fully and be able to learn from an experience. We know that these kids can't. Therefore, we need to have a less adversarial and a more community focused way of doing justice.[111]

5.101 Discussing the risks of indefinite detention and the need for further safeguards and a broader, rehabilitative approach, the Australian Human Rights Commission recommended:

> All state and territory governments should also establish, as a matter of urgency, an appropriate range of appropriate facilities to accommodate people who are found unfit to stand trial and/or not guilty by reason of mental impairment.[112]

5.102 Danila Dilba Health Service (NT) argued that there needs to be alternative living options for young people with severe neurodevelopmental and trauma-related impairments. This could include therapeutic secure-care units, as used overseas, as an alternative to the existing punitive approach to juvenile justice.[113]

Diversionary programs

5.103 The committee heard that there is a growing understanding amongst legal practitioners of the benefits of diagnostic assessments that may enable diversionary pathways to be developed for First Nations youth with FASD.[114]

5.104 Professor Blagg suggested that there have been several successful examples in Australia of diversionary programs in First Nations communities that should be replicated:

> It is our belief that far more could be done at the point of first contact with the criminal justice system to identify children and their families who may have FASD and ensure that there is speedy assessment to divert the child from the system.[115]

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111 Professor Harry Blagg, Private capacity, *Committee Hansard*, 25 June 2020, p. 12.

112 AHRC, *Submission 17*, p. 15.

113 Danila Dilba Health Service, answers to questions on notice 20 October 2020 (received 3 November 2020), pp. 4–5.

114 Ms Tess Kelly, Senior Policy Officer, Danila Dilba Health Service, *Committee Hansard*, 14 October 2020, p. 5.

115 Professor Harry Blagg, Private capacity, *Committee Hansard*, 25 June 2020, p. 11.

Recognising FASD as a disability

5.105 FASD is not currently recognised as a disability in Australia. According to the Australian Medical Association, this is restricting access to traditional support mechanisms.[116]

5.106 The committee heard that, because FASD is not recognised as a disability within Australian health and education systems, families experience difficulties accessing supports unless their child has a comorbid diagnosis such as an intellectual disability or autism spectrum disorder.[117]

5.107 In addition, access to government disability supports, and recognition of a disability within the criminal justice system, hinges on having a disability as defined in law or policy, and demonstrating certain impairments as a result of that disability.[118]

5.108 According to Gilbert and Tobin, people with FASD are frequently denied support and recognition of their disability because 'FASD does not fit the relevant definition of disability'.[119]

List of Recognised Disabilities

5.109 The Hidden Harm report recommended in 2012 that FASD be recognised in the Australian Government's List of Recognised Disabilities. However, when the List of Recognised Disabilities was last updated in 2014, FASD was not included.[120]

5.110 The Department of Social Services told the committee that the List of Recognised Disabilities only includes those disabilities that would always be severe enough to qualify a parent or carer for government supports.[121]

5.111 The committee heard that, because FASD manifests in a broad range of disabilities for individuals, ranging from mild to severe, a further assessment process is required in relation to certain payments.[122]

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116 AMA, *Submission 5*, Position statement, p. 3.

117 Guidelines and Economists Network International, answer to written question on notice no. 1, 29 September 2020, (received 26 October 2020), p. 7.

118 Gilbert and Tobin, *Submission 63*, p. 12.

119 Gilbert and Tobin, *Submission 63*, p. 12.

120 Emerging Minds, *Submission 15*, [p. 14]; Parliament of Australia, *FASD: The hidden harm: Inquiry into the prevention, diagnosis and management of Fetal Alcohol Spectrum Disorders*, House of Representatives Standing Committee on Social Policy and Legal Affairs, November 2012. See Recommendation 1, which recommended that the Commonwealth Government include FASD in the List of Recognised Disabilities and the Better Start for Children with Disability initiative.

121 Mr Andrew Seebach, Branch Manager, Carer and Disability Payments Branch, Department of Social Services, *Committee Hansard*, 10 March 2021, p. 9.

5.112 However, the department was not able to explain why other spectrum disorders, such as autism spectrum disorder, are explicitly recognised on the List of Government Disabilities.[123]

5.113 Emerging Minds submitted that recognising FASD in the List of Recognised Disabilities would also have broader policy benefits:

> Recognition in policy is important for developing awareness of the nature of FASD and accommodations that can help support children in families with FASD. Recognition in policy is also an important implementation driver, supporting efforts for prevention of disability and early intervention for emotional and behavioural difficulties associated with FASD, including professional development among existing and emerging workforces.[124]

5.114 According to roundsquared, recognising FASD as a disability would contribute to a more integrated multidisciplinary approach to support, rather than 'piecemeal interventions based on particular aspects of the disorder such as depression, mood and anxiety disorders, ADHD and conduct disorders'.[125]

5.115 Recognising FASD on the List of Recognised Disabilities would also have potential flow-on impacts for funding mechanisms, including eligibility for social security payments, as discussed below.[126]

Social security payments

Carer Allowance

5.116 In the social security context, the committee also heard that the definition of 'disability' has the effect of excluding people with FASD and their carers from receiving support.[127]

5.117 The Australian Government's Carer Allowance, for example, is an income supplement available to people who provide daily at-home care to a person with a disability or severe medical condition. It is paid in recognition of a person's unpaid caring responsibilities and inability to undertake substantial paid work.[128]

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[122] Mr Andrew Seebach, Branch Manager, Carer and Disability Payments Branch, Department of Social Services, *Committee Hansard*, 10 March 2021, p. 9.

[123] Mr Andrew Seebach, Branch Manager, Carer and Disability Payments Branch, Department of Social Services, *Committee Hansard*, 10 March 2021, pp. 11–12.

[124] Emerging Minds, *Submission 15*, [p. 14].

[125] roundsquared, *Submission 11*, p. 9.

[126] Gilbert and Tobin, *Submission 63*, p. 30.

[127] Gilbert and Tobin, *Submission 63*, p. 29.

[128] Gilbert and Tobin, *Submission 63*, pp. 29–30.

5.118 According to Gilbert and Tobin, the criteria for the Carer Allowance can operate to exclude people with FASD because:

- FASD is not on the List of Recognised Disabilities; and
- a child with FASD may not meet the definition of 'disabled child' in section 16 of the *Social Security Act 1991*.[129]

5.119 Gilbert and Tobin submitted that establishing eligibility for the Carer Allowance outside of this criteria is difficult:

> … even if a child has an intellectual, physical and/or psychiatric disability, their carer will be required to establish their eligibility for the Carer Allowance through the Disability Care Load Assessment (Child) Determination process. This can be time-consuming and challenging. The List of Recognised Disabilities is intended to streamline the application process for carers of children with disability, but due to the exclusion of FASD on the List of Recognised Disabilities carers of children with FASD miss the benefit of that streamlining.[130]

Disability Support Pension

5.120 The Australian Human Rights Commission told the committee that failure to recognise FASD as a disability also affects the Disability Support Pension. [131]

5.121 Individuals over the age of 16 with FASD can access the Disability Support Pension, but only if their IQ is assessed as being low, that is, between 70 and 85. According to the Foundation for Alcohol Research and Education (FARE), this has not changed since 2012, and 'precludes many people with FASD who have IQs within the normal range'.[132]

5.122 FARE suggested that the Australian Government's Tables for the Assessment of Work-related Impairment for the Disability Support Pension (in particular, Table 7 – Brain Function) should be amended to include FASD as a condition alongside 'a person with Autism Spectrum Disorder who does not have a low IQ'.[133]

5.123 The Department of Social Services noted that, although the tables for assessment in the legislative instrument have not been revised to include FASD, the department's guide to social security has been updated to outline that FASD should be assessed in relation to Table 7.[134]

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129 Gilbert and Tobin, *Submission 63*, p. 30.

130 Gilbert and Tobin, *Submission 63*, p. 30.

131 AHRC, *Submission 17*, p. 10.

132 Foundation for Alcohol Research and Education (FARE), *Submission 50*, p. 45. See also, for example, AHRC, *Submission 17*, p. 10.

133 FARE, *Submission 50*, p. 45. See also, for example, AHRC, *Submission 17*, p. 10.

134 Mr Andrew Seebach, Branch Manager, Carer and Disability Payments Branch, Department of Social Services, *Committee Hansard*, 10 March 2021, pp. 11–12.

Committee view

5.124 The committee is concerned about the limited support services available after a diagnosis of FASD. As one witness described it, accessing support services can be like a 'postcode lottery'.[135] Adults with FASD are in a particularly difficult situation, as there is limited recognition of their disability and few specific supports available.

5.125 The committee was moved by evidence outlining the significant impact of FASD on parents and carers, who provide the care and meet the financial and personal costs, with very limited support. Holistic wraparound support is needed for families in recognition of the broad-ranging impacts of FASD on an individual's life, and to assist parents and carers to navigate fragmented services and implement treatment plans.

Improving access to Early Childhood Early Intervention and NDIS support

5.126 The committee acknowledges that individuals with FASD require support throughout all life stages, ideally from early childhood, to achieve the best life outcomes.

5.127 Therefore the NDIA's Early Childhood Early Intervention (ECEI) funding must be further streamlined to improve access for families. Streamlined documentary evidence requirements, as proposed in the NT, should be adopted more broadly.

Recommendation 19

5.128 The committee recommends that the National Disability Insurance Agency implement improvements to the Early Childhood Early Intervention program to streamline access and documentary evidence requirements.

5.129 The committee notes the NDIA announcement of the implementation of an ECEI Reset has the potential to improve NDIS access beyond early childhood and throughout key developmental stages. The ECEI program must be responsive enough to support children potentially through to adolescence, recognising that there are often delays in identifying impairments associated with FASD and achieving a diagnosis.

Recommendation 20

5.130 The committee recommends that the National Disability Insurance Agency ensure that the planned Early Childhood Early Intervention Reset focus on improving access to support for children throughout key developmental stages.

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[135] Dr Chinar Goel, Fellow, Royal Australian and New Zealand College of Psychiatrists, *Committee Hansard*, 16 September 2020, p. 12.

5.131 Once a person has access to NDIS funding, the quality of the plan and accessibility to service providers is fundamental. The committee notes that the issues raised during this inquiry regarding access to the NDIS within the justice system, the adequacy of NDIS plans, the capability of NDIS planners, and the lack of appropriate service providers across Australia, are known problems and have been raised on many occasions by the Joint Standing Committee on the National Disability Insurance Scheme.

5.132 The committee strongly supports the recommendation of the Joint Standing Committee on the National Disability Insurance Scheme in its recent inquiries into general issues and planning, and in particular:

- the recommendation that the NDIA develop and implement a mechanism to encourage planners to develop specialisation in particular types of disability or particular groups of participants;[136] and
- recommendations to improve access to the NDIS, including by publishing further information about the planning process, and providing more information and direct support to participants before planning meetings.[137]

Disability supports

5.133 The committee recognises that NDIS support, which is available for individuals with permanent and significant disability and through ECEI funding, will not capture everyone.

5.134 The committee is of the view that further reforms are necessary to the Carer Allowances and the Disability Support Pension to recognise FASD and its associated impairments, and the significant impact that it has on the individual and/or their carer's ability to engage in paid work.

5.135 The committee strongly recommends that FASD is included in the Australian Government's List of Recognised Disabilities, to explicitly recognise FASD as a disability, and improve access to Carer Support payments and other supports. Eligibility for the Disability Support Pension must also be reviewed to ensure eligibility for individuals with FASD, who do not necessarily have a low IQ (between 70 and 85), as is the case for autism spectrum disorder.

Recommendation 21

5.136 The committee recommends that the Australian Government include FASD in the List of Recognised Disabilities.

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136 See Recommendation 30, Joint Standing Committee on the National Disability Insurance Scheme, *NDIS planning final report*, December 2020, p. xxi.

137 See Recommendations 38 to 42 in Joint Standing Committee on the National Disability Insurance Scheme, *NDIS planning final report*, December 2020, pp. xxii–xxiii.

Recommendation 22

5.137 The committee recommends that the eligibility requirements for the Disability Support Pension be reviewed to include individuals with FASD with an IQ above the low range (between 70 and 85).

Schools

5.138 The committee has concerns about the variable levels of schools' capability to support children with FASD depending on their funding, staffing, FASD awareness and training, and learning and behaviour management approach. The committee notes that, despite the significant investment in teacher training and resources by state and territory governments, and recent funding announced by the Australian Government for further teaching resources, more needs to be done to improve the supports available for children with FASD within the education system.

Recommendation 23

5.139 The committee recommends that the Australian Government work with State and Territory Governments to provide all educators with professional development training in the awareness, understanding and management of FASD.

Recommendation 24

5.140 The committee recommends that the Australian Government work with State and Territory Governments to ensure all schools can deploy and resource FASD-specific strategies and assistance to support educators and to support students with FASD and suspected FASD, irrespective of IQ level.

Support for parents and carers

5.141 The committee notes that, beyond organisations like the Russell Family Fetal Alcohol Disorders Association and NOFASD that run FASD-specific support groups and a helpline, there are limited available supports for parents and carers. Practical and community-based programs, aimed at supporting parents to manage the range of impairments related to FASD, must be further fostered. The committee was impressed by programs that are supporting parents to implement FASD-specific strategies, including challenging behaviours, through the Triple P Positive Parenting Program delivered by Jandu Yani U.

Recommendation 25

5.142 The committee recommends that the Australian Government allocate funding for the development and delivery of practical parenting programs to complement existing supports and the FASD hotline.

Child protection and justice systems

5.143 There is clear evidence to suggest a high prevalence of FASD amongst children and young people in contact with child protection, and in the youth justice system, therefore routine screening and assistance to access supports must be prioritised nationally.

Recommendation 26

5.144 The committee recommends that all children and young people entering the youth justice and child protection systems are screened for FASD.

Recommendation 27

5.145 The committee recommends that the Australian Government, in partnership with State and Territory Governments, develop and trial protocols for screening children and young people within child protection and youth justice systems for FASD.

5.146 In the justice system, the committee considers that more needs to be done to recognise the specific behavioural impairments associated with FASD. The custodial workforce requires further training and FASD-specific strategies for dealing with young people in correctional facilities.

Recommendation 28

5.147 The committee recommends that the Australian Government provides further funding to train custodial officers in FASD-specific strategies for dealing with youth with FASD or suspected FASD in correctional facilities.

5.148 The evidence received throughout the inquiry clearly shows that conventional sentencing and correctional facilities are often inappropriate for people with FASD. The committee is of the view that diversionary programs and alternative therapeutic facilities are an underexplored area, and must have further consideration.

5.149 The committee notes that some of the findings and recommendations directed at the Northern Territory Government from the Royal Commission into the Protection and Detention of Children in the Northern Territory may be more broadly applicable, particularly in relation to the use of youth diversion programs and a therapeutic model of youth detention.[138]

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[138] Royal Commission and Board of Inquiry into the Protection and Detention of Children in the Northern Territory, *Findings and recommendations*, November 2017. See, for example, recommendations 19.1, 25.7–25.14, 25.39, 25.43, 28.2, 33.10, 33.11 and 41.4.

Recommendation 29

5.150 The committee recommends that the Australian Government fund an independent study into best-practice diversionary programs and alternative therapeutic facilities for individuals with FASD or suspected FASD within the justice system.

5.151 The committee is concerned about evidence of the significant challenges faced by carers in their attempts to have child protection services acknowledge FASD and to access supports before care placements risk breaking down.

Recommendation 30

5.152 The committee recommends that more funding and support is provided by State and Territory Child Protection authorities to carers who are caring for and supporting children with FASD.

Chapter 6
First Nations communities

6.1 Compared to the broader population, a greater percentage of First Nations people do not drink alcohol at all.[1] However, First Nations people who do drink are more likely to do so at levels that are risky.[2] As discussed in Chapter 2, this has translated in a high incidence of FASD in some First Nations communities such as Fitzroy Crossing in Western Australia (WA).[3]

6.2 Firstly, the chapter examines the factors that have led to consumption of alcohol at harmful levels in some First Nations communities. Then, the chapter discusses the specific barriers faced by First Nations communities to accessing diagnostic and support services.

6.3 The rest of the chapter focuses on how to best support First Nations communities and the successful initiatives that have been developed at community levels.

Alcohol consumption

6.4 Inquiry participants explained to the committee that the reasons for the misuse of alcohol in First Nations communities are complex and multi-faceted. Submitters emphasised that the high levels of alcohol use in contemporary First Nations communities should be seen in the context of inter-generational trauma, poverty, suppression of culture and language, and the experience of racism and discrimination.[4]

6.5 At a hearing, Dr John Boffa, Chief Medical Officer Public Health at Central Australian Aboriginal Congress (Congress), acknowledged that there are many aspects to alcohol-related harms but stressed that in the context of First Nations peoples:

> The root cause of everything is colonisation, dispossession, poverty and inequality.[5]

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1 See, for example, Australian Human Rights Commission (AHRC), *Submission 17,* p. 12; Danila Dilba Health Service, *Submission 61,* p. 6.

2 See, for example, AHRC, *Submission 17,* p. 12; Foundation for Alcohol Research & Education (FARE), *Submission 50,* Attachment 1, p. 43; NACCHO, *Submission 56,* p. 3.

3 See, for example, Professor Harry Blagg, Mrs Suzie May, Dr Tamara Tulich and Dr Robyn Williams, *Submission 22,* p. 2; Australian Medical Association (AMA), *Submission 5,* p. [5].

4 See, for example, Central Australian Aboriginal Congress, *Submission 59,* p. 8; Mr John Paterson, CEO, Aboriginal Medical Services Alliance Northern Territory (AMSANT), *Committee Hansard,* 14 October 2020, p. 17; Emerging Minds, *Submission 15,* pp. 6–7.

5 Dr John Boffa, Chief Medical Officer Public Health, Central Australian Aboriginal Congress (Congress), *Committee Hansard,* 14 October 2020, p. 10.

Impacts of colonisation

6.6 The Australian Human Rights Commission and other submitters expressed the view that alcohol-related harm is inextricably linked to the ongoing impacts of colonisation and inter-generational trauma.[6] For example, Congress submitted:

> The high prevalence of alcohol related harm (including FASD) in Aboriginal communities is strongly linked to the processes of colonisation which have undermined the capacity of some families to care for their children.[7]

6.7 Mr John Paterson, CEO of Aboriginal Medical Services Alliance Northern Territory (AMSANT), also talked about how FASD should be considered within the context of the impacts of colonisation, entrenched poverty and 'discriminatory government policy that serves to disempower people and disconnect people from their right to land, culture and language', and concluded:

> These are interacting factors that cannot be viewed in isolation and bear relevance to any discussion on FASD and Aboriginal people.[8]

6.8 Ms Emily Carter, CEO of the Marninwarntikura Women's Resource Centre, stressed that government policies have negatively impacted First Nations communities, pointing out that:

> The impact of underinvestment in our communities is seen in domestic violence, ongoing disadvantage, drug and alcohol abuse, alcohol-related deaths, and suicides.[9]

Poverty and inequality

6.9 Congress noted that deprivation, whether absolute (poverty) or relative (inequality), is strongly correlated with increased rates of substance misuse including alcohol misuse.[10]

6.10 AMSANT also stressed that entrenched poverty and disadvantage were factors that were relevant in the context of FASD.[11]

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6 See, for example, AHRC, *Submission 17*, p. 12; Professor Harry Blagg, Mrs Suzie May, Dr Tamara Tulich and Dr Robyn Williams, *Submission 22*, p. 3; Ms Emily Carter, CEO, Marninwarntikura Women's Resource Centre, *Committee Hansard*, 14 October 2020, p. 29.

7 Central Australian Aboriginal Congress, *Submission 59*, p. 3.

8 Mr John Paterson, CEO, AMSANT, *Committee Hansard*, 14 October 2020, p. 17.

9 Ms Emily Carter, CEO, Marninwarntikura Women's Resource Centre, *Committee Hansard*, 14 October 2020, p. 29.

10 Central Australian Aboriginal Congress, *Submission 59*, p. 9.

11 Mr John Paterson, CEO, AMSANT, *Committee Hansard*, 14 October 2020, p. 17.

Alcohol controls

6.11 In addition to the need to address the systemic issues linked to the misuse of alcohol, some submitters talked about the immediate need to limit alcohol supply. They recommended measures to address the density of alcohol retail outlets and the introduction of a floor price for alcohol products to reduce access to cheap alcohol.[12]

6.12 Congress contended that there is 'a very strong international evidence-base' that indicates that:

> (a) increasing the price of alcohol, and particularly that of cheap alcohol, is a 'best buy' for reducing consumption and hence alcohol related harm at a population level; […] and
> (b) physical availability is the next most important determinant of alcohol harm, in particular through reducing trading hours and license density.[13]

6.13 Ms Pat Turner, CEO of the National Aboriginal Community Controlled Health Organisation (NACCHO), also discussed the issue of alcohol supply with the committee and expressed the view that 'jurisdictions must reduce the number of liquor licences that are handed out, which impairs people from drinking in a safe environment'.[14]

6.14 In WA, localised restrictions on alcohol apply in several communities, including Fitzroy Crossing.[15] In Queensland, there are alcohol restrictions in 19 communities, which ban or limit the amount and type of alcohol within the community.[16] In the Northern Territory, alcohol reforms have been introduced more broadly and apply across the Territory (see Box 6.1).[17]

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[12] See, for example, Danila Dilba Health Service, *Submission 61,* pp. 8–9; Joint submission Drug ARM and the Queensland Coalition for Action on Alcohol, *Submission 45,* p. 12.

[13] Congress, *Submission 59,* pp. 12–13.

[14] Ms Pat Turner, CEO, National Aboriginal Community Controlled Health Organisation (NACCHO), *Committee Hansard,* 24 June 2020, p. 25.

[15] Western Australian Government, Department of Local Government, Sport and Cultural Industries, *Liquor restrictions*, https://www.dlgsc.wa.gov.au/racing-gaming-and-liquor/liquor/liquor-restrictions (accessed 9 March 2021).

[16] Queensland Government, *Community alcohol restrictions*, https://www.qld.gov.au/atsi/health-staying-active/alcohol-smoking-drugs/community-alcohol-restrictions (accessed 9 March 2021).

[17] Northern Territory Government, *Submission 2,* p. 1.

Box 6.1 Northern Territory Government alcohol reforms

In 2017, the Northern Territory Government appointed an independent Expert Advisory Panel to undertake a review of the NT's alcohol policies and legislation.[18]

In response to the review, the Northern Territory Government has introduced a package of reforms to address alcohol-related harm, including:

- a floor price to prevent the sale of cheap alcohol;
- a Banned Drinkers Register (BDR) to reduce the access to take-away alcohol by problem drinkers;
- point-of-sale interventions at all bottle shops in three regional centres;
- a new Liquor Act that includes risk-based licensing and greater monitoring of on-licence drinking; and
- a commitment to high-quality, ongoing independent evaluation.[19]

Congress reported that these reforms 'have already demonstrated very significant reductions in alcohol-related harm across the NT' and concluded that 'they can be expected to lead to significant reductions in the prevalence of FASD'. [20]

Danila Dilba Health Service also commented on the promising early results of these reforms and recommended the Northern Territory Government maintain its commitment to implement broad measures to limit alcohol supply.[21]

Barriers to accessing services

6.15 In addition to the b6arriers to accessing the diagnostic, management and support services discussed in Chapters 4 and 5 of the report, First Nations communities face additional barriers due to a critical lack of services for those living in remote and rural areas and, more broadly, a lack of culturally appropriate services.[22]

6.16 Another issue raised during the inquiry was the Northern Territory's mandatory reporting requirements, which can be a barrier for women to discuss alcohol use or difficulties in caring for their children as they fear mandatory reporting and the child protection system.[23]

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[18] Northern Territory Government, *Submission 2*, p. 1.

[19] See, for example, Congress, *Submission 59*, p. 13; Northern Territory Government, *Submission 2*, p. 1.

[20] Congress, *Submission 59*, p. 13.

[21] Danila Dilba Health Service, *Submission 61*, p. 9.

[22] See, for example, AHRC, *Submission 17*, p. 27; Royal Far West, *Submission 68*, p. 2.

[23] Dr Andrew Webster, Head of Clinical Governance, Danila Dilba Health Service, *Committee Hansard*, 14 October 2020, pp. 5–6.

6.17 Submitters identified that historical government policies of child removal have created inter-generational trauma for the Stolen Generations and others and have led to an 'underlying fear and mistrust'[24] of the child protection system by First Nations families.[25]

Rural and remote communities

6.18 The Public Health Association Australia and other submitters explained that many First Nations people with FASD are yet to be diagnosed with FASD as access to diagnostic services, particularly in regional and remote communities, is limited.[26] Support and treatment services are also generally lacking in First Nations communities.[27]

NDIS market failure

6.19 A key issue is the lack of National Disability Insurance Scheme (NDIS) services available in rural and remote communities:

> Many NDIS plans are left with unspent funds, and participants are going without essential services. The underspend is a fiction. It is not an underspend; it's an inability to spend. It is a failure in the market economy created by the NDIS.[28]

6.20 Dr Andrew Webster from Danila Dilba Health Service also talked about the general lack of providers to deliver services in the NT and described the situation as an 'example of NDIS market failure':

> … when a single professional leaves it can cause a huge hole in the services that are provided to NDIS clients in Darwin. So it is a very major challenge. There's always this 'Is it on or is it off?' and whether the services can be provided in a consistent, long–term way. That is of significant concern.[29]

6.21 Dr Lauren Rice, a Research Fellow at the Brain and Mind Centre at the University of Sydney, questioned the relevance of joining the NDIS for First Nations people living in remote WA:

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[24] Victorian Alcohol & Drug Association, *Submission 61*, p. 10.

[25] See, for example, Emerging Minds, *Submission 15*, p. 10; Royal Australian College of General Practitioners, *Submission 53*, p. 4; *Submission 59*, p. 8; Victorian Alcohol & Drug Association, *Submission 61*, p. 10; North Australian Aboriginal Justice Agency (NAAJA), *Submission 66*, pp. 15–16.

[26] See, for example, Public Health Association Australia (PHAA), *Submission 33*, p. 9; AHRC, *Submission 17*, p. 27.

[27] Gilbert and Tobin, *Submission 63*, p. 28.

[28] North Australian Aboriginal Justice Agency, *Submission 66*, p. 24.

[29] Dr Andrew Webster, Head of Clinical Governance, Danila Dilba Health Service, *Committee Hansard*, 14 October 2020, p. 7.

> We are being pressured every week by the NDIS to sign people up on plans, and we're saying, 'What's the point of signing people up when people have plans but they're not being used?'[30]

Suitability of the NDIS model

6.22 Another issue raised by submitters is the lack of understanding and engagement by the National Disability Insurance Agency (NDIA).[31]

6.23 For example, Dr Lauren Rice expressed the view that 'the NDIA is very rigid' and does not understand the needs of First Nations communities, stating:

> The NDIS is designed for the Western world, not for an Aboriginal community.[32]

6.24 Submitters explained to the committee that the fact that the NDIS precludes family members of an NDIS participant from getting any funding to support that person is limiting and not practical in a remote and First Nations context.[33]

6.25 For example, Mr Blair McFarland from the Central Australia Youth Link Up Service in Central Australia commented on the case of a young man in a school who has FASD:

> He had an $80,000 program but they were unable to access any of it, because there were no services that could be brought in, and the rules of the NDIS preclude family from getting any funding to support that person, even though it was a full-time job for his mother. The school got around that, when the mother brought the kid to school, by paying her as a teacher's aide so that there'd be a bit of extra support going to the family.[34]

NDIA response

6.26 In its submission, the NDIA recognised that more work needs to be done to assist First Nations people, particularly those in remote areas, to understand and access the NDIS.[35]

6.27 To improve the situation, the NDIA has initiated the Remote Community Connectors Program, which is based on the principle of employing local

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30 Dr Lauren Rice, Research Fellow, University of Sydney: Brain and Mind Centre, *Committee Hansard,* 14 October 2020, p. 38.

31 See, for example, Ms Pat Turner, CEO, NACCHO, *Committee Hansard,* 24 June 2020, p. 29; Dr Lauren Rice, Research Fellow, University of Sydney: Brain and Mind Centre, *Committee Hansard,* 14 October 2020, pp. 38–39.

32 Dr Lauren Rice, Research Fellow, University of Sydney: Brain and Mind Centre, *Committee Hansard,* 14 October 2020, pp. 38–39.

33 See, for example, Dr Lauren Rice, Research Fellow, University of Sydney: Brain and Mind Centre, *Committee Hansard,* 14 October 2020, p. 38; Mr Blair McFarland, Operations Manager, Central Australia Youth Link Up Service (CAYLUS), *Committee Hansard,* 14 October 2020, p. 25.

34 Mr Blair McFarland, Operations Manager, CAYLUS, *Committee Hansard,* 14 October 2020, p. 25.

35 NDIA, *Submission 67*, p. 9.

people in communities. The program started in parts of the Northern Territory where there were no local area coordinators. Mr Daniel English, the NDIA Territory Manager, Northern Territory, further explained:

> We structure it very much in collaboration with the Aboriginal community controlled organisations to ensure that we get the best possible outcome.[36]

6.28 Mr Scott McNaughton, General Manager, NDIA, told the committee that the role of community connector is now evolving from helping community members to understand what the NDIS is to helping people get the most from their NDIS plans.[37]

6.29 The NDIA also informed the committee that it is working with NACCHO to support local Aboriginal Community Controlled Health Organisations (ACCHOs) to register as NDIS providers and provide NDIS services locally in their communities.[38]

Culturally appropriate services and programs

6.30 In addition to poor access to services, there is also a lack of culturally appropriate and sensitive services.[39]

6.31 The Australian Medical Association (AMA) and other submitters stressed the importance of culturally and linguistically appropriate services being made available in communities.[40]

6.32 In its FASD Action Plan, the Foundation for Alcohol Research and Education stated:

> Aboriginal and Torres Strait Islander peoples require culturally appropriate diagnostic and treatment services to assist them in preventing new cases of FASD and to provide support to those who are currently affected, their families and their carers.[41]

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[36] Mr Daniel English, Branch Manager, Connectors; and Territory Manager, Northern Territory, NDIA, *Committee Hansard,* 4 December 2020, p. 3.

[37] Mr Scott McNaughton, General Manger, NDIA, *Committee Hansard,* 4 December 2020, p. 3.

[38] NDIA, answer to question on notice SQ21-000011, 4 December 2020 (received 14 January 2021), [p. 16].

[39] See, for example, FARE, *Submission 50,* Attachment 1, p. 46; RACGP, *Submission 53,* p. 2; NAAJA, *Submission 66,* pp. 12 and 25.

[40] See, for example, AMA, *Submission 5,* p. 4; Gold Coast Hospital and Health Service, Child Development Service, *Submission 35,* p. 7; Royal Australian College of Physicians, *Submission 64,* p. 7; WA Government, *Submission 65,* p. 3.

[41] FARE, *Submission 50,* Attachment 1, p. 43.

6.33 Submitters also identified the need for better communication and prevention campaigns, emphasising the need for culturally sensitive and appropriate programs.[42]

6.34 NACCHO recommended investment in culturally sensitive, awareness-raising programs, targeting First Nations peoples and communities through mainstream media, school curriculums and health delivery services.[43]

Box 6.2 Northern Territory's mandatory reporting requirements

In its submission to the inquiry, Danila Dilba Health Service discussed the issue of the Northern Territory's mandatory requirements, particularly under section 26 of the Care and Protection of Children Act (NT). It contended that it leads to women not disclosing their drinking habit to health services as they fear to have their children removed from their care.[44]

Danila Dilba Health Service explained that '[t]here is a lot of confusion and misinformation, particularly in the community, about what types of harm need to be reported and the consequences of reporting.' This is deterring people from attending clinics and seeking treatment.[45]

At a public hearing, Dr Andrew Webster from Danila Dilba Health Service expressed the view that the mandatory reporting laws are 'absolutely not hitting the mark in all situations' and 'can certainly cause harm'. He recommended a review of the legislation and added that 'the impact requirements are having on women seeking support with alcohol cessation or antenatal care should be considered'.[46]

Successful strategies for supporting First Nations communities

6.35 The committee heard that programs and services designed and implemented with local communities and led by First Nations peoples are more effective and are leading to better outcomes.[47]

6.36 Inquiry participants highlighted the importance of community-led approaches to effectively tackle FASD, both in its prevention and in providing services to those affected by FASD.[48]

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42 See, for example, roundsquared, *Submission 11,* p. 11; Queensland Family & Child Commission, *Submission 14,* p. 4; AHRC, *Submission 17,* p. 29; PHAA, *Submission 33,* p. 9.

43 NACCHO, *Submission 56,* p. 10.

44 Danila Dilba Health Service, *Submission 61,* p. 12.

45 Danila Dilba Health Service, *Submission 61,* p. 12.

46 Dr Andrew Webster, Head of Clinical Governance, Danila Dilba Health Service, *Committee Hansard,* 14 October 2020, p. 5, quoting Danila Dilba Health Service, *Submission 61*, p. 5.

47 See, for example, AHRC, *Submission 17,* p. 16; PHAA, *Submission 33,* p. 8.

6.37 For example, the Australian Human Rights Commission expressed the view that 'interventions imposed without community control or culturally appropriate adaption can be counterproductive', and emphasised that strategies led by First Nations peoples ensure cultural appropriateness, leading to better outcomes.[49]

Aboriginal Community Controlled Health Services

6.38 AMSANT and other organisations were of the view that programs to prevent, assess, diagnose and manage FASD should be led by Aboriginal Community Controlled Health Services (ACCHSs).[50]

6.39 Mr John Paterson, CEO of AMSANT, explained that ACCHSs were best placed to lead activities and programs focused on FASD prevention, screening and treatment because ACCHSs 'already work with vulnerable populations through an Aboriginal workforce that supports families to engage with these services'.[51]

6.40 Congress submitted that ACCHSs have structural advantages in delivering services compared to non-Indigenous services because they:

- have a holistic approach to service delivery;
- are providing culturally responsive services;
- have strong relationships with communities;
- have a commitment to attract, train and retain First Nations staff;
- encourage First Nations individuals and communities to participate in decisions on service delivery, including through formal governing boards; and
- have high levels of accountability.[52]

6.41 Submitters cited a number of specific programs and services assisting families and people affected by FASD that have been initiated by ACCHSs and ACCHOs and have proven successful.[53]

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[48] See, for example, Dr Tamara Tulich, private capacity, *Committee Hansard,* 25 June 2020, p. 9; Gold Coast Hospital and Health Service, Child Development Service, *Submission 35,* p. 14; FARE, *Submission 50,* Attachment 3, p. 7.

[49] AHRC, *Submission 17,* p. 16.

[50] See, for example, AMSANT, *Submission 62,* p. 7; Dr Andrew Webster, Head of Clinical Governance, Danila Dilba Health Service, *Committee Hansard,* 14 October 2020, p. 4; Congress, *Submission 59,* Attachment 1, p. 1; NACCHO, *Submission 56,* p. 4; NAAJA, *Submission 66,* p. 25.

[51] Mr John Paterson, CEO, AMSANT, *Committee Hansard,* 14 October 2020, p. 17.

[52] Congress, *Submission 59,* p. 11.

[53] See, for example, AMSANT, *Submission 62,* pp. 5 and 7; NACCHO, answers to questions taken on notice, 24 June 2020 (received 10 July 2020), p. 3.

National programs

6.42 The Australian Nurse Family Partnership Program (ANFPP) is a national nurse-led, home visiting program that supports women pregnant with a First Nations child. Clients receive continuity of care through regular home visits from 16 weeks' gestation until the baby is two years old.[54]

6.43 NACCHO told the committee that the ANFPP was an effective avenue for preventing FASD and was delivered by many ACCHOs across Australia.[55]

6.44 Danila Dilba Health Service, which offers this program to its clients, noted that the current ANFPP program 'can only really have an impact on FASD prevention in future pregnancies' as women are referred at 16 weeks' gestation. It recommended expanding the program into the first trimester of pregnancy or developing an alternative, culturally-appropriate program to provide intensive supports to women at the very early stages of pregnancy.[56]

Child and Youth Assessment and Treatment Service

6.45 In response to the prevalence of developmentally vulnerable First Nations children in Central Australia, Congress initiated the Child and Youth Assessment and Treatment Service (CYATS) in 2018.[57]

6.46 CYATS provides a best-practice service for the early detection of neurodevelopmental conditions such as FASD, Attention-Deficit/Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD), providing a multidisciplinary approach to diagnostic assessment, early intervention, and support for families to access the NDIS.[58]

6.47 In addition to specific assessments, the team also provides interventions including direct individual therapy, community support, educational support and family support. CYATS always seeks to operate in collaboration with families, and cultural expertise is provided by a First Nations support worker.[59]

6.48 Dr John Boffa told the committee about the funding issues faced by CYATS:

> It's funded by four different sources. To get it funded has been a nightmare: to continue its funding is an ongoing nightmare. But, luckily, Minister Hunt just announced a new program to fund the diagnosis and

54 Danila Dilba Health Service, *Submission 61*, p. 11.

55 NACCHO, *Submission 56*, p. 4.

56 Danila Dilba Health Service, *Submission 61*, p. 12.

57 Congress, *Submission 59*, pp. 17–18.

58 Congress, *Submission 59*, p. 18.

59 Congress, *Submission 59*, p. 18.

> treatment of FASD. But it's a national program—it's got $24 million over four years—so there is no single funding source for that service.[60]

6.49 AMSANT reported that demand for the service is high and the waitlist for assessment is long. AMSANT recommended the expansion of this type of service.[61]

Gidgee Healing

6.50 Gidgee Healing is a community-led program in Mount Isa, Queensland, which has partnered with Griffith University to deliver a holistic FASD care model that draws on primary health care run by Aboriginal Health Practitioners and Aboriginal Health Workers who are from that community.[62]

6.51 The program sits within a broader health service, which includes mums and bubs programs that provide information and support for alcohol harm reduction.[63]

6.52 NACCHO told the committee that, although the program is early in its implementation, the shift away from a clinical specialist setting to a community primary healthcare mode has already had an impact:

> The long term consequences of this approach remain to be seen, however the logical impact of the community driving the response is that the community has greater awareness and understanding of the causes of FASD and the best ways to support children and families impacted by it.[64]

Children's Ground

6.53 The committee also heard from Children's Ground in relation to its work in First Nations communities. It outlined how prevention efforts must be community and family led, and start with education from pregnancy and early childhood, including focusing on high-risk young people and young mothers.[65]

6.54 The CEO of Children's Ground, Jane Vadiveloo, told the committee that, care must be holistic and take into account the individual circumstances of children:

> When kids have come in and started with Children's Ground, we can see it manifest in their behaviour, concentration, emotional ability and all sorts

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60 Dr John Boffa, Chief Medical Officer Public Health, Congress, *Committee Hansard*, 14 October 2020, p. 11.

61 AMSANT, *Submission 62*, pp. 5–6.

62 NACCHO, answers to questions taken on notice, 24 June 2020 (received 10 July 2020), [p. 2].

63 NACCHO, answers to questions taken on notice, 24 June 2020 (received 10 July 2020), [p. 2].

64 NACCHO, answers to questions taken on notice, 24 June 2020 (received 10 July 2020), [p. 2].

65 Ms Jane Vadiveloo, Chief Executive Officer, Children's Ground, *Committee Hansard*, 10 March 2021, pp. 32 and 34.

> of things, so the other area we work in is trauma-informed practise in our early childhood care… We have family members working alongside both cultural practitioners and western practitioners in education. The conversations around the child are on their wellbeing, their needs, what happened at home the night before, what their emotional requirements are and what their nutritional requirements are. They're all indicators that can impact the expression of FASD.[66]

Other initiatives

6.55 NACCHO provided to the committee information about other examples of best practice in preventing and identifying FASD and supporting people affected by FASD delivered by ACCHOs. This includes the Wuchopperen Health Service in Cairns and Kimberley Aboriginal Medical Services (KAMS).[67]

Marulu Strategy

6.56 Submitters discussed at length the benefits of community-led approaches and cited the Marulu Strategy as world's best practice in tackling FASD.[68]

6.57 Marulu, a Bunuba word meaning 'worth nurturing', has been set up to create a community response to FASD and trauma in the Fitzroy Valley in Western Australia. Led by community organisations Marninwarntikura Women's Resource Centre and Nindilingarri Cultural Health Service, it is a collaborative effort involving a number of essential partners, including the Telethon Kids Institute, Royal Far West and the University of Sydney.[69]

6.58 At a public hearing, Ms Sue Thomas, Strategic Priority Lead, Marninwarntikura Women's Resource Centre, described the strategy:

> The Marulu Strategy is a community-led initiative that draws on Aboriginal controlled organisations, government services and all those working with children with FASD and complex trauma. […] The strategy has been designed to make FASD history but also to strengthen capacity in the community by building on resilience and employing wellbeing.[70]

6.59 The Marulu Strategy focuses on prevention, supporting children and families living with FASD, building capacity and enhancing services for those affected

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66 Ms Jane Vadiveloo, Chief Executive Officer, Children's Ground, *Committee Hansard*, 10 March 2021, p. 34.

67 NACCHO, answers to questions taken on notice, 24 June 2020 (received 10 July 2020), [pp. 2–3].

68 See, for example, AHRC, *Submission 17*, p. 20; Alcohol and Drug Foundation, *Submission 37*, p. 9; Jandu Yani U Project Team, *Submission 49*, pp. 2 and 10.

69 Marninwarntikura Women's Resource Centre, *Marulu Strategy: Making FASD history*, https://www.marulustrategy.com.au/ (accessed 14 January 2021).

70 Ms Sue Thomas, Strategic Priority Lead, Marninwarntikura Women's Resource Centre, *Committee Hansard*, 14 October 2020, pp. 30–31.

by FASD, and developing a sustainable community-driven response to FASD.[71]

6.60 A number of Marulu Strategy initiatives are currently in place across the Fitzroy Valley, including research projects and support programs.

Jandu Yani U

6.61 Janu Yani U is a Triple P Positive Parenting Program which has been modified to suit the needs of the community.[72]

6.62 The Jandu Yani U project started in 2014 with a partnership between the Marninwarntikura Women's Resource Centre and researchers from the University of Sydney and the University of Queensland. Researchers undertook consultation with the Fitzroy Valley community to adapt the Triple P model.[73]

6.63 Following the modification of the Triple P model, local workers from the Fitzroy Valley community were trained and accredited to deliver the program.[74] Professor Elizabeth Elliot who works on the project further explained:

> We were able to train nearly 30 parent coaches—mostly Aboriginal women and a couple of men—and improve their skills in, and their knowledge of, parenting. They all said that they'd had very few opportunities for higher education, and they got certification from Triple P International and the University of Queensland. They also said this empowered them both at home and at work.[75]

6.64 A recent evaluation of the program has shown positive results with:

- a significant decrease in parent perceptions of the intensity and number of their child's challenging behaviours;
- a decline in the number of parents or family members using dysfunctional parenting styles; and
- a significant decline in the number of family members who reported symptoms of anxiety.[76]

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71 Marninwarntikura Women's Resource Centre, additional information, received 14 October 2020, [p. 2].

72 Jandu Yani U Project Team, *Submission 49,* p. 5.

73 Jandu Yani U Project Team, *Submission 49,* pp. 5–7.

74 Jandu Yani U Project Team, *Submission 49,* p. 7.

75 Professor Elizabeth Elliott, Research Lead, Lililwan Project, Jandu Yani U and Bigiswun Kid Project, University of Sydney and Marninwarntikura Women's Resource Centre, *Committee Hansard,* 14 October 2020, p. 30.

76 Jandu Yani U Project Team, *Submission 49,* p. 7.

6.65 The program is now an integral component of a suite of programs led by the Marninwarntikura Women's Resource Centre to support healthy communities across the life span, and is an entry point into engagement with other services.[77]

6.66 However, Ms Emily Carter, the CEO of the Marninwarntikura Women's Resource Centre, explained that they need more funding due to the high demand for their services:

> We are struggling to exist, let alone keep up with the demand for services required to help our communities heal. We need to have secure funding so we can establish sustainable programs and supports for our community, including funding so we can provide Jandu Yani U parenting program to the 80 families that are on our waitlist.[78]

Bigiswun Kid Project

6.67 Another collaboration between the Marulu team and the University of Sydney is the Bigiswun Kid Project, which aims to identify the needs and build the knowledge to improve services and the health and wellbeing of adolescents in remote First Nations communities.[79]

6.68 As part of the research project, the team is offering a range of services to young people during the data collection process, including helping with applying for the NDIS.[80]

6.69 During the course of the project, a key concern being raised by parents and young people is the lack of access to services, including mental health services.[81]

6.70 At a hearing, the committee was advised there is only one clinical psychologist employed by an NGO for the whole region and WA Country Health Service does not currently have clinical psychologists working in the Fitzroy Valley.[82]

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77 Jandu Yani U Project Team, *Submission 49,* p. 7.

78 Ms Emily Carter, Chief Executive Officer, Marninwarntikura Women's Resource Centre, *Committee Hansard,* 14 October 2020, p. 32.

79 Marninwarntikura Women's Resource Centre, additional information, received 14 October 2020, [p. 3].

80 Marninwarntikura Women's Resource Centre, additional information, received 14 October 2020, [pp. 3–4].

81 Marninwarntikura Women's Resource Centre, additional information, received 14 October 2020, [p. 4].

82 Dr Lauren Rice, Research Fellow, University of Sydney: Brain and Mind Centre, *Committee Hansard,* 14 October 2020, p. 32.

Committee view

Alcohol consumption

6.71 The committee acknowledges that alcohol-related harm in First Nations communities is strongly linked to the impacts of colonisation, entrenched poverty and inter-generational trauma.

6.72 The committee believes that the alcohol controls in place in several states and territories are, in the long term, likely to help reduce the prevalence of FASD. The committee is of the view that other jurisdictions should consider introducing alcohol reforms, including a floor price to prevent the sale of cheap alcohol, and banning problem drinkers from access to take-away alcohol.

Barriers to accessing services

6.73 The issue of access to services in rural and remote areas is not new. Thin markets and issues related to accessing NDIS supports have been identified in several inquiries undertaken by the Joint Standing Committee on the National Disability Insurance Scheme.[83] The committee urges the NDIA to implement the recommendation made by the Joint Standing Committee on the National Disability Insurance Scheme in the *NDIS planning final report* released in December 2020, which recommends that NDIA review its Rural and Remote Strategy and create a new strategy to address the issues of access to the NDIS in rural and remote areas.[84]

6.74 The committee notes that the NDIA has introduced the Remote Community Connectors Program to better engage with First Nations communities. However, the committee has received mixed messages about the effectiveness and appropriateness of the program. The committee encourages the NDIA to consult Aboriginal Community Controlled Health Services and First Nations organisations to improve the model and better engage with families requiring disability support services.

Recommendation 31

6.75 The committee recommends the NDIA undertake consultation and a co-design process with First Nations organisations to improve its Remote Community Connectors Program to enable better access to disability support services for eligible NDIS participants living in remote Australia.

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[83] See, for example, Joint Standing Committee on the National Disability Insurance Scheme, *Market readiness for provision of services under the NDIS*, September 2018, pp. 70–73; *Progress report*, March 2019, pp. 43–44; *NDIS planning final report*, December 2020, Chapter 9, pp. 201–212.

[84] Joint Standing Committee on the National Disability Insurance Scheme, *NDIS planning final report*, December 2020, Recommendation 31, p. 212.

Community-led approaches

6.76 The Marulu Strategy is a stellar example of an effective community-led collaboration between a First Nations community, health experts and philanthropic organisations.

6.77 The committee notes the ongoing struggle faced by the Marninwarntikura Women's Resource Centre to meet demand for its programs and services. For example, the Jandu Yani U parenting program alone has 80 families that are on a waitlist. The committee also heard about the lack of psychologists and mental health services in the Fitzroy Valley region. Sustained funding is urgently required to ensure the Marulu Strategy can effectively deliver services and operate without constantly looking for new funding sources.

6.78 The committee believes that the Marulu Strategy could be adapted to other communities that struggle with alcohol-related harm and have a high prevalence of FASD. However, the committee is of the view that only a community-led process can result in the development of a fit-for-purpose strategy. Each community has unique needs and must be given the support and resources it needs to develop its own strategy and programs to prevent and manage FASD.

Aboriginal Community Controlled Health Services

6.79 A holistic approach to care that is culturally appropriate is paramount to support First Nations people and families affected by FASD. Aboriginal Community Controlled Health Services (ACCHSs) are delivering effective programs which prevent, diagnose and manage FASD in First Nations communities.

6.80 The Child and Youth Assessment and Treatment Service (CYATS) in Alice Springs set up by Congress is an example of a successful program initiated by an ACCHS. Similar clinics should be set up in other locations where there is an identified need for such services. The committee is concerned that CYATS funding is ad hoc, fragmented and uncertain in the long term.

6.81 The committee notes that the Australian Nurse Family Partnership Program (ANFPP) is designed to support women pregnant with a First Nations child from 16 weeks' gestation until the baby is two years old. The program has been successful but does not support women at the very early stage of pregnancy. The committee is of the view that rather than developing an alternative program to provide supports to women in the very early stage of pregnancy, it would be more appropriate to expand the ANFPP program.

Recommendation 32

6.82 The committee recommends the Department of Health allocate specific funding aimed at supporting First Nations community-led projects to prevent and manage FASD.

Senator Rachel Siewert
Chair

Government Senators' Additional Comments

1.1 Government Senators note and generally support the recommendations of the committee.

1.2 The Government is determined to continue working to prevent babies from being born with FASD, supporting women and families to stop drinking if they are planning to have a baby and during the pregnancy, and helping babies born with this condition.[1]

1.3 This is expressed in the Department of Health Submission:

> The Australian Government is committed to reducing alcohol related harms including FASD.[2]

1.4 Government Senators support the Morrison Government's commitment to investing nearly $24 million of funding for FASD Diagnostic and Support Services,[3] as well as the investment of over $140 million to prevent and reduce the harms from alcohol, tobacco, and other drugs.[4]

1.5 Government Senators note that Recommendation 9 recommends that '[t]he committee recommends that the Australian Government implement as a matter of priority marketing, pricing and taxation reforms as set out in the National Alcohol Strategy 2019-2028'.

1.6 Government Senators consider Australia's current alcohol taxation setting are appropriate and acknowledges that the Morrison Government has no plans to make any changes to the taxation settings.

1.7 The National Alcohol Strategy notes that Australia's levels of alcohol taxation are already in the top third of countries within the OECD and that excise rates for alcohol are indexed twice a year in line with the consumer price index.[5]

1.8 Furthermore, the National Alcohol Strategy noted that, other pricing mechanisms such as a Minimum Unit Price on alcohol are a matter for the States and Territories.

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1 The Hon Greg Hunt MP, Minister for Health, Australia leading the fight against FASD, Media Release, 9 September 2020.

2 Department of Health, *Submission 25*, p. 2.

3 The Hon Greg Hunt MP, Minister for Health, Over $140 million to address alcohol and drug harm, Media Release, 2 December 2019.

4 Department of Health, *National Alcohol Strategy 2019-2028*, p. 19.

5 Department of Health, *National Alcohol Strategy 2019-2028*, p. 19.

Senator Wendy Askew

Senator Hollie Hughes

Labor Senators' Additional Comments

1.1 The Government needs to take the recommendations of this report seriously and respond to it in a prompt and comprehensive fashion.

1.2 Labor accepts the principles and general aims of the recommendations contained in the Committee's report. However we note the Committee was not able to prepare detailed recommendations, including fiscal impacts from the implementation of recommendations.

1.3 As a result, recommendations which involve expenditure of public money should be considered through a budget process in the ordinary way.

1.4 Labor will settle its policies in relation to health ahead of the next election in the usual manner.

Senator Malarndirri McCarthy

Senator Anne Urquhart

Appendix 1
Submissions and additional information

Submissions

1 National Drug Research Institute, Curtin University

2 Northern Territory Government
- Supplementary submission

3 NSW Office of the Children's Guardian

4 Child Death and Serious Injury Review Committee

5 Australian Medical Association

6 Australian Institute of Health and Welfare

7 Drug and Alcohol Nurses of Australasia
- Attachment

8 Dr Sharman Stone

9 Ms Nikki Mortier

10 Royal Australian and New Zealand College of Obstetricians and Gynaecologists

11 roundsquared

12 Illawarra Shoalhaven Local Health District

13 Alcohol Programs Team, Public Health Advocacy Institute of WA; and Cancer Council WA

14 Queensland Family and Child Commission

15 Emerging Minds

16 Dr Vanessa Spiller

17 Australian Human Rights Commission

18 Goulburn Valley Health

19 Alcohol Policy Coalition

20 Australian Grape and Wine Incorporated

21 Queensland Advocacy Incorporated

22 Professor Harry Blagg, Mrs Suzie May, Clinical Associate Professor Raewyn Mutch, Dr Tamara Tulich, Dr Robyn Williams

23 University of Western Australia

24 *Name Withheld*

25 Department of Health

26 Catholic Women's League Australia Inc.

27 National Alliance for Action on Alcohol

28 Alcohol Beverages Australia

29 Victorian FASD Special Interest Group

30 Murdoch Children's Research Institute

31 Australian College of Midwives

32 Office of the Children's Commissioner Northern Territory

33 Public Health Association of Australia
34 VicFAS
35 Gold Coast Hospital and Health Service, Child Development Service
36 University of Queensland
37 Alcohol and Drug Foundation
38 DrinkWise
39 WANADA
40 NOFASD Australia
- 2 Attachments

41 Legal Aid Western Australia
42 FASD Research Australia
43 Royal Australian and New Zealand College of Psychiatrists
44 Australian Health Promotion Association
45 Drug ARM; and Queensland Coalition for Action on Alcohol
46 Aboriginal Legal Service of Western Australia
47 Ms Prue Walker
- Attachment

48 Dr Kathryn Antioch
- Supplementary submission
- Attachment

49 Jandu Yani U Project Team
50 Foundation for Alcohol Research and Education
- 3 Attachments

51 Dr Vicki Russell
52 Australian Association of Social Workers
53 Royal Australian College of General Practitioners
54 Neurodevelopmental and Behavioural Paediatric Society of Australasia
55 Russell Family Fetal Alcohol Disorders Association
56 National Aboriginal Community Controlled Health Organisation
57 NSW Government
- Supplementary submission

58 Royal Australasian College of Surgeons
59 Central Australian Aboriginal Congress
- Attachment

60 Victorian Alcohol and Drug Association
61 Danila Dilba Health Service
62 Aboriginal Medical Services Alliance of the Northern Territory
63 Gilbert and Tobin
64 Royal Australasian College of Physicians
65 Western Australian Government
66 North Australian Aboriginal Justice Agency

67 National Disability Insurance Agency
68 Royal Far West
69 Newcastle Local Drug Action Team
- 5 Attachments

Additional Information

1 Many hands project, from Newcastle Local Drug Action Team, received 27 January 2020
2 Additional evidence, from National Drug Research Institute, received 21 May 2020
3 Additional evidence, from FASD Research Australia, received 5 June 2020
4 Updated data - VicFAS Diagnostic Clinic - August 2019 to June 2020, from VicFAS, received 23 June 2020
5 Information on the FASD Court in Winnipeg, Manitoba Canada, from Dr Tamara Tulich, received 20 July 2020
6 Australian and New Zealand Fetal Alcohol Spectrum Disorder Clinical Network, Annotated Bibliography, 1st Edition, June 2019-June 2020, from Dr Natasha Reid, received 16 September 2020
7 Good practice standards/model for youth programs in remote communities in Central Australia, from Central Australian Youth Link Up Service, received 14 October 2020
8 Investing in the future, The impact of youth programs in remote central Australia: a Social Return on Investment (SROI) analysis, from Central Australian Youth Link Up Service, received 14 October 2020
9 Background information, from Marninwarntikura Women's Resource Centre, received 14 October 2020
10 'Listening and hearing are two different things', Report on Community and Service Provider Workshops 2018, from Danila Dilba Health Service, received 16 October 2020
11 Summary of events in the support of a client accessing NDIS entitlements, from Central Australian Youth Link Up Service, received 11 November 2020
12 Evidence-based alcohol policies: Building a fairer and healthier future for Aotearoa New Zealand, from Associate Professor Doug Shelton, received 11 March 2021
13 Documents referred to during 10 March public hearing, from Northern Territory Government Department of Health, received 12 March 2021

Answer to Question on Notice

1 Answers to Questions taken on Notice during 19 May public hearing, received from FASD Research Australia, 5 June 2020
2 Answers to Questions taken on Notice during 19 May public hearing, received from National Drug Research Institute, 5 June 2020

3 Answers to Questions taken on Notice during 19 May public hearing, received from Department of Health, 12 June 2020

4 Answers to Questions taken on Notice during 19 May public hearing, received from Department of Health, 12 June 2020

5 Answers to Questions taken on Notice during 19 May public hearing, received from Department of Health, 20 July 2020

6 Answers to Questions taken on Notice during 19 May public hearing, received from Australian Institute of Health and Welfare, 4 September 2020

7 Answers to Questions taken on Notice during 19 May public hearing, received from Department of Health, 16 October 2020

8 Answers to Questions taken on Notice during 24 June public hearing, received from National Aboriginal Community Controlled Health Organisation, 10 July 2020

9 Answers to Questions taken on Notice during 24 June public hearing, received from VicFAS, 10 July 2020

10 Answers to Questions taken on Notice during 24 June public hearing, received from Alcohol Change Vic, 10 July 2020

11 Answers to Questions taken on Notice during 24 June public hearing, received from NOFASD Australia, 21 July 2020

12 Answers to Questions taken on Notice during 25 June public hearing, received from National Disability Insurance Agency, 22 July 2020

13 Answers to Questions taken on Notice during 25 June public hearing, received from Gilbert and Tobin, 28 July 2020

14 Answers to Questions taken on Notice during 16 September public hearing, received from DrinkWise, 7 October 2020

15 Answers to written Questions taken on Notice, received from Ms Nikki Mortier, 1 October 2020

16 Answers to written Questions taken on Notice, received from Dr Natasha Reid, 1 October 2020

17 Answers to written Questions taken on Notice, received from Royal Australian and New Zealand College of Psychiatrists, 13 October 2020

18 Answers to written Questions taken on Notice, received from Gold Coast Hospital and Health Service, 13 October 2020

19 Answers to written Questions taken on Notice, received from DrinkWise, 13 October 2020

20 Answers to written Questions taken on Notice, received from Royal Australian and New Zealand College of Obstetricians and Gynaecologists, 15 October 2020

21 Answers to written Questions taken on Notice, received from Royal Australian College of General Practitioners, 16 October 2020

22 Answers to written Questions taken on Notice, received from Australian College of Midwives, 16 October 2020

23 Answers to written Questions taken on Notice, received from Australian Medical Association, 21 October 2020
24 Answers to written Questions taken on Notice, received from Guidelines and Economists Network International, 23 October 2020
25 Answers to written Questions taken on Notice, received from Danila Dilba Health Service, 3 November 2020
26 Answers to written Questions taken on Notice, received from Royal Far West, 6 November 2020
27 Answers to Questions taken on Notice during 4 December public hearing, received from National Disability Insurance Agency, 14 January 2021

Correspondence

1 Response to Ms Nikki Mortier's answers to written questions on notice, received from South Australian Department for Child Protection, 23 October 2020

Tabled Documents

1 Additional statement of evidence, tabled by National Drug Research Institute, at Canberra public hearing, 19 May 2020
2 Mindmap – research evidence of factors associated with alcohol-exposed pregnancies, tabled by National Drug Research Institute, at Canberra public hearing, 19 May 2020
3 Opening statement, tabled by Royal Australasian College of Physicians, at Canberra public hearing, 16 September 2020
4 Opening statement, tabled by Guidelines and Economists Network International, at Canberra public hearing, 16 September 2020
5 Opening statement, tabled by Dr Natasha Reid, at Canberra public hearing, 16 September 2020
6 Opening statement, tabled by Danila Dilba Health Service, at Canberra public hearing, 14 October 2020

Appendix 2
Public hearings

Tuesday, 19 May 2020
Committee Room 2S3
Parliament House
Canberra

Department of Health

- Ms Sharon Appleyard, First Assistant Secretary, Population Health and Sport Division
- Mr Jack Quinane, A/g Assistant Secretary, Alcohol and Tobacco and other Drugs Branch

Australian Institute of Health and Welfare

- Mr Michael Frost, Group Head, Primary and Maternal Health and Veterans Group

National Drug Research Institute

- Associate Professor Nyanda McBride, Prevention and Early Intervention Program Leader

Murdoch Children's Research Institute

- Professor Jane Halliday, Group Leader, Reproductive Epidemiology
- Ms Evelyne Muggli, Senior Research Officer

FASD Research Australia Centre of Research Excellence

- Professor Carol Bower, Co-Director
- Professor Elizabeth Elliott, Co-Director
- Dr Hayley Passmore, Research Officer

Wednesday, 24 June 2020
Committee Room 2S3
Parliament House
Canberra

Foundation for Alcohol Research and Education

- Ms Caterina Giorgi, Chief Executive Officer
- Ms Sarah Ward, Acting Head of Health Promotion

National Alliance for Action on Alcohol

- Dr Susan Adams, Paediatric Surgeon, Royal Australasian College of Surgeons

Alcohol Change Vic

- Ms Sarah Jackson, Senior Legal Policy Adviser, Cancer Council Victoria

Alcohol and Drug Foundation

- Dr Erin Lalor, Chief Executive Officer

NOFASD Australia

- Ms Louise Gray, Chief Executive Officer
- Cheryl
- Sophie

VicFAS

- Dr Katrina Harris, Head of VicFAS
- Dr Alison Crichton, Clinical Coordinator
- Ms Prue Walker, Social Worker/Service Coordinator

National Aboriginal Community Controlled Health Organisation

- Ms Patricia Turner, Chief Executive Officer
- Dr Adam Heaton, Senior Policy Officer

Thursday, 25 June 2020

Committee Room 2S3
Parliament House
Canberra

National Disability Insurance Agency

- Mr Martin Hoffman, Chief Executive Officer
- Ms Sarah Johnson, Scheme Actuary
- Mr Scott McNaughton, General Manager, National Delivery
- Mr Daniel English, Territory Manager, NT and Connectors
- Mr Peter De Natris, Strategic Advisor, Early Childhood Intervention and Autism

Professor Harry Blagg, Private capacity

Dr Raewyn Mutch, Private capacity

Dr Tamara Tulich, Private capacity

Dr Robyn Williams, Private capacity

Australian Human Rights Commission

- Ms June Oscar, Aboriginal and Torres Strait Islander Social Justice Commissioner
- Dr Ben Gauntlett, Disability Discrimination Commissioner
- Mr Nick Devereaux, Director, Aboriginal and Torres Strait Islander Social Justice
- Mr Graeme Edgerton, Deputy General Counsel

Gilbert and Tobin

- Ms Nicole Lojszczyk, Lawyer
- Ms Anne Cregan, Partner

Wednesday, 16 September 2020

Committee Room 2S3
Parliament House
Canberra

Royal Australasian College of Physicians

- Professor Elizabeth Elliott, Fellow

Australian Medical Association

- Professor Stephen Robson, Council Member

Royal Australian College of General Practitioners

- Dr Tim Senior, Medical Advisor, RACGP National Faculty of Aboriginal and Torres Strait Islander Health

Australian College of Midwives

- Professor Jenny Gamble, Member

Royal Australian and New Zealand College of Obstetricians and Gynaecologists

- Dr Vijay Roach, President

Royal Australian and New Zealand College of Psychiatrists

- Dr Chinar Goel, Fellow

Royal Australasian College of Surgeons

- Dr Susan Adams, Paediatric Surgeon

DrinkWise

- Mr Simon Strahan, Chief Executive Officer

Guidelines and Economists Network International

- Dr Kathryn Antioch, Chief Executive Officer

Gold Coast Hospital and Health Service

- Associate Professor Doug Shelton, Clinical Director, Women's Newborn's and Children's Health
- Dr Haydn Till, Senior Neuropsychologist, Child Development Service
- Dr Francoise Butel, Medical Director, Child Development Service

Ms Nikki Mortier, Private capacity

Dr Natasha Reid, Private capacity

Newcastle Local Drug Action Team – Make FASD History

- Mr Tony Brown, Chairperson
- Ms Nell Skinner, Children's Court Magistrate, Children's Court of New South Wales
- Dr Murray Webber

Wednesday, 14 October 2020

Committee Room 2S1
Parliament House
Canberra

Danila Dilba Health Service

- Dr Andrew Webster, Head of Clinical Governance
- Ms Tess Kelly, Senior Policy Officer

Central Australian Aboriginal Congress

- Dr John Boffa, Chief Medical Officer Public Health
- Mrs Gayle Simpson, Team Leader, Child and Youth Assessment and Treatment Service

Aboriginal Medical Services Alliance Northern Territory

- Mr John Paterson, Chief Executive Officer
- Dr Liz Moore, Public Health Medical Officer, Central Australia
- Ms Emma Delahunty, Senior Policy Officer

Central Australian Youth Link Up Service

- Mr Blair McFarland, Operations Manager
- Mr Tristan Ray, Policy and Project Manager

Marninwarntikura Women's Resource Centre

- Ms Emily Carter, Chief Executive Officer
- Ms Sue Thomas, Strategic Priority Lead
- Dr Lauren Rice, Research Fellow, The University of Sydney: Brain and Mind Centre

- Professor Elizabeth Elliott, Research Lead, Lililwan, Jandu Yani U and Bigiswun Kid Project

Royal Far West

- Ms Lindsay Cane AM, Chief Executive Officer
- Mrs Katherine Burchfield, Health Director

Friday, 4 December 2020

Committee Room 1S4
Parliament House
Canberra

National Disability Insurance Agency

- Ms Lisa Studdert, Deputy Chief Executive Officer, Markets, Government and Engagement
- Ms Sarah Johnson, Scheme Actuary
- Mr Scott McNaughton, GM National Delivery
- Mr Daniel English, Territory Manager NT and Connectors
- Mr Peter De Natris, Strategic Advisor, Early Childhood Intervention and Autism

Wednesday, 10 March 2021

Committee Room 2S1
Parliament House
Canberra

Foundation for Alcohol Research and Education

- Ms Caterina Giorgi, Chief Executive Officer
- Ms Sarah Ward, National Health Campaign Manager

Department of Social Services

- Mr Peter Broadhead, Group Manager, Participant and Performance Group
- Mr Andrew Seebach, Branch Manager, Carer and Disability Payments Branch

Department of Health

- Mr David Laffan, Acting First Assistant Secretary, Population Health Division
- Mr Dave McNally, Acting Assistant Secretary, Alcohol, Tobacco and Other Drugs Branch, Population Health Division

Northern Territory Government Department of Health

- Ms Cecelia Gore, Senior Director, Mental Health Alcohol and Other Drugs Branch

Children's Ground

- Mr William Tilmouth, Chairperson
- Ms Jane Vadiveloo, Chief Executive Officer
- Ms Stacey Campton, Director