



Three-year formal review of the implementation of the National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018-2028

Final Evaluation Report

June 2022

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TABLE OF ACRONYMS

Acronym	Definition
ABS	Australian Bureau of Statistics
ACT	Australian Capital Territory
AOD	Alcohol and Other Drug
ARC	Australian Research Council
BDR	Banned Drinker Register
DOHAC	Australian Government Department of Health and Aged Care
FARE	Foundation for Alcohol Research and Education
FASD	Fetal Alcohol Spectrum Disorder
FAS	Fetal Alcohol Syndrome
FASDAR	National FASD Australian Register
MBS	Medicare Benefits Schedule
MOC	Models of Care
MRFF	Medical Research Future Fund
MUP	Minimum Unit Price
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NDSHS	National Drug Strategy Household Survey
NHMRC	National Health and Medical Research Council
NOFASD	National Organisation for Fetal Alcohol Spectrum Disorders Australia
NSW	New South Wales
NT	Northern Territory
PALIs	Police Auxiliary Liquor Inspectors
pFAS	Fetal Alcohol Syndrome with partial physical features
QLD	Queensland
SA	South Australia
TAS	Tasmania
VIC	Victoria
WA	Western Australia

1. EXECUTIVE SUMMARY

This report presents the findings of a formal review of the implementation of the National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018-2028 (Strategic Action Plan). This was undertaken by Deakin University between October 2021 and May 2022 at the three-year mark of a 10-year plan. This evaluation will act as a benchmark for future formal reviews which are planned at the mid-point and ninth year of the Plan's implementation.

The aim of this review is to inform the Australian Government about whether the Strategic Action Plan is on-track in achieving its aim to 'reduce prevalence of FASD and the impact it has on individuals, families, carers, and communities'. The review will also provide an indication to the National FASD Advisory Group, the expert body that monitors implementation of the Plan, about how the Plan is being implemented three years into its 10-year lifespan.

Method

This review utilised the evaluation questions outlined in the Strategic Action Plan to examine the process of implementation and outcomes of the Plan. The following methodologies were chosen based on their appropriateness for assessing these outcomes within the proposed project timeframes:

- Review of key documents
 - This involved the identification and analysis of legislative, policy, process, and information documents which were identified through online searches and feedback through interviews and surveys. Documents varied in scope regarding how it addresses the evaluation questions, and data were extracted from documents for analysis and synthesis.
- Key stakeholder interviews
 - Interviews were conducted with representatives from the DOHAC, state and territory health departments, state and territory justice departments, National FASD Advisory Group, and FASD Registry. Interviewees were recruited via email, and interviews were conducted online.
- Online surveys
 - Online surveys were conducted with other relevant professionals, including FASD researchers, health care practitioners, maternal and child health practitioners, alcohol and other drug practitioners, mental health practitioners, and FASD service providers. Surveys were advertised on social media and through relevant organisations around Australia.

Results

There are some overarching caveats that should be considered when interpreting the findings of the current evaluation. These include:

- Difficulty attributing initiatives to the Strategic Action Plan
 - It is difficult to quantify the role of the Strategic Action Plan in many current initiatives, however, the Plan should be recognised as aligning and both directly and indirectly contributing to current initiatives. The Strategic Action Plan has provided funding to key FASD activities, and has represented a successful policy framework from which many positive developments have evolved.
- Low participation rate

- Participation in the stakeholder interviews and online surveys was low, which means the findings from such may not be generalisable to all relevant peoples nation-wide. This has, however, been considered when explaining findings throughout the report.
- Time to complete the evaluation
 - This evaluation was completed in a short time period (October 2021 to May 2022), therefore there were limits to what groups of individuals could be realistically targeted in the interviews and surveys in the timeframe proposed. As such, the perspectives of all relevant persons could not be included in the proposed methodology, therefore findings need to be viewed in light of this, recognising that not every FASD-related initiative or activity has been captured.
- The COVID-19 pandemic
 - The impact of the COVID-19 pandemic likely impacted the ability of health departments and the health workforce to implement the Strategic Action Plan. While progress has still been made, it should be acknowledged that this was likely.

Progression in the priority areas

Of the four priority areas outlined in the Strategic Action Plan (prevention, screening and diagnosis, support and management, and priority groups), the work and activities to date show the greatest progression in the prevention and screening and diagnosis areas.

- Prevention
 - Good progress has been made to increase community knowledge and awareness about the harms and consequences of drinking during pregnancy or when planning a pregnancy. This is evidenced through the number of FASD public education and awareness campaigns launched since 2018 ($n = 42$) that align, either fully or partly, with the advice detailed in the Strategic Action Plan regarding raising awareness about the risk of drinking in pregnancy and FASD, the belief that not drinking is the safest choice and intention to not drink whilst pregnant, and increasing support for women not drinking in pregnancy while minimising stigmatising the individual. In addition, aligning with priorities under the Strategic Action Plan, the Australian Government has funded one of the biggest national FASD campaigns to date (the National Awareness Campaign for Pregnancy and Breastfeeding Women).
 - Policy change concerning mandatory pregnancy warning labels on alcohol products and the development of FASD short courses run through the University of WA have further improved the opportunity for people to obtain knowledge of the harms/consequences of drinking during pregnancy or when planning a pregnancy, and awareness of FASD.
- Screening and diagnosis
 - Good progress has been made in providing opportunities for frontline professionals to increase their FASD knowledge and screening and diagnosis skills. This is evidenced through the development of the first FASD university course run through the University of WA, targeting health professionals in one of the four streams of the National FASD Campaign, establishing the Australian and New Zealand FASD Clinical Network, and through research projects which have aimed to support clinicians to diagnose and support clients with FASD, such as the FASD Diagnostic Services and Models of Care project.
 - Additional funding allocated to FASD diagnostic services has helped to improve capacity for screening, diagnosis, and surveillance.

- However, online surveys with health and human service workers highlighted that FASD training in the workplace is not common, and there was a common theme of not having/not being aware of procedures for supporting people with FASD in the workplace.
- There are several available resources (25 were identified) that teachers can use to help support children with FASD in the classroom. It is noted, however, that these are not compulsory resources, and it is unclear how much these are being used in educational settings.
- **Support and management**
 - The FASD Diagnostic Services and Models of Care project has demonstrated a good foundation to supporting FASD support and management through developing models of care specific to each service.
 - The Making FASD History project has improved the diagnosis and management of FASD in young people engaged with the justice system.
 - There is research currently underway to assist adults in the criminal justice system to obtain supportive employment post-release.
 - Funding to support websites such as the FASD Hub and NOFASD Australia have provided individuals the opportunity to obtain information about FASD management and supports.
- **Priority groups**
 - There have been some targeted prevention campaigns and resources for First Nations peoples and those in the criminal justice sector, however co-design is essential.
 - How the Strategic Action Plan and FASD screening/diagnostic tools are used in priority groups may need some adjustment to ensure it is relevant and appropriate to particular communities and the resources they have.
 - Recognition of FASD in the criminal justice system is lacking in many jurisdictions. However, the processes undertaken in Western Australia are promising.

Funding

There has also been an increase in funding provided to FASD projects and activities Australia wide since the launch of the Strategic Action Plan, in particular from the DOHAC (who have funded 24 projects between 2019 and 2022). The funding aligns with, and assists in the progression of, the four priority areas detailed in the Strategic Action Plan. Funding from four national funding bodies from 2012 – 2022 were examined (NHMRC, DOHAC, ARC, MRFF), and while it was difficult to confirm an increase in targeted funding, the increase in NHMRC funding from three-years before the launch of the Strategic Action Plan (2015 – 2017) to the three-years after (2019 – 2021) suggests a 50% increase in FASD focused research project funding. Funding has mainly targeted activities to raise FASD awareness (i.e., \$27 million to funding the National Awareness Campaign for Pregnancy and Breastfeeding Women) or to increase diagnostic services.

Future considerations

In sum, the review raises the following considerations regarding the further roll-out and evaluation of the Strategic Action Plan.

- More effectively communicate the Strategic Action Plan to priority populations, including First Nations peoples.

- Greater emphasis on training for all healthcare services in recognising the signs of FASD, referral/assessment, diagnosis, models of care, and management strategies. This may involve incorporating FASD training into training/university courses as well as role-specific training for those already in the workforce. This should include recognition of FASD in department policy and practice guidelines.
- Develop a network to facilitate the sharing of information across jurisdictions. This will allow researchers, policy makers, and service providers greater opportunity to collaborate and use the learnings of other states/territories, and therefore increase the shared sense of responsibility for action concerning FASD.
- Greater emphasis on screening and diagnosis in education and criminal justice sectors.
- Consideration of alternative ways to assess, diagnose, and manage FASD to ensure communities with limited resources still have effective models of care to follow.
- Consideration of co-design methodology when developing initiatives and resources to assist in the prevention, assessment, diagnosis, and management of FASD, especially with at-risk populations.
- Consideration of whether there could be a widespread rollout of the FASD Diagnostic Services and Models of Care Project throughout Australia. This project has been successful in select sites to date, which has important implications for FASD service delivery in Australia.
- In future reviews, include women with alcohol dependence, pregnant women, youth in the justice system, First Nations peoples, FASD service providers, representatives from Aboriginal Community Controlled Health Organisations and First Nations services, individuals diagnosed with FASD and their families, staff from detention centres and community programs, and court case managers in stakeholder interviews.
- In future reviews, include education and justice staff in online surveys.
- Examine community awareness of FASD public education and awareness campaigns.
- Assess the number of young people in detention centres and community programs identified with FASD compared to national/state FASD rates, and the number of persons accessing post-release and treatment services and/or non-custodial sentencing options.

Conclusion

The Strategic Action Plan, at the three-year mark of a 10-year plan, seems to be on track to meeting the actions specified within the plan. The 'prevention' and 'screening and diagnosis' priority areas have obtained more funding and seen greater progression compared to the 'support and management' and 'priority groups' priority areas. However, there has been promising developments in all priority areas to date considering disruptions from the COVID-19 pandemic during this time. Future evaluations would benefit from greater time allocated to evaluate the progress of the Strategic Action Plan, as this would allow for more time to collect data and more relevant persons the opportunity to contribute their data.

2. INTRODUCTION

Fetal Alcohol Spectrum Disorder (FASD) is defined by the Canada Fetal Alcohol Spectrum Disorder Research Network (2019), and endorsed by the National Organisation for Fetal Alcohol Spectrum Disorder (NOFASD) Australia, as:

A diagnostic term used to describe impacts on the brain and body of individuals prenatally exposed to alcohol. FASD is a lifelong disability. Individuals with FASD will experience some degree of challenges in their daily living, and need support with motor skills, physical health, learning, memory, attention, communication, emotional regulation, and social skills to reach their full potential. Each individual with FASD is unique and has areas of both strengths and challenges.

The diagnostic terms Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Syndrome with partial physical features (pFAS) fall under the broader definition of FASD, however, many FASD prevalence studies report only FAS/pFAS as these diagnoses are most strongly associated with prenatal alcohol exposure (Fitzpatrick et al., 2015). The Australian Guidelines to Reduce Health Risks from Drinking Alcohol, published by the National Health and Medical Research Council (2020), advise that there is no safe level of prenatal alcohol exposure, and that any exposure to alcohol prenatally can result in a child being born with FASD.

The prevalence of FASD in Australia is difficult to determine due to several factors; including a lack of routine assessment and screening for maternal alcohol use and FASD, a lack of Australian national diagnostic criteria prior to 2016, inconsistent use of diagnostic criteria, the need for a multidisciplinary team to confirm a FASD diagnosis, and a lack of nationally consistent data collection and reporting on alcohol consumption in pregnancy (Fitzpatrick et al., 2015; Pedruzzi et al., 2020). Findings from a recent review and meta-analysis also highlighted that it can be difficult to differentiate the neurocognitive profile of FASD from other childhood conditions, particularly attention deficit-hyperactivity disorder (ADHD), which may impact on FASD diagnosis and prevalence estimate efforts (Kingdon et al., 2016; Mattson et al., 2019). Further, for children living in out-of-home care, obtaining a diagnosis of FASD is difficult if they are no longer connected with their birth families (Bakhireva et al., 2018); however, the rates of FASD are thought to be considerably higher in children placed in out-of-home care (Rangmar et al., 2015). This excludes a potentially large group of individuals with FASD in recorded prevalence data.

Prevalence studies in Australia are limited and tend to focus on at-risk populations rather than the general population. In a population-based sample of children living in remote Australia ($N = 108$), it was found that FAS or pFAS was diagnosed in 13 children, equating to a prevalence rate of 120 per 1000 children (Fitzpatrick et al., 2015). A later study conducted by Fitzpatrick et al. (2017) examined the prevalence of neurodevelopmental disorder and FASD in First Nations children living in remote communities in Western Australia, and found that 34 children ($N = 108$) met the criteria for neurodevelopmental disorder (equating to a rate of 314.8 per 1000 children), while 21 children met the criteria for any diagnosis on the FASD spectrum (equating to a rate of 194.4 per 1000 children). Finally, a recent Australian study conducted with young people in detention in Western Australia ($N = 99$) found that over a third (36%) who were assessed were diagnosed with FASD (Bower et al., 2018). When considering just the First Nations youth diagnosed with FASD in this sample ($n = 34$), the prevalence of FASD was 47%, which is more than twice that of the highest population estimate of FASD in Australia (19%, as reported in a remote, mainly First Nations, population aged 7–8 years; Fitzpatrick, 2015). This prevalence figure of 36% represents a higher proportion than similar studies conducted internationally (i.e., FASD rates of 11% - 23% in Canadian youth detention samples)

(Bower et al., 2018). However, these findings may still be an underestimation of FASD prevalence as researchers were unable to measure all key domains needed for FASD diagnosis, including affect regulation, adaptive functioning/social skills/social communication, and the presence of prenatal alcohol exposure.

Compared to prevalence studies internationally, rates of FASD reported in the aforementioned research are amongst the highest in the world. However, this may be in part due to the Australian research focusing on at-risk populations rather than the general population. For example, a FASD prevalence study in four communities in the United States ($N = 6639$) reported the total estimated prevalence of FASD ranged between 31.1 – 98.5 per 1000 children (May et al., 2018). Further, a systematic review and meta-analysis of the worldwide prevalence of FASD conducted by Roozen et al. (2016) reported the pooled prevalence rates (which refers to the ‘pooled’ number of cases across studies instead of an average rate to more accurately reflect the number of cases in a sample) of FASD in South Africa at 113.2 per 1000 children, with lower rates yielded for Canada (30.5 per 1000 children), Italy (47.1 per 1000 children), and the United States (33.5 per 1000 children). Notably, research from Australia was included in this review, highlighting an extremely low FASD pooled prevalence rate of 1.06 per 1000 children. Compared to recent research (Fitzpatrick et al., 2015; Fitzpatrick et al., 2017), this demonstrates the difficulties associated with accurate reporting of FASD in Australia. Studies examining the prevalence of FASD in at-risk groups, such as youth or young adults in correctional facilities and studies amongst First Nations peoples, suggest that FASD is higher in such groups compared to the general population (Fitzpatrick et al., 2017).

Most individuals with FASD live with significant cognitive, behavioural, health, and learning difficulties. This includes problems with memory, attention, language, executive functioning, impulse control, affect regulation, receptive language, and social skills (Bower et al., 2016). As FASD is a lifelong condition, these difficulties can impact many aspects of daily life. As such, individuals with FASD can be at higher risk for lifelong secondary conditions, such as mental health problems and addiction, and also be more likely to engage in inappropriate sexual behaviours, have a disrupted schooling experience, and be involved with the criminal justice system (Flannigan et al., 2020; Streissguth et al., 2004; Tsang et al., 2016). The impacts of these difficulties can contribute to poor quality of life for individuals with FASD, however with early and accurate diagnosis and individualised interventions, long term outcomes can be substantially improved.

As detailed in the Strategic Action Plan (Australian Government Department of Health, 2018), a lack of understanding and recognition of FASD as a lifelong condition is a significant barrier to people who are living with, or impacted by FASD, for accessing appropriate diagnostic, early intervention, and support services. It is important that research on FASD continues to occur and grow to provide the evidence needed for governments and funding bodies to implement policies and initiatives to assist in the prevention, management, and support of FASD in Australia.

2.1 Evaluation Process and Timelines

The National Strategic Action Plan 2018-2028 was developed after a series of consultations, including an initial DOHAC facilitated roundtable discussion in December 2016 with key FASD stakeholders and government agencies. This roundtable discussion involved a review of the FASD Action Plan 2013-14 to 2016-17, and preparation of advice regarding the implementation of the 2016-17 Federal Budget Measure known as ‘Taking More Action to Prevent FASD’. One of the key recommendations to come from the roundtable discussion was to develop the current National FASD Strategy Action Plan for Australia (Australian Government Department of Health, 2018).

Deakin University was successful in obtaining the tender to evaluate the National Strategic Action Plan 2018-2028 on October 8, 2021, with the final report of the evaluation due on the 27th of May, 2022.

2.2 The Current Review

The aim of this review is to inform Australian Governments about whether the Strategic Action Plan is on-track in achieving its aim to 'reduce prevalence of FASD and the impact it has on individuals, families, carers, and communities'.

As such, the current evaluation of the Strategic Action Plan was designed to address the key evaluation questions outlined within the plan (pages 45-52; Australian Government Department of Health, 2018). To answer these questions, we have adopted a range of methodologies to ensure a comprehensive understanding of the progress of the plan to date, and to allow us to make recommendations based on our findings for future implementation and roll-out of the plan.

3 METHODS

The methods used in this evaluation are 3-fold, comprising key informant interviews, online surveys, and reviews of key documents.

3.1 Ethical Approval

Ethical approval was obtained from Deakin University (HEAG-H 197-2021).

3.2 Key Informant Interviews

3.2.1 Recruitment

Recruitment emails were sent by the DOHAC on two occasions (November 2021 and January 2022) to a range of key stakeholders involved in the implementation of the Strategic Action Plan, inviting participation in the interviews. This included informants from the DOHAC, state and territory health and justice departments, the National FASD Advisory Group, and those involved in the management of the FASD Australian Registry. It was made clear to potential interviewees that participation was voluntary, and responses would be kept confidential. Due to human ethics requirements, Deakin University could not contact individuals directly to participate in the interviews. Rather, interested stakeholders were advised to contact the research team to organise an interview time.

3.2.2 Procedure

Interviews were conducted online, and audio recorded for the purpose of transcription. Interviews were originally organised to be conducted on Zoom, however upon feedback that Zoom was not a supported application for some interested stakeholders, the research team modified ethics to allow interviews to be conducted on Microsoft Teams and Webex if required. Interviews were conducted by research team members between December 2021 and February 2022, and interviewees were given the option to review and edit their transcript prior to it being analysed by the research team. The interview schedule was tailored to informants based on their role, given each group were involved in different aspects of the Strategic Action Plan. Interviews were transcribed by a professional transcription company.

3.3 Online Surveys

Given the short timeframe of the project, key informant interviews were not a feasible method of data collection for all key informant groups. As such, anonymous online surveys were developed and distributed to capture a greater number of responses from key informant groups in a shorter period of time.

3.3.1 Recruitment

Participant recruitment for a short online survey was undertaken via two avenues: social media and through direct contact with relevant organisations in Australia. To be eligible for the survey, participants had to work in Australia and work in an occupation that is relevant to researching, diagnosing, and/or treating individuals with FASD.

Survey information and a link to the survey was posted by the research team on a variety of social media platforms, including Facebook (using paid and unpaid advertisements), Twitter, and LinkedIn. The paid Facebook advertising ran from 17 January 2022 to 6 February 2022, and was set to target healthcare and medical services, and community and social services. During this time, the advertisement reached 29,807 people, had 68,441 impressions (number of times the ad was on screen), and resulted in 290 link clicks (number of times people followed the link to the survey from the post). Further, the research team contacted relevant Facebook groups to post recruitment information on our behalf, including: Maternity Research in Australia, Nursing newgrads Australia, FASD Tasmania Inc., FASD Consultants Australia, and Russell Family Fetal Alcohol Disorders Association (RFFADA). The research team also emailed relevant organisations requesting assistance in forwarding on the recruitment information to relevant staff/members, as well as advertising the survey (through paid and unpaid means) on organisational websites, in organisational newsletters/bulletins, and on their social media platforms. Table 1 summarises the organisations contacted.

Table 1.
Organisations Contacted for Survey Recruitment Assistance

Sector	Organisations Contacted
Mental Health	<ul style="list-style-type: none">- Australian & New Zealand Mental Health Association- Mental Health Community Coalition ACT- Mental Health Coordinating Council NSW- Northern Territory Mental Health Coalition- Queensland Alliance for Mental Health- Mental Health Coalition of South Australia- Mental Health Council of Tasmania- Mental Health Victoria- Western Australian Association of Mental Health
AOD	<ul style="list-style-type: none">- The Alcohol Tobacco and Other Drug Association ACT (ATODA)- The Network of Alcohol and Other Drugs Agencies NSW (NADA)- The Association of Alcohol and Other Drug Agencies Northern Territory (AADANT)- The Queensland Network of Alcohol and Other Drug Agencies (QNADA)- The South Australian Network of Drug & Alcohol Services (SANDAS)- The Alcohol, Tobacco and Other Drugs Council Tasmania (ATDC)- The Victorian Alcohol and Drug Association (VAADA)- The Western Australian Network of Alcohol and Other Drug Agencies (WANADA)
FASD	<ul style="list-style-type: none">- FASD Hub- NOFASD
Community-specific networks	<ul style="list-style-type: none">- CDNET – Community Development Network ACT- Northern Territory Council of Social Service

Healthcare	<ul style="list-style-type: none"> - Australian College of Midwives (ACM) - Hospitals in Melbourne and Regional Victoria - The Royal Australian College of General Practitioners (RACGP) - Maternal, Child and Family Health Nurses Australia (MCAFHN) - Royal Australasian College of Physicians (RACP) - Australian College of Rural & Remote Medicine (ACRRM) - The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG)
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3.3.2 Procedure

The surveys collected both quantitative and qualitative data to respond to the evaluation questions detailed in the Strategic Action Plan. In line with the Strategic Action Plan evaluation questions, the questions posed in the online survey were tailored for each of the key informant groups of interest: FASD researchers, healthcare practitioners, mental health practitioners, alcohol and drug practitioners, maternal and child health practitioners, and FASD service providers. The online surveys were advertised through the various outlined means from December 2021 to March 2022.

3.4 Document Review

Many of the evaluation questions posed in the Strategic Action Plan involved a review of documents that had been developed as a result of the plan or since the launch of the plan. As such, a key methodology employed in the current evaluation was a document review.

The document review involved the identification and analysis of all relevant documents, including legislative documents, policy documents, and process and information documents. These documents were identified through online searches and through feedback from key informant interviews.

Each document review varied based on the type of information it provided to address the evaluation questions posed in the Strategic Action Plan. This may have involved a comparison of the document to best practice evidence in the literature; an identification of the quality of the document being reviewed; or the recording of whether the existence of the document itself addresses a key evaluation question.

4 DATA ANALYSIS

All analyses were conducted using the appropriate software (i.e., SPSS v26, NVivo v12).

4.1 Key Informant Interviews

Seventeen key stakeholders expressed interest in the interviews; however, three could not complete the interview due to technological difficulties or an inability to find a suitable time for the interview to take place. Overall, 11 interviews were conducted, comprising 14 interviewees (i.e., some interviews had more than one interviewee present). Interviewees had a range of experience in the FASD space, ranging from 1 year to 25 years. Of note, there were not representatives from each state and territory in the groups involved in the interviews: there was only one state represented in the Department of Justice group, and three states represented in the Health Department group.

Key informant interviews were transcribed and entered into NVivo 12, a qualitative data analysis software program. Responses were analysed by two researchers, which was initially based on the question asked as this was often directly related to an evaluation question to be addressed. Key themes were then constructed by one researcher based on common narratives using thematic analysis. Thematic analysis is a method of qualitative data analysis that involves researchers

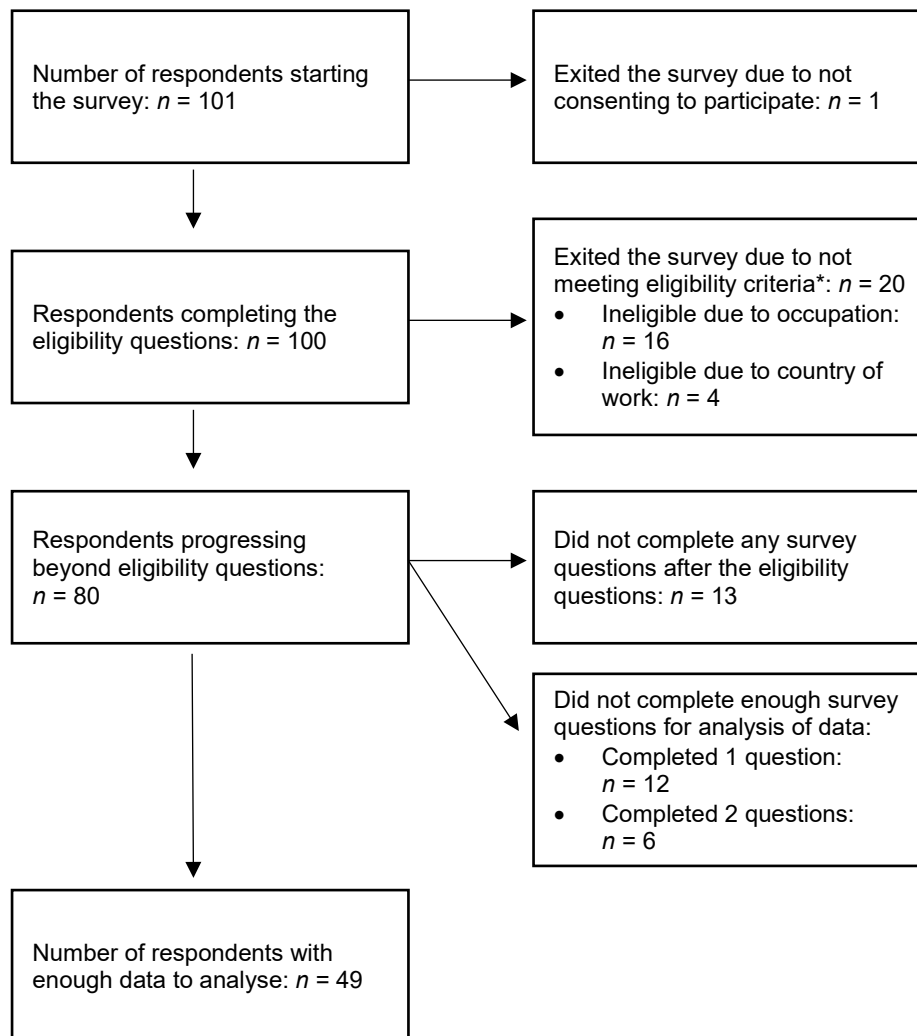
familiarising themselves with participant responses, identifying, revising, and collating common themes emerging from the data.

4.2 Online surveys

Online surveys were conducted in Qualtrics, and data were downloaded and analysed in SPSS v26 (quantitative) and Excel (qualitative). Quantitative data were analysed based on frequency counts and qualitative data were content analysed.

As can be seen in Figure 1, 101 participants opened the survey and read the plain language statement. Of these, only one did not consent to participate. Of the 100 individuals who consented, 51 responses were unable to be analysed due to large amounts of missing data. Reasons for this are detailed in Figure 1 below. Table 2 provides further detail of the analysed responses ($n = 49$) by occupation and location. For eligible respondents, the survey took, on average, approximately 10 minutes to complete.

Figure 1.
Diagram of Survey Responses



Notes. *The eligibility questions are “what is your occupation?” (options include FASD researcher, healthcare practitioner, mental health practitioner, alcohol and drug practitioner, maternal and child health practitioner, FASD service providers, and none of the above, with ‘none of the above’ resulting in that respondent being deemed ineligible); and “are you currently working in this occupation in Australia” (options include yes or no, with ‘no’ resulting in that respondent being deemed ineligible).

Table 2.*Number of Survey Responses Based on Occupation and Location.*

Occupation	Sample size (%)	Sample size per state/territory
FASD researcher	4 (8%)	ACT = 1; NSW = 1; TAS = 1; WA = 1
Maternal and child health practitioner	23 (47%)	ACT = 1; NSW = 9; QLD = 4; SA = 1; VIC = 7; WA = 1
Healthcare practitioner*	10 (20%)	NSW = 1; QLD = 2; SA = 2; VIC = 5
Alcohol and other drug practitioner	6 (12%)	NSW = 4; VIC = 2
Mental health practitioner	4 (8%)	TAS = 1; VIC = 3
FASD service provider	2 (4%)	NT = 1; VIC = 1
Total	49 (100%)	ACT = 2; NSW = 15; NT = 1; QLD = 6; SA = 3; TAS = 2; VIC = 18; WA = 2

Notes. Percentage is based off those responses remaining after data cleaning ($n = 49$).

*Respondents who selected this occupation were asked to specify their work type; three specified hospital-based healthcare (including operating theatre, nurse, and paediatric hospital), two specified social welfare (including social work and child protection), one specified aged care, one specified physical therapy, one specified tertiary education, and two did not disclose their work type.

4.3 Document Reviews

Relevant documents were obtained from online searches and those provided from key stakeholders in the FASD field. Documents were analysed according to the evaluation question/s each document was relevant to and was either summarised in paragraph or table format.

5 EFFECT OF THE STRATEGIC ACTION PLAN NATIONALLY, AND AT STATE AND TERRITORY AND LOCAL LEVELS

To assess the effect of the Strategic Action Plan at the national, state and territory, and local levels, each evaluation question posed in the plan (pages 45-52), will be addressed using the methodology deemed most appropriate for that question.

5.1 To what extent has the Strategic Action Plan been implemented in a way that aligns with the National Alcohol Strategy Priority Areas?

The National Alcohol Strategy 2019-2028 (Australian Government Department of Health, 2019b) aims to prevent and minimise alcohol-related harm in the Australian community. The National Alcohol Strategy is the product of collaborations from the Commonwealth, state, and territory governments, and presents a comprehensive overview of approaches, guided by evidence and experts in the field, to prevent and reduce the harm resulting from alcohol. Along with the National Strategic Action Plan 2018–2028 (Australian Government Department of Health, 2018), the National Alcohol Strategy forms part of the National Drug Strategy 2017-2026.

The National Alcohol Strategy contains four priority areas of focus for preventing and minimising alcohol-related harm, with priority area 2 and 3 applicable to the Strategic Action Plan.

Priority area 1: Improving community safety and amenity

This priority area involves working to better protect the health, safety, and social wellbeing of those consuming alcohol and those around them. Objectives within this priority area include promoting

less injury and violence, safer drinking environments, and better offender treatment and rehabilitation.

Priority area 2: Managing availability, price, and promotion

This priority area involves reducing opportunities for availability, promotion and pricing contributing to risky alcohol consumption.

Objectives within this priority area include strengthening controls on access and availability of alcohol, implementing pricing and taxation reforms to reduce risky alcohol consumption, and minimising the promotion of risky drinking behaviours by promoting measures that support changing individual and community attitudes towards risky alcohol consumption. The 'prevention' priority area within the Strategic Action Plan aligns with priority area 2 of the National Alcohol Strategy, particularly through the Strategic Action Plan objective of increasing community knowledge and awareness about the harms and consequences of drinking in pregnancy.

In particular, the National Awareness Campaign for Pregnancy and Breastfeeding Women, which is funded through the Strategic Action Plan and launched by the Foundation for Alcohol Research and Education (FARE) (see section 5.3 for more information), aims to promote the message that the safest choice is not consuming alcohol when trying for a baby, or when pregnant or breastfeeding. This campaign has a specific stream targeting the general Australian population to help lead community attitudes toward not drinking alcohol during any moment of the pregnancy journey.

Priority area 3: Supporting individuals to obtain help and systems to respond

This priority area involves facilitating access to appropriate treatment, information, and support services. Objective three within this priority area is specifically focused on implementing the Strategic Action Plan. The following policy options are mentioned within this objective:

- Implement the National Strategic Action Plan
- Improve FASD prevention through community awareness, and improved FASD detection, diagnosis, and access to therapy
 - The Strategic Action Plan has made good progress in this area. There have been prevention campaigns (see section 5.3 for an in-depth overview) that have been launched since the plan, with a notable mention to the National Awareness Campaign for Pregnancy and Breastfeeding Women (launched by FARE and funded through the Strategic Action Plan) which aims to improve community awareness of FASD and how to prevent such.
 - The Australian Government also announced an investment of \$9 million to expand diagnostic services in New South Wales (including regional locations; approx. \$2 million), regional Victoria (approx. \$1 million) and Southern and Central Queensland (approx. \$1.5 million), and to improve FASD services through the Sydney Children's Hospital Network in multiple rural and regional communities in NSW and Sydney (almost \$5 million) (DOHAC 2021). The funding to expand FASD diagnostic services was announced to directly support the Strategic Action Plan.
 - Further, there has been work conducted around Australia to improve FASD detection and diagnosis. While the Strategic Action Plan may not have directly initiated such efforts, much of this is funded through the DOHAC and the Strategic Action Plan has helped to support the direction and goals of projects. One example of this is the FASD Diagnostic Services and Models of Care Project (see question 6.2.6 for an overview).

- Increase awareness of the full range of treatment options for women at risk, including outpatient counselling and relapse prevention medicines for dependence
- Promote harms to developing baby as a result of maternal alcohol consumption in school and post-secondary and tertiary education
 - The Strategic Action Plan does not specifically focus on prevention messaging in education settings, however, there has been a recent development in FASD-specific courses and units through the University of Western Australia (UWA) (tertiary education; see question 6.2.6 for an overview).
- Disseminate, promote, and provide training to support the use of established resources
 - The Strategic Action Plan supports the use of the Australian Guide to the Diagnosis of FASD and the Australian FASD Diagnostic Tool and Referral Guidelines. Specifically, diagnostic services who receive funding through the DOHAC/the Strategic Action Plan are required to use the FASD diagnostic tool in their service setting, and the Strategic Action Plan is currently funding a review of the diagnostic tool to ensure it is up to date.
- Improve access to support services, including through the National Disability Insurance Scheme

Priority area 4: Promoting healthier communities

This priority area involves improving the understanding and awareness of alcohol-related harms in the Australian community. Objectives within this priority area include improving the awareness and understanding of alcohol harms and improving communication to target groups.

5.1.1 Are there any of the Priority Areas that require additional focus?

Overview of response:

All priority areas have made some positive advancements since the launch of the Strategic Action Plan in 2018, however the 'Prevention' and 'Screening and Diagnosis' priority areas have perhaps seen more attention and funding so far. Moving forward, it would be beneficial to expand services and available healthcare to ensure people who are diagnosed with FASD have the ability to effectively manage such. In addition, continuing work in First Nations populations, education settings, and criminal justice sectors would be beneficial due to the high proportion of people with FASD belonging to such communities and/or engaging in such settings. This may involve modifying existing resources to be applicable to such environments.

Details:

Prevention

- Objective 1: Reduce access and consumption of alcohol in the Australian community.
- Objective 2: Increase community knowledge and awareness about the harms and consequences of drinking during pregnancy or when planning a pregnancy.

Key stakeholders discussed the Strategic Action Plan may not have had much direct influence on the first objective within this priority area, noting that the role of the Strategic Action Plan is more to support other strategies, such as the National Alcohol Strategy, to promote the reduction in access and consumption of alcohol. A review of the literature revealed that there have been some advancements in reducing access and consumption of alcohol, including the Banned Drinkers

Register, liquor licencing laws during the COVID-19 pandemic, and national alcohol consumption trends; see question 6.1.1.3 Alcohol Access and 6.1.1.4 Alcohol Consumption, respectively, for an overview. However, while these advancements do impact FASD, they are not a direct result of the Strategic Action Plan.

There has been good progress in the second objective; as detailed in section 5.3, there have been a number of FASD prevention campaigns since the launch of the Strategic Action Plan which align with the key messages proposed in the plan. Notably, the Strategic Action Plan has funded one of the biggest national FASD campaigns, which aims to increase the awareness and knowledge of FASD in Australia. Interviewees further noted that recent policy changes concerning mandatory pregnancy warning labels on alcohol products (see question 6.1.1.1 Alcohol promotion for more information) and the development of FASD short courses run through the University of WA (see question 6.1.4 for more information) have further improved the opportunity for people to have knowledge and awareness of the harms/consequences of drinking during pregnancy or when planning a pregnancy. While there has been good progress in this objective, it should be noted that prevention campaigns in this space are rarely evaluated, thus representing an area for future consideration.

Screening and Diagnosis

- Objective 1: Increase screening, diagnostic skills, and knowledge in frontline professionals.
- Objective 2: Improve capacity for screening, diagnosis, and surveillance.

A review of the literature and interviews with key stakeholders revealed that there has been good progress made in providing opportunities for frontline professionals to increase their FASD knowledge and screening and diagnosis skills. This can be seen through the recent development of the first FASD university course run through the University of WA; which aims to upskill professionals in FASD knowledge and diagnosis (see question 6.1.4 for more information), through targeting health professionals in one of the four streams of the National FASD Campaign, through establishing the Australian and New Zealand FASD Clinical Network (which has been endorsed by the Commonwealth Government since 2018, and involves a group of clinicians from various disciplines around Australia and New Zealand), and through research projects which have aimed to support clinicians to diagnose and support clients with FASD; such as the FASD Diagnostic Services and Models of Care project (see question 6.1.4 for more information).

However, while these positive advancements have occurred since the launch of the Strategic Action Plan, online surveys with health and human service workers demonstrated that this improvement in frontline professionals' knowledge still needs work; less than one-third of respondents reported having received training for FASD in their workplace, and there was a common theme of not having, or not being aware of, procedures/MOC for supporting people with FASD in their workplace. Further, question 6.3.6 outlines the available resources that teachers can use to help support children with FASD in the classroom, however it is noted that these are not compulsory resources and may therefore only be accessed by educators who are seeking more information about FASD, thus missing those who are not knowledgeable in this space.

Additional funding has assisted in the progression of objective two. Specifically, Table 7 outlines 33 funded projects since the launch of the Strategic Action Plan, with many of these specifically addressing FASD screening, diagnosis, or surveillance. Stakeholder interviews discussed the impact that this has had on diagnostic services, with many having a much larger capacity due to the funding received. However, waitlists are still extremely long, and there needs to be greater emphasis on

developing innovative ways to support screening and diagnosis in areas that do not have access to multidisciplinary healthcare services.

Support and Management

- Objective 1: Implement and evaluate better models of management, support, and care.
- Objective 2: Support for parents, carers and families in education and employment settings.

Stakeholder interviews, online surveys and reviews of the literature revealed that this priority area has had less advancement to date, however, there have been some efforts made to start progression in this area. Specifically, the work done through the FASD Diagnostic Services and Models of Care project demonstrated a good foundation to supporting FASD support and management through developing models of care specific to each service which promotes care from FASD assessment through to the management of FASD. Further, there has been some work in the youth justice space through the Making FASD History project to improve the diagnosis and management of FASD in young people engaged with the justice system. It was noted, however, that greater recognition of FASD as a disability through national healthcare schemes (i.e., Medicare, NDIS) would help ensure people with FASD are able to receive the ongoing support that they need. Overall, it seems that this priority area will flourish as the prevention and screening and diagnosis priority areas continually improve, as support and management of FASD is largely dependent upon people recognising FASD as something that requires ongoing support and management.

In terms of support for parents, carers, and families – there has been a lot of advancement concerning available information about FASD that people can access. Funding to support websites such as the FASD Hub and NOFASD Australia have allowed parents, carers, and families to obtain information about FASD, education and training opportunities, and supports and resources. There has not been a large focus on FASD support in education and employment settings to date, however these settings would benefit from greater resources moving forward as they represent key settings that individuals with FASD need support in. Reviews of the literature revealed there is a notable amount of information available concerning supporting children with FASD in schools (see question 6.3.6 for more information). However, this information is not compulsory for teachers, and may therefore only reach the teachers who are specifically seeking the information. There is also one current project aiming to assist people with FASD in the criminal justice system to obtain appropriate employment post-release. Specifically, this project highlights the efforts being made to assist employment agencies around Australia to be better informed about FASD and how to support people with FASD to succeed in the workforce (see here for more information: <https://patches.com.au/fasd/>).

Priority Groups

- Objective 1: Continue to support and evaluate targeted strategies and models of care for groups who are at higher risk than the general population.
- Objective 2: Work with the criminal justice system to implement therapeutic justice interventions.

There has been some progress in this priority area, however there is still a long way to go to effectively support and manage individuals with FASD in these spaces. Notably, there have been targeted prevention campaigns and resources for specific groups, such as First Nations peoples and those in the criminal justice sector. For the former, it has been emphasised that any initiatives or resources targeting First Nations populations needs to be in consultation with First Nations communities themselves to be effective. Modifications to how the Strategic Action Plan is used and

any FASD screening/diagnostic tools needs to occur within each community to ensure it is relevant and appropriate to that community and the resources in which they have.

Recognition of FASD in the criminal justice system is lacking in many jurisdictions. WA seem to be leading the way in terms of offering FASD training to staff working in such settings and supporting referrals for FASD assessment prior to sentencing. However, there is less known about what procedures are undertaken in other jurisdictions around Australia. Question 6.4.4 and 6.4.5 in particular discuss this in more detail, noting that there are diversion programs available for people with cognitive impairment to access, however whether these are utilised by people with FASD is unclear due to FASD not being routinely screened in these settings.

5.1.2 Are there any changes in external factors outside the scope of the Strategic Action Plan that have enabled or limited the capacity to implement the Strategic Action Plan?

Overview of response:

Stakeholder interviews discussed having strong support for the Strategic Action Plan from advocates in the FASD field and in government positions, funding, and broader alcohol policies bringing the issue of FASD into the focus of public attention as enablers to implementing the Strategic Action Plan, while the COVID-19 pandemic and issues in accessing appropriate professionals in a timely manner was discussed as external factors that significantly limited capacity to implement the Strategic Action Plan.

Details:

This question was addressed through stakeholder interviews with representatives from the National FASD Advisory Group and state and territory health departments.

External enablers to implementing the Strategic Action Plan

Interviewees noted that having the support of passionate people in the FASD field and in influential government positions is crucial to promoting and implementing the Strategic Action Plan.

We need to have strong leadership from that ministerial level. We need to have strong leadership within the department. We need to make sure that a range of people have a voice in the continued implementation [of the Strategic Action Plan] if we're going to continue to see the sorts of success that we've seen.

In addition, funding was also deemed an enabler to implementing the plan. The recent funding of a consultation liaison service in SA was discussed, which provides specialist AOD support to tertiary hospitals and has facilitated increased recognition of AOD issues and referral for people with AOD issues. Through this service, clinicians are able to seek support and information to better treat their clients, therefore improving professionals' ability to confidently treat and manage cases impacted by FASD.

An improvement in the model of care used for Drug and Alcohol services in SA was also discussed. Specifically, this model of care has made pregnant women who use alcohol and other drugs a priority, with specific and timely protocols in place to support these women throughout their pregnancy to limit harms and promote healthy choices.

... that increase in service across the public sector did allow for increased visibility of drug and alcohol concerns. And it did also create greater opportunities for a referral of people attending the hospital sector. So I think that was something that perhaps improved our opportunity to influence on more of a direct patient level, rather than that bigger policy level.

Finally, national alcohol policies, including mandatory warning labels on packaged alcohol products and the national drinking guidelines, were discussed as having a positive impact on the implementation of the Strategic Action Plan in TAS by assisting in FASD being seen as a current concern in society.

External factors that may have limited capacity to implement the Strategic Action Plan

Interviewees were in agreement that the COVID-19 pandemic has slowed the progression of actions specified in the Strategic Action Plan. For example, interviewees noted that there has been less media focused on FASD, more lenient alcohol policies nation-wide, and less resources directed at FASD and into other health services instead (to help manage the pandemic).

I actually think that alcohol has probably become more accessible, particularly during COVID, because of the rapid expansion of online delivery of alcohol. And the move towards that really easy transition through the digital marketing and purchase of alcohol.

it's definitely influenced our time available to be able to focus on some of these activities. We've had times where we've had to deploy drug and alcohol staff into the mainstream health services, so reducing our service capability capacity.

The accessibility of health professionals to be able to facilitate FASD screening, diagnosis, and appropriate management was also discussed. Long wait times and limited professionals to see remains a barrier to individuals with FASD accessing the support that they need.

5.2 To what extent has the Strategic Action Plan been used by key stakeholders in the Commonwealth government, state and territory governments and the non-government organisations? What, if any, legislative and policy changes have emerged as a result of the Strategic Action Plan, e.g., in relation to recognising FASD as a disability?

Overview of response:

There have been some legislative and policy changes that influence the recognition of FASD as a disability in Australia. These include changes in alcohol pricing, promotion, access, and consumption; and specific recognition of FASD in some justice sectors. However, it is difficult to specifically state if legislative and policy changes have emerged as a result of the Strategic Action Plan.

Details:

To answer this question, legislation and policy in the areas of disability, alcohol, mental health, and justice were examined through online searches to determine their relevance to improving the recognition of FASD in Australia. In addition, contact with key stakeholders in the FASD field prompted additional insight into legislative and policy change that has impacted FASD since the Strategic Action Plan was launched in 2018.

Disability

Recommendation 21 in the report by The Senate Community Affairs References Committee (2021) states that the Australian Government should include FASD in the List of Recognised Disabilities. There has been no change to this list, which was last updated in 2014 (see here: <https://www.dss.gov.au/our-responsibilities/disability-and-carers/benefits-payments/carers-allowance/guide-to-the-list-of-recognised-disabilities>). However, it should be noted that the List of Recognised Disabilities refers to those disabilities that would always be severe enough to qualify a parent or carer for government supports. Due to the impairment/s associated with FASD being different for all people, it may be difficult to include FASD on such a list. Irrespective of this, people with FASD can still access support through the National Disability Insurance Scheme (NDIS), which recognises FASD as a permanent disability with varying functional impacts across a persons' life.

In May 2022, the NDIS updated the access lists to include FASD; specifically, FASD is now included under List B (permanent conditions for which functional capacity are variable and further assessment of functional capacity generally is required) and List D (Permanent impairment/early intervention, under 7 years - no further assessment required). Prior to this, the NDIS included 'Fetal Alcohol Syndrome' (FAS) within these access lists, however this change now provides greater clarity that people with FASD may be eligible for funding through the NDIS. This represents a positive change to recognition of FASD as a disability.

While no longer government policy, issues regarding the inclusion of independent assessments for accessing support through the NDIS, and the possibility of NDIS reforms seeing people with FASD becoming ineligible for funding, emerged in 2019. It was argued these issues could have hindered the recognition of FASD as a disability. This was formally rejected by disability ministers in July 2021, and a person-centred form of assessment for the NDIS is now being co-designed with the disability community. This is discussed in detail below in question 6.3.4.

Alcohol

There have also been a range of local and national legislative and policy changes regarding alcohol pricing (e.g., the introduction of a minimum unit price), alcohol promotion (e.g., mandatory pregnancy warning labels), access to alcohol (e.g., the Banned Drinker Register and the establishment of Police Auxiliary Liquor Inspectors), and the consumption of alcohol (e.g., prohibited areas for alcohol consumption). While these changes are relevant to reducing alcohol harms in the community, including FASD, they are not specifically a result of the Strategic Action Plan. More information about these alcohol legislative and policy changes are detailed below in question 6.1.1.

Mental health

While there has not been any legislative change regarding mental health that has resulted from the Strategic Action Plan, or directly impacted individuals with FASD and their families, there has been an increase in awareness concerning the links between FASD and mental health problems. FASD is associated with cognitive vulnerabilities that are also known to contribute to mental health conditions, with research suggesting that there is considerable overlap between the features of FASD and some mental health difficulties (Flannigan et al., 2020; McLean, 2019). For example, one review highlights that children living with a FASD diagnosis are more likely to also have comorbid mental health problems compared to children living without a FASD diagnosis (Weyrauch et al., 2017), whereby it was found that of those children living with a FASD diagnosis:

- 50.2% had a diagnosis of ADHD (10 times the expected population rate)
- 23.0% had an intellectual disability (23 times the expected population rate)
- 19.9% had a learning disorder (2 times the expected population rate)

- 16.3% had a diagnosis of oppositional defiant disorder (5 times the expected population rate)
- 14.1% had a diagnosis of depression (4 times the expected population rate)
- 12.3% had a psychotic disorder (25 times the expected population rate)
- 8.6% had a diagnosis of bipolar disorder (3 times the expected population rate)
- 7.8% had a diagnosis of anxiety (11 times the expected population rate)
- 6.0% had a diagnosis of PTSD (1.5 times the expected population rate)
- 4.9% had a diagnosis of OCD (4 times the expected population rate)
- 4.7% had a diagnosis of reactive attachment disorder (9 times the expected population rate)

Justice

There have been some legislative changes contributing to the recognition of FASD in certain settings, such as in the criminal justice sector. For example, there have been improvements to policy and procedure within the Department of Justice in Western Australia (WA), whereby FASD has been acknowledged in the procedures for persons in prison with disability as part of the Commissioner's Operating Policies and Procedures (Government of Western Australia, 2021c). Further, stakeholder interviews revealed that courts in WA and the NT can initiate a FASD assessment if they are concerned with the cognitive capacity of an individual, with the assessment report impacting the eventual sentencing and management of the person in question.

Other states and territories have procedures for persons in prison with a disability (or cognitive impairment) more generally; however, WA is leading the way with specific FASD recognition in the justice system. This is significant given the recent research in WA suggests a large proportion (over one third) of youth in prison have FASD (Bower et al., 2018). However, discussions with key stakeholders revealed cohesive, systemic changes have not yet happened. For example, no child protection jurisdictions screen for FASD, despite alcohol and drugs being the key reason for children entering care. FASD screening of young people in child protection and youth justice systems is a current recommendation of the report by The Senate Community Affairs References Committee (2021).

In addition, the Australian Capital Territory (ACT) Government recently announced their commitment to raising the age of criminal responsibility from 10 to 14 years. This was in response to the state's aspirations for providing better alternatives to children entering custody, including a more comprehensive wraparound and case management services model of care (MOC) and more options for therapeutic and restorative care. Further details, including the independent review conducted, public submissions on the discussion paper, and media releases about the proposed reform can be found elsewhere (<https://justice.act.gov.au/safer-communities/raising-age>). While this legislative change is not FASD-specific, this change may result in more young people with FASD in the ACT receiving individualised intervention rather than entering the criminal justice system, and therefore has the potential to positively impact the management and support of individuals with FASD.

There has also been a policy implemented in New South Wales (NSW), the First 2000 Days Framework (NSW Government: Health and Social Policy, 2019), that outlines the importance of a child's development in the first 2000 days (conception to age 5), and how their early development impacts their life course. Commencing on July 1st 2019, this policy requires Local Health Districts and Speciality Health Networks in NSW to include strategies within the First 2000 Days Framework in their local plans, and use the information provided in the Framework to inform local priority setting and planning against the Framework's strategic objectives. This policy is centred around staff in the

NSW health system promoting the importance of the first 2000 days to increase the likelihood of children having the best possible start to life. Whilst this policy is not specific to FASD, there is mention of alcohol consumption during pregnancy being a key risk that can be targeted within this strategy, with messaging within this policy consistent with the Australian guidelines to reduce health risks from drinking alcohol – being that there is no safe amount of alcohol consumption during pregnancy.

Taken together, while there have been changes across several domains that may have benefits for the improved recognition of FASD and continued support for individuals with FASD, the current evaluation was unable to identify any specific legislative or policy changes that directly stemmed from the Strategic Action Plan.

5.2.1 Has the Strategic Action Plan effectively promoted shared responsibility for the prevention and management of FASD between Commonwealth agencies, state and territory governments and the non-government sector?

Overview of response:

Stakeholder interviews revealed that shared responsibility for the prevention and management of FASD between Commonwealth agencies, state and territory governments and the non-government sector has not occurred. Development of an appropriate governance mechanism to better promote this shared responsibility, as well as greater communication and the opportunity for collaboration between federal and state and territory representatives were noted as ways to improve this moving forward.

Details:

This question was addressed through stakeholder interviews with representatives from the DOHAC, National FASD Advisory Group, and state and territory health departments. Interviewees were in agreement that shared responsibility for the prevention and management of FASD between Commonwealth agencies, state and territory governments and the non-government sector has, for the most part, not occurred. Further, interviewees agreed that the Strategic Action Plan creates a platform to facilitate such shared responsibility, however, more work needs to occur to see this be achieved. It was noted that a lack of governance structure has limited the ability for this shared responsibility to occur between the sectors. This issue was also acknowledged in the Review of Council of Australian Governments (COAG) Councils and Ministerial Forums (Conran, 2020) which identified key governance and process issues; recommending streamlined intergovernmental architecture to focus on key federation priorities. They recommended the disbanding of the Ministerial Drug and Alcohol Forum, noting that the items discussed would be better redirected to engagement between departmental officials. All recommendations were enacted in May 2020.

One state health department representative discussed a shared spreadsheet detailing all the activities occurring in each state and territory which helps to promote shared responsibility by keeping everyone informed of what is happening in the FASD space.

Further, interviewees discussed the role of the National FASD Advisory Group, noting that greater communication between this group and state and territory ministers and non-government representatives would be beneficial. However, representatives from the National FASD Advisory Group noted that while the Strategic Action Plan provides a good foundation to facilitate this shared responsibility between the sectors, more may need to be done to help facilitate this.

I think strengthening the communication from the outputs from the [National] FASD Advisory Group to state and territory governments would be really valuable too.

State and territory health department representatives commented that there is more communication within states rather than between Commonwealth agencies and state and territory governments. However, it was also noted that there are instances where contact between states has occurred, although this represents more one-on-one contact for a specific reason and often occurs through personal contacts rather than official inter-state communication.

In terms of how to improve this notion of shared responsibility between federal, state/territory, and local agencies moving forward, interviewees commented that greater opportunities for collaboration between Commonwealth agencies and states and territories, and greater communication between the National FASD Advisory Group and states and territories, would be beneficial. In particular, one National FASD Advisory Group member suggested that additional stipulations to FASD funding that promotes greater communication between Commonwealth agencies and state and territory governments, and the sustainability of this funding (i.e., states and territories contributing funding as well), might be a solution worth trialling.

5.2.2 Has the Strategic Action Plan contributed to the development of national, state and territory and local initiatives to eliminate or reduce stigma experienced by people living with FASD and their families?

Overview of response:

While there have not been any stigma-specific initiatives that have emerged as a result of the Strategic Action Plan, interviewees were in agreement that the plan has promoted activities that subsequently have had a positive impact on reducing the stigma experienced by people living with FASD and their families.

Having a stronger focus on FASD awareness in young people and in professionals outside of the health field, and greater engagement with people with lived experience with FASD, were noted by interviewees as ways to further improve stigma reduction efforts. FASD service providers further suggested a greater focus on improving the understanding about and awareness of FASD in First Nations communities, and ensuring that the messaging about FASD is consistent by healthcare providers nation-wide.

Details:

This question was addressed through stakeholder interviews with representatives from the DOHAC, National FASD Advisory Group, state and territory health departments, and state and territory justice departments, as well as online surveys with FASD service providers.

Stakeholder interviews

Interviewees from the DOHAC, National FASD Advisory Group, and TAS health department discussed the indirect way the Strategic Action Plan supports the reduction of stigma – through greater awareness of FASD in the community. Through FASD campaigns that aim to improve the understanding and recognition of FASD, interviewees discussed advancements in making this a topic of mainstream conversation and the positive impact this can have on stigma.

... just making the condition a little bit more familiar to people as well so that they know what it is. That can help de-stigmatise certain misconceptions.

I think that the National Action Plan has helped by naming FASD. By identifying that it's something that needs to be addressed, by committing funding, having the health minister say that this is something that he's passionate about and speaking about it consistently is very helpful. And so, I would just say, that the more we speak about it the more we would be able to address stigma.

Similarly, greater awareness and recognition of FASD from health professionals was also discussed as assisting in the reduction of stigma. One state health department representative noted that the inclusion of FASD in clinical guidelines has been beneficial to reducing the stigma associated with diagnosing FASD, while another health department representative discussed research which aimed to increase clinician's knowledge of FASD, and subsequently improved clinicians' confidence to discuss AOD issues (including FASD) with patients and thus contribute to reducing the stigma often associated with these topics. While both examples are not directly influenced by the Strategic Action Plan, this further supports interviewees comments about FASD campaigns more broadly contributing to stigma reduction via increasing knowledge and awareness of FASD.

Interviewees were in agreement that raising awareness of FASD is essential to facilitating a reduction in stigma toward FASD. However, it was noted that FASD awareness amongst young people and in professions outside the health field, such as police, represent areas that need greater focus moving forward.

... for the most part it feels as though the people who have the most awareness are the people who work in human services or where it's been targeted at a very specific community ... but in the kind of everyday conversational lexicon of regular people I don't know that the awareness is where it should be.

Finally, one interviewee mentioned that greater engagement with people with lived experience with FASD is one way to further reduce stigma in this area. It was discussed that this has been done in SA, albeit not as a result of the Strategic Action Plan, through the use of publicly available videos with people who share their experiences receiving AOD treatment.

I think a mechanism for reducing stigma would be to engage those who live with FASD in telling their own story. Rather than, for instance, a research institute or even an advocacy group telling everyone not to stigmatise people with FASD. That you have people with FASD sharing their stories and then people with FASD become someone that people are familiar with and then some of the stigma can be reduced.

We have a community advisory council, which is basically clients or carers for whom have had some involvement with the Drug and Alcohol Services in SA, that basically provide us with advice about what would be important to people who use our service. And they came up with a proposal to develop a stigma reduction campaign. I think there's four videos that have been developed where people who use substances or families of people who use substances have come together to share their experiences and they're publicly available on SA Health's website to talk about.

Online surveys

Two FASD service providers responded to this question in the online survey, noting that while there have been advancements made in “*promoting FASD as a serious issue*”, they were unsure whether the Strategic Action Plan has provided any change to the stigma associated with FASD to date.

Specifically, both respondents commented on the lack of impact that the Strategic Action Plan has in First Nations communities. One respondent noted that FASD is still frowned upon in some First Nations communities which proves to be a barrier to screening and diagnostic efforts, and that a simpler version of the plan might increase its use and its subsequent impact on stigma.

“I don’t think it has [had an impact on stigma] where I work. People don’t know about it. I don’t think Indigenous people will engage with it. If you could make a simpler visual version or even translate a simpler version into various languages would help.”

This was supported by the second respondent, who also discussed that there needs to be specific initiatives in Indigenous communities to reduce the stigma associated with FASD. This suggests that local targeted initiatives may need to be employed, specific to particular areas and populations, as more national attempts at increasing FASD awareness and promoting FASD (such as the plan) may not be as effective if they are not easily understood by at-risk communities.

“I think there is still stigma particularly in Aboriginal communities, and there needs to be open discussion with community leaders. FASD services and supports that are developed with Aboriginal health services are important because they have community buy-in. But in Vic[toria] there has been little discussion of FASD in the Aboriginal health sector and I feel there is a high degree of stigma than in other states.”

This second respondent also discussed the misconception of who FASD is likely to impact, noting that misinformation from health professionals can further perpetuate this myth and the stigma associated with such.

“There is also stigma for middle class families who are told by professionals that FASD only affects alcoholics, which doesn’t make women feel safe to disclose alcohol use. Women in Vic[toria] are still being told a drink of alcohol won’t do any harm.”

A lack of training delivered to professionals was subsequently highlighted as a key barrier to the reduction of FASD-related stigma by this second respondent, who noted that this can result in the illusion that FASD is rare and unlikely to occur.

“Lack of targeted interventions. Training promised has not been delivered ... There is still very limited information to help midwives and medical practitioners discuss alcohol in pregnancy in a non-stigmatising way ... Asking about alcohol in pregnancy is still very problematic.”

“... stigma contributes to the idea that FASD is a rare condition and unlikely to occur. Stigma also leads to professionals avoiding the topic of alcohol, or minimising it when women disclose alcohol use.”

In sum, the information provided from these two FASD service providers in the online survey is not necessarily representative of the efforts made by all service providers nation-wide, however, they do suggest that the Strategic Action Plan perhaps has not yet addressed the stigma experienced by people living with FASD and their families as strongly as other areas detailed in the plan, such as FASD prevention. These FASD service providers suggest that improving the understanding about and awareness of FASD in First Nations communities, and ensuring that the messaging about FASD is consistent by healthcare providers nation-wide, is essential to improving the stigma associated with

FASD. To do this, a stronger focus on the areas of prevention and screening/diagnosis in the Strategic Action Plan is initially necessary, which is consistent with what is currently underway (as outlined in question 5.1.1).

5.3 Is there evidence that public education and awareness raising campaigns are aligned with the advice contained in the Strategic Action Plan that focus on raising awareness about the risk of drinking in pregnancy and FASD; belief that not drinking is the safest choice and intention to not drink whilst pregnant; and increase support for women not drinking in pregnancy while minimising stigmatising the individual?

Overview of response:

Since the launch of the Strategic Action Plan in 2018, 42 (identified) FASD public education and awareness campaigns have been launched. The key messages portrayed were consistent, with many clearly specifying that there is no safe amount of alcohol consumption at any time during pregnancy, and that drinking alcohol during pregnancy can lead to FASD.

Details:

There have been several public education and awareness raising campaigns to address alcohol consumption during pregnancy launched since the Strategic Action Plan was initiated in 2018. The key method used to answer this question is the analysis of documents that have been sourced from online searches and provided within key informant interviews.

The largest campaign, which is delivered at a national level, is the National Awareness Campaign for Pregnancy and Breastfeeding Women. This 4-year campaign was developed by the FARE and endorsed and funded by the DOHAC (\$27.4 million). The campaign has four streams, targeting FASD education and awareness toward the general public (via the 'Every Moment Matters' campaign (www.everymomentmatters.org.au/), which was launched in November 2021), priority groups (including women at higher risk of alcohol exposed pregnancies), health professionals, and First Nations populations. This campaign is directly aligned with the advice contained in the Strategic Action Plan, with an aim to increase Australians' awareness of the risks associated with alcohol consumption during pregnancy and while breastfeeding (including FASD). It also aims to increase the proportion of Australians who are aware that alcohol should not be consumed during pregnancy, that it is safest not to drink alcohol when breastfeeding, and to increase the proportion of Australian women who intend to not drink any alcohol during pregnancy or when breastfeeding (Foundation for Alcohol Research and Education, 2021c).

The first stream of this national campaign, which targets the general Australian population, highlights the following key messages: alcohol at any stage of pregnancy can damage a developing baby's brain, body, and organs, and lead to FASD; alcohol increases the risk of miscarriage, stillbirth, babies being small for gestational age, having low birth weight, and being born prematurely; alcohol passes from the mother's blood to the baby's blood via the placenta; alcohol can damage the development of all the organs and systems of the developing baby's body, including the brain; the moment you start trying to get pregnant is the moment to stop drinking alcohol (Foundation for Alcohol Research and Education, 2021a). Stakeholder interviews revealed that the other three campaign streams will be released throughout 2022 by different organisations relevant to that stream (i.e., NACCHO will lead the fourth stream, which is targeting First Nations peoples).

Tables 3-6 present information regarding 15 national campaigns (Table 3) and 27 state-specific campaigns that align with advice presented in the Strategic Action Plan surrounding raising awareness about the risk of drinking in pregnancy and the prevention of FASD. Of note, campaigns launched in the NT and WA are presented in their own separate tables (Table 5 and Table 6, respectfully), while all other state-specific campaigns are presented in Table 4. This is due to there being a greater amount of campaigns in the NT and WA compared to other states, therefore summarising these two states in separate tables assists with readability. The overarching message that is consistently conveyed across these campaigns is that there is no safe amount of alcohol at any time during pregnancy, while many campaigns also include reference to alcohol consumption not being safe when planning a pregnancy or breastfeeding. Other key topics/messages include increasing knowledge of FASD and how to prevent it, emphasising the importance of partners, families, and communities in helping women achieve alcohol-free pregnancies, and reducing stigma associated with FASD. Most campaigns targeted women who are pregnant, breastfeeding, or planning a pregnancy; however, there were also campaigns directed to the general public and health professionals. There were also many campaigns for First Nations women who are pregnant or planning a pregnancy and their communities, which feature key information from the Strategic Action Plan delivered in a culturally accessible format.

Table 3.

An Evaluation of National Public Education and Awareness Campaigns in Reference to the Strategic Action Plan by Date of Implementation

Campaign name	Who launched it/who funded it?	Timeline	Target population	Overview and aim of campaign	Key messages of campaign	Detail whether the campaign aligns with advice in the SAP (see notes for what A-C stands for)	Setting/method of promotion	Resources included with the campaign
FASD awareness day	Launched: NOFASD Funded: DOHAC	1999-current	General population	Aim: provide information about the risks of alcohol consumption during pregnancy Examples of events conducted include: - Monash Children's Hospital launch of the VicFAS FASD clinic, seminar for child protection workers in Dandenong (VIC), and FASD awareness event in Bendigo (regional VIC) (Link) - NYPC Women's Council FASD awareness breakfast, in-service training event and awareness workshops. - Red Shoes Rock campaign (Link)	There is no safe amount of alcohol that can be consumed during pregnancy The whole community is responsible for supporting alcohol free pregnancies	A: discusses alcohol-related harms and FASD B: key message across initiatives is that no amount of alcohol is safe C: increases support and reduces stigma	Multiple platforms including social media as well as in person at various events (when allowed).	NOFASD Australia provides materials for hosting FASD awareness events Information pack
Women Want to Know	Launched: DOHAC and FARE Funded: DOHAC	Program was first initiated in 2014, however there have been resources added recently (2018-2019)	Women who are planning a pregnancy, are pregnant, and health professionals	Overview: provides information about alcohol and pregnancy, breastfeeding, or planning a pregnancy; dispels myths about pregnancy and alcohol; provides guides for health professionals to have conversations about alcohol use with patients; discusses how misinformation impacts the choices of women who are pregnant Aim: help ensure women have the right advice they need to give their baby the best start in life; give professionals the skills and knowledge they need to discuss alcohol and pregnancy with women (Link)	There is no safe amount of alcohol use during pregnancy It is never too late to stop drinking	A: discusses FASD and alcohol-related harms B: no amount of alcohol is safe C: increases support and reduces stigma	DOHAC website FARE website	Brochures and posters about pregnancy and alcohol Various videos discussing pregnancy and alcohol

Pregnancy and alcohol poster	Launched: DOHAC and FARE Funded: DOHAC	2018	General population	Overview: part of the Women Want to Know campaign. When planning a pregnancy, experts advise that no amount of alcohol is safe Aim: to raise awareness of alcohol-related harms (Link)	Alcohol in pregnancy: no safe amount, no safe time, no safe type	A: does not mention FASD but mentions alcohol-related harms B: no safe amount or type C: limited support and reduction of stigma	Poster is available to be ordered	Poster
Fetal Alcohol Spectrum Disorder Awareness Program	Launched: DrinkWise Funded: DOHAC, Australian Grape & Wine, Lion, Coca-Cola Amatil, Coopers and Cub	2018-2020	Women who are planning a pregnancy, are pregnant, or breastfeeding	Aim: increase community awareness and understanding of FASD by supporting two educational advertisements which feature Deborah Mailman and Aaron Pedersen (First Nations actors) (Link)	If mum drinks so does the baby Drinking alcohol in pregnancy can lead to FASD	A: discusses FASD and alcohol-related harms B: not drinking alcohol is the safest choice C: increases support and reduces stigma	YouTube	Short educational videos, brochures, posters Extended versions produced for school programs

Pregnancy and Alcohol: The Surprising Reality	Launched: NOFASD Funded: NA	2019-2021	General population	Podcast series includes 25 episodes Key topics include: - alcohol in pregnancy - alcohol guidelines - impacts of FASD and how to prevent it - dismantling stigma and misinformation - examples of lived experience with FASD - importance of community support - experts from NOFASD Australia, FASD clinics, and GPs (Link)	There is no safe amount of alcohol use during pregnancy	A: discusses FASD and raises awareness of alcohol-related harms B: no amount of alcohol is safe C: increases support and reduces stigma	NOFASD Australia webpage	Podcast audio clips ranging from 20-50 minutes
Australian Guide to the Diagnosis of FASD: e-learning modules	Launched: University of Sydney, Telethon Kids Institute Funded: DOHAC	2019	Health professionals	Aim: provide health professionals with an understanding of risks of alcohol consumption in pregnancy, information needed for diagnostic assessment, general principles for discussing diagnoses, supporting families, and improving understanding of referral and screening criteria for FASD (Link)	Improving the knowledge of health professionals is key to achieving alcohol free pregnancies	A: discusses FASD and alcohol-related harms B: cannot be determined C: increases support	FASDhub webpage	e-learning modules
Information You Might Not Know About Pregnancy and Alcohol	Launched: Australian Government DOHAC Funded: NA	2020	General population	Overview: brochure provides information about the effects of alcohol consumption during pregnancy fertility of men and women - developmental harms and FASD - impact of alcohol during breastfeeding	To prevent harm from alcohol to an unborn child Women who are pregnant or planning a pregnancy should not drink alcohol	A: discusses FASD and alcohol-related harms B: no amount of alcohol is safe C: increases support and reduces stigma	DOHAC website (Link)	Brochure

Australian Guidelines to Reduce Health Risks from Drinking Alcohol	Launched: National Health and Medical Research Council (NHMRC) Funded: The DOHAC and NHMRC	2020	Women who are planning a pregnancy, are pregnant, or breastfeeding	Aim: increase awareness of alcohol-related harms during pregnancy (guideline three) Overview: provides an evidence-based overview of the literature surrounding the alcohol use during pregnancy and the associated risk of harm to a foetus or baby that is being breastfed. Emphasises that the risk of harm to foetus increases the more a mother drinks (Link)	There is no safe amount of alcohol that pregnant women or breastfeeding mothers can drink	A: discusses FASD and alcohol-related harms B: conveys no amount of alcohol is safe C: increases support and reduces stigma	NHMRC website	PDF of the guidelines Evaluation report
The Alcohol and Drug Foundation Fetal Alcohol Spectrum Disorder Mini bulletin	Launched: The Alcohol and Drug Foundation Funded: NA	2020 (last updated 2021)	People planning a pregnancy and health professionals	Aim: to covers characteristics and diagnosis, impacts of FASD Overview: explains FASD and related deficits, and the harms created by alcohol consumption	Women need support from partners, families, friends and healthcare and social service providers to avoid alcohol when planning a pregnancy, and during pregnancy	A: discusses alcohol-related harms and FASD B: alcohol must be avoided entirely C: increases support and reduces stigma	Alcohol and Drug Foundation Website YouTube	FASD Mini Bulletin and a 60 second video (Link)

Your Healthy Pregnancy	Launched: DOHAC Funded: NA	2021	General population	Aim: to explain how to eat well and stay active to support a healthy pregnancy Overview: as a part of the three steps for a healthier pregnancy, the foods to avoid section states women should not drink alcohol but does not mention why it is important (Link)	Keeping yourself and your baby healthy during pregnancy starts with 3 steps: eat well, stay active, and ask for support	A: FASD is not mentioned B: advice provided is to not drink alcohol C: increases support and reduces stigma	DOHAC Website YouTube	Brochure Preparing for healthy pregnancy factsheet Nutrition advice factsheet Supporting someone who is pregnant factsheet
Every Moment Matters	Launched: FARE Funded: DOHAC	2021	People planning a pregnancy, pregnant women	Aim: to provide alcohol-related education Overview: Alcohol should be avoided entirely during pregnancy Any alcohol consumed when pregnant passes directly to the developing baby and can damage their brain body and organ. Can lead to FASD (Link)	The moment you start trying is the moment to stop drinking	A: mentions FASD and alcohol-related harms B: no alcohol is the safest option C: increases support and reduces stigma	FARE website - Includes additional information sections, one for health professionals and one for women who are pregnant or planning a pregnancy	Video Links to the pregnancy guidelines, breastfeeding guidelines, support options
Review of Fetal Alcohol Spectrum Disorder (FASD) among Aboriginal and Torres Strait Islander people	Launched: University of Sydney and Telethon Kids Institute Funded: DOHAC	2021	First Nations peoples	Aim: to review key information regarding FASD among First Nations peoples in Australia - health impact of FASD - historical, social, and cultural context - prevention and management - relevant programs - possible future directions (Link)	To raise awareness of FASD within First Nations populations through increased education and prevention	A: discusses FASD and alcohol-related harms B: key message delivered is that no amount of alcohol is safe C: increases support and reduces stigma	Video is posted on YouTube Factsheet can be found on Australian Indigenous Health/ <i>InfoNet</i>	Educational video Factsheet (Link)

Russell Family Fetal Alcohol Disorders Association FASD Prevention	Launched: Russel Family Fetal Alcohol Disorders Association (RFFADA) Funded: NA	2021	People who are planning a pregnancy, are pregnant, or living with FASD	Aim: to promote prevention of FASD and ensure that individuals at risk of FASD, or living with FASD, have access to diagnostic services and support Overview: features a range of FASD resources that range from discussing alcohol use in pregnancy to managing FASD (Link)	No alcohol when planning a pregnancy, during pregnancy, and while breastfeeding means no risk	A: raises awareness of FASD and alcohol-related harms B: key message is that no amount of alcohol is safe C: increases support and reduces stigma	RFFADA website and YouTube	Educational videos and international conferences
Alcohol Treatment Guidelines	Launched: A range of experts in the field of alcohol Funded: Australian Government	2021	Health professionals	Aim: to provide up-to-date, evidence-based information to clinicians on available treatments for people with alcohol problems. Overview: regarding alcohol and pregnancy, the guidelines provide clinicians with information about screening and intervention, withdrawal, treatment, and FASD (Link)	Not drinking alcohol when planning a pregnancy, when pregnant, and when breastfeeding is the safest option	A: raises awareness of FASD and alcohol-related harms B: key message is that no amount of alcohol is the safest option C: increases support	Online via the alcohol treatment guidelines website	PDF of the guidelines
NOFASD Educational Workshops	Launched: NOFASD Funded: DOHAC	2022	General population and health professionals	Aim: to deliver education and training to a wide range of audiences across Australia. The content and format of workshops is tailored according to the level of knowledge in the group and identified interests. Also includes: webinars about managing alcohol use in pregnancy as a practitioner strategies for responding to and supporting clients (Link)	Health professionals must advise and support women to achieve alcohol-free pregnancies	A: raises awareness of FASD and alcohol-related harms B: not stated C: increases support	Online via NOFASD	Webinars, training classes and workshops

Notes. NA refers to information that was not publicly available. A = Raising awareness about the risk of drinking in pregnancy and FASD; B = Belief that not drinking is the safest choice and intention to not drink whilst pregnant; C = Increase support for women not drinking in pregnancy while minimising stigmatising the individual

Table 4.

An Evaluation of Public Education and Awareness Campaigns in the ACT, NSW, QLD, TAS, and VIC, in Reference to the Strategic Action Plan by Date of Implementation

Campaign name (state/territory)	Who launched it/who funded it?	Timeline Target population	Overview and aim of campaign	Key messages of campaign	Detail whether the campaign aligns with advice in the SAP (see notes for what A-C stands for)	Setting/method of promotion	Resources included with the campaign
Pregnant Pause campaign (ACT)	Launched: FARE Funded: NA	2016- 2021	Community members and organisations (to create supportive environments for mums to be to go alcohol free)	Aim: raise awareness of the advice that no amount of alcohol is safe for an unborn baby to help reduce the number of alcohol-exposed pregnancies. Overview: to support women who are pregnant to not drink during pregnancy and create a community of support for mums-to-be (Link) (Link)	There is no safe amount, no safe time, and no safe type of alcohol during pregnancy. A: discusses alcohol harms but not FASD B: ad directly states it is safest to not drink any alcohol C: increases support and decreases stigma	30 second ad via Vimeo for be a hero take zero Instagram (Last social media activity was June 2021)	Community Heroes pack of resources
Alcohol. The facts (NSW)	Launched: NSW Ministry of Health and St Vincent's Alcohol and Drug Information Funded: NA	Originally developed in 2014, last updated in 2021	General population	Aim: discusses the short and long-term effects of alcohol, including during pregnancy, in reference to the Australian National Health and Medical Research Council Guidelines Overview: broadly provides information on reducing health risks	The safest option for women who are trying to get pregnant, who are pregnant, or who are breastfeeding is not to drink alcohol A: discusses FASD and alcohol-related harms B: there is no safe amount of alcohol C: reduces stigma but does not discuss support option	Booklet can be downloaded online, or 20 hardcopies can be ordered	Booklet

Campaign name (state/territory)	Who launched it/who funded it?	Timeline Target population	Overview and aim of campaign	Key messages of campaign	Detail whether the campaign aligns with advice in the SAP (see notes for what A-C stands for)	Setting/method of promotion	Resources included with the campaign
Stay Strong and Healthy Facebook Campaigns (NSW)	Launched: NSW Ministry of Health and St Vincent's Alcohol and Drug Information Funded: NA	2021 Women who are planning a pregnancy or pregnant, their partners and families	Aim: to raise awareness by postings a range of information about FASD. Overview: includes facts about the prevalence of alcohol consumption during pregnancy, information about FASD, advice for how to say no to alcohol and links for further information	Stay strong by saying no to grog during pregnancy	A: discusses FASD and describes the impact of alcohol B: have no alcohol when planning a pregnancy or pregnant C: increases support and reduces stigma	Stay Strong and Healthy Facebook page Last Facebook post was on FASD Awareness Day 2021	No resources, just social media posts
Queensland Mental Health, Alcohol and Other Drugs Strategic Plan 2018-2023 (QLD)	Launched: Queensland Government Funded: NA	2018 General public	Aim: to convey how alcohol consumption is common among Australian women of childbearing age. Overview: acknowledges that awareness, prevention and early intervention for FASD well before the point of conception and over the life course is required	Problematic alcohol use can have a significant impact on the health and wellbeing of an individual as well as their family and broader community	A: FASD is mentioned and alcohol-related harms B: not present C: not present	Queensland Government webpage	Strategy document (Link)
Drug Education Network (DEN): Fetal Alcohol Spectrum Disorder Prevention (TAS)	Launched: Drug Education Network (DEN) Funded: NA	First developed in 2017, lasted updated in 2021	Women who are pregnant Aim: to prevent FASD in Tasmania through a variety of campaigns and resources Overview: a key focus was to engage with dads-to-	No alcohol in pregnancy is the safest choice	A: does not mention FASD but mentions alcohol-related harms B: no amount of alcohol is safe	Available to be ordered online through DEN website	Postcards and posters

Campaign name (state/territory)	Who launched it/who funded it?	Timeline Target population	Overview and aim of campaign	Key messages of campaign	Detail whether the campaign aligns with advice in the SAP (see notes for what A-C stands for)	Setting/method of promotion	Resources included with the campaign
			be, and friends who can support pregnant mums to be alcohol free (Link)		C: increases support and reduces stigma		
Using Alcohol During Pregnancy and Breastfeeding (VIC)	Launched: The Women's (the Royal Women's Hospital) Funded: NA	2021 Women who are pregnant or breastfeeding	Aim: provide information about alcohol, pregnancy, and FASD Overview: information about alcohol counselling during pregnancy and links to additional services, and information for women with ongoing drinking problems (Link)	There are no known safe levels of alcohol use in pregnancy. It is safest to stop drinking alcohol before you get pregnant	A: discusses FASD and raises awareness alcohol-related harms B: states there is no safe amount of alcohol C: increases support and reduces stigma	Royal Women's hospital website	Factsheet

Notes. NA refers to information that was not publicly available. A = Raising awareness about the risk of drinking in pregnancy and FASD; B = Belief that not drinking is the safest choice and intention to not drink whilst pregnant; C = Increase support for women not drinking in pregnancy while minimising stigmatising the individual

Table 5.

An Evaluation of Public Education and Awareness Campaigns in the NT, in Reference to the Strategic Action Plan by Date of Implementation

Campaign name	Who launched it/who funded it?	Timeline	Target population	Overview and aim of campaign	Key messages of campaign	Detail whether the campaign aligns with advice in the SAP (see notes for what A-C stands for)	Setting/method of promotion	Resources included with the campaign
No safe amount - the growing brain	Launched: Indigenous Community Television under the NPY council The Growing Brain campaign Funded: NA	2018	First Nations women	Aim: to promote awareness about some of the dangers of alcohol Overview: provides personal stories regarding FASD and drinking during pregnancy	Drinking any amount of alcohol during pregnancy is not safe for the baby	A: discusses alcohol harms but not FASD B: video conveys the message that there is no safe amount of alcohol C: may not decrease stigma or increase support	Indigenous Community Television (Link)	Short video recommended to be included in health promotion campaigns
NT Health Facebook campaign	Launched: NT Health Funded: NA	2018	Women who are pregnant	Aim: to raise awareness that when a pregnant woman drinks, so does the baby. Overview: FASD is a preventable, lifelong condition	No alcohol is safe during pregnancy	A: discusses FASD and alcohol-related harms B: no amount of alcohol is safe C: support conveyed	NT Health Facebook page	Link to social media resource 1 Link to social media resource 2

Campaign name	Who launched it/who funded it?	Timeline	Target population	Overview and aim of campaign	Key messages of campaign	Detail whether the campaign aligns with advice in the SAP (see notes for what A-C stands for)	Setting/method of promotion	Resources included with the campaign
Making FASD History: A multisite prevention program (MFH Program)*	Launched: Telethon Kids Institute Funded: DOHAC	2018-2020	Women who are pregnant	<p>Aim: to increase sustainability and the capacity of local health services for FASD prevention based on the Marulu strategy (community led intervention program), targeting community health promotion and workforce education/training</p> <p>Overview: initiatives implemented in New Castle and Alice Springs that focus on FASD prevention through alcohol use in pregnancy training and education</p> <ul style="list-style-type: none"> - Improved referral pathways - Community education activities <p>(Link)</p>	There are risks associated with alcohol consumption for pregnant women	<p>A: explains alcohol-related harms and FASD</p> <p>B: materials include the message that there is no safe amount of alcohol</p> <p>C: decreases stigma and increases support</p>	Alice Springs and New Castle, TV, radio	Media (tv, radio), posters, booklets, information sheets, workshops

Campaign name	Who launched it/who funded it?	Timeline	Target population	Overview and aim of campaign	Key messages of campaign	Detail whether the campaign aligns with advice in the SAP (see notes for what A-C stands for)	Setting/method of promotion	Resources included with the campaign
Addressing Fetal Alcohol Spectrum Disorder (FASD) in the Northern Territory 2018-2024	Funded: Northern Territory Department of Health Launched: Northern Territory Department of Health	2019	Adolescents, women of childbearing age, youth in juvenile justice settings	Aim: to increase community knowledge of FASD Overview: promote positive health messages to increase health enhancing behaviour amongst childbearing population and avoid alcohol during pregnancy. Encourage collaboration and the creation of local network groups and partnerships (Link)	To raise awareness of FASD and implement proactive methods to ensure women at risk are connected to appropriate services to prevent the occurrence of FASD	A: discusses alcohol-related harms and FASD B: not drinking is the safest option C: increases support and decreases stigma	Northern Territory Department of Health Website	Strategy document
Healthy Pregnancy, Healthy Baby	Launched: Northern Territory Government's Closing the Gap of Indigenous Disadvantage Funded: NA	2019	First Nations women and their families	Aim: to provide information about antenatal care and tests, healthy lifestyle choices during pregnancy, labour and birth options, and being a new parent Overview: approaches pregnancy health in a holistic way and emphasises the benefits of a healthy pregnancy, provides tips for stopping alcohol use (Link)	Not drinking while pregnant is the safest option	A: explains alcohol-related harms and FASD B: contains message that drinking any amount of alcohol is not safe C: increases support and decreases stigma	NT Health website	Booklet
NT Health FASD social media campaign	Launched: NT Health Funded: NA	2019	Women who are pregnant, planning a pregnancy, breastfeeding	Aim: to raise awareness of, and increase community responsibility for, supporting alcohol-free pregnancies (Link)	No amount of alcohol is safe during pregnancy	A: mentions FASD and alcohol-related harms	NT Health Facebook page	No resources - social media post

Campaign name	Who launched it/who funded it?	Timeline	Target population	Overview and aim of campaign	Key messages of campaign	Detail whether the campaign aligns with advice in the SAP (see notes for what A-C stands for)	Setting/method of promotion	Resources included with the campaign
						B: no amount of alcohol is safe C: increases support and reduces stigma		
Yarning about alcohol and pregnancy*	Launched: New South Wales Ministry of Health And Northern Territory Department of Health Funded: NA	2019	First Nations peoples	Aim: provide information about the risks of drinking alcohol during pregnancy and strategies to support women to not drink Overview: promotes the availability of professional services to support women in not drinking alcohol during pregnancy and the role family and friends play in supporting a pregnant woman (Link)	No amount of alcohol is safe when pregnant or breastfeeding It is never too late to stop drinking during pregnancy	A: discusses harms of alcohol consumption and FASD B: no amount of alcohol is safe C: encourages support and reduces stigma	NSW Your Room website	Booklet
NT Health: No alcohol is safe during pregnancy campaign	Launched: NT Health Funded: NA	2020	Women who are pregnant, breastfeeding, or planning a pregnancy, their friends, families, and communities	Aim: to create awareness that FASD is a lifelong condition which is entirely preventable. Overview: everyone is responsible for supporting women not to drink alcohol when pregnant, planning a pregnancy or breastfeeding (Link)	No alcohol is safe during pregnancy	A: mentions FASD and alcohol-related harms B: no amount of alcohol is safe C: increases support and reduces stigma	NT Health Facebook page	Social media post and video depicting a pregnant woman and alcohol with a large X over the alcohol
FORWAARD Aboriginal	Launched: FORWAARD	2020-2021	Women who are pregnant	Aim: to support pregnant women who struggle with	Empowering women is	A: not mentioned	Five residential places in the	Clients have the assistance if a

Campaign name	Who launched it/who funded it?	Timeline	Target population	Overview and aim of campaign	Key messages of campaign	Detail whether the campaign aligns with advice in the SAP (see notes for what A-C stands for)	Setting/method of promotion	Resources included with the campaign
Corporation Pregnancy Program	Aboriginal Corporation Pregnancy Program Funded: NA			substance misuse use Overview: this program provides up to five residential places and offers clients with AOD awareness program as well as antenatal support throughout their pregnancy It finished in June 2021 and became the Women's Support Program (Link)	important for reducing the use of alcohol during pregnancy	B: not mentioned C: not mentioned	FORWAARD rehabilitation centre	multi-disciplinary and multi-agency program
Vision, future, cycle and effect: A community life course approach to prevent prenatal alcohol exposure in central	Launched: Aboriginal Community Controlled Health Service health promotion team Health Promotion Journal of Australia Funded: DOHAC	2020 (evaluated in 2021)	First Nations women in Alice Springs who are pregnant, planning a pregnancy or breastfeeding, their partners and families	Aim: to develop a health promotion campaign to prevent prenatal alcohol exposure Overview: four health promotions TV commercials to address alcohol use, prenatal alcohol exposure, and FASD. These were reviewed by an expert panel (including FASD researchers) and via six yarning sessions with community members from Alice Springs (Link)	Drinking grog when pregnant can cause Foetal Alcohol Spectrum Disorder (FASD). Grog during and after pregnancy is No Good for Dad, Mum and Bub	A: discusses FASD and alcohol-related harms B: there is no safe amount of alcohol during pregnancy or while breastfeeding C: increases support and reduces stigma	TV and radio	Commercials on TV and radio
Grog in pregnancy videos	Launched: Katherine West Health Board	2021	First Nations peoples	Aim: to improve the health and wellbeing of individuals in a culturally secure way	If mum drinks while pregnant the baby can be born with FASD	A: mentions risk of drinking and FASD	YouTube Australian Indigenous	3 videos. One targeting men , one targeting partners , and

Campaign name	Who launched it/who funded it?	Timeline	Target population	Overview and aim of campaign	Key messages of campaign	Detail whether the campaign aligns with advice in the SAP (see notes for what A-C stands for)	Setting/method of promotion	Resources included with the campaign
	Funded: NA			Overview: Videos act as an educational resource for explaining FASD and how to prevent it in a culturally accessible way (Link)	Men can support women who are pregnant by not drinking If you are breastfeeding, you should not drink alcohol	B: no amount of alcohol is safe C: increases support without stigmatising the individual	HealthInfoNet website	one targeting women .
NT Health social media post- Every moment matters Alcohol Guideline: Pregnancy	Launched: NT Health, FARE Funded: DOHAC	2022	Women who are pregnant or planning a pregnancy	Aim: to advise of Australian alcohol guidelines advise Overview: raise awareness of FASD (Link) NT Health post contains a link to further information on the FARE website	Every moment matters when it comes to ensuring a mum and developing are healthy and well	A: discusses FASD B: advice is to not drink any alcohol C: increases support and reduces stigma	Social Media post by NT Health, shared the FARE poster on Facebook	Facebook post

Notes. NA refers to information that was not publicly available. * refers to campaigns that were run in both the NT and NSW

A = Raising awareness about the risk of drinking in pregnancy and FASD; B = Belief that not drinking is the safest choice and intention to not drink whilst pregnant; C = Increase support for women not drinking in pregnancy while minimising stigmatising the individual

Table 6.

An Evaluation of Education and Awareness Campaigns in WA, in Reference to the Strategic Action Plan by Date of Implementation

Campaign name	Who launched it/who funded it?	Timeline	Target population	Overview and aim of campaign	Key messages of campaign	Detail whether the campaign aligns with advice in the SAP (see notes for what A-C stands for)	Setting/method of promotion	Resources included with the campaign
FASD Prevention Program	<p>Launched: Ord Valley Aboriginal Health Service (OVAHS)</p> <p>Funded: Originally through the Miriwung Gajerrong Ord Enhancement Scheme, now funded by the Council of Australian Governments</p>	2011-current	First Nations women who are pregnant, of childbearing age, and their family	<p>Aim: to educate the community about alcohol consumption during pregnancy</p> <p>Overview: promote awareness of the long-term effects of alcohol and alcohol-free pregnancies (Link)</p>	No amount of alcohol is safe during in pregnancy	<p>A: raises awareness of alcohol-related harms but not specifically FASD</p> <p>B: no amount of alcohol is safe</p> <p>C: increases support and reduces stigma</p>	Resources displayed at places frequently visited by the community such as OVAHS clinics, local hotels, schools, picture theatre, and supermarkets	Community education programs and resources
What Our Women need to know about alcohol. Strong Spirit Strong Mind	<p>Launched: Strong Spirit Strong Mind Aboriginal Programs and the Government of Western Australia Mental Health Commission</p> <p>Funded: NA</p>	2019	First Nations women living in Western Australia	<p>Aim: to provide culturally appropriate information on the use of alcohol</p> <p>Overview: describes how alcohol use affects the body, the harmful effects of drinking alcohol while pregnant, references the alcohol guidelines, and how to get help and information (Link)</p>	Alcohol can weaken your spirit, connections with community, family, and country	<p>A: discusses alcohol related harms but not FASD</p> <p>B: there is no safe amount of alcohol or other drug use in pregnancy</p> <p>C: increases support and decreases stigma</p>	Strong Spirit Strong mind website	Pamphlet

Campaign name	Who launched it/who funded it?	Timeline	Target population	Overview and aim of campaign	Key messages of campaign	Detail whether the campaign aligns with advice in the SAP (see notes for what A-C stands for)	Setting/method of promotion	Resources included with the campaign
Making FASD History	<p>Launched: Rotary Clubs WA, PATCHES, Telethon Kids Institute</p> <p>Funded: Healthway, Children's Orchard foundation, Minara Community Foundation, Stan Perron Foundation, Goldfields Australia Foundation, Rotary International Global Grant, and a range of other rotary clubs provided sponsorships</p>	2019-2021	First Nations peoples in Fitzroy Valley, Kimberly, Pilbara, Leonora and Perth	<p>Aim: to improve the capacity of local health services and enable communities to continue with FASD prevention activities</p> <p>Overview: intervention model was developed, offering a unique approach that crossed traditional service boundaries, co-ordinating local community, health, disability, child protection, education, police and justice to achieve results (Link)</p>	FASD is a lifelong condition caused by consumption of alcohol whilst pregnant, resulting in permanent brain damage for the infant	<p>A: discusses FASD and alcohol-related harms</p> <p>B: not specified</p> <p>C: increases support and decreases stigma</p>	Promotional video on Vimeo Link	Diagnosis research, treatment program, and community educational program
The Bigiswun Kid Project	<p>Launched: University of Sydney Telethon Health Institute, Marninwarntikura Fitzroy Women's Resource Centre</p> <p>Funded: Lowitja Institute grant, Ian Potter Foundation Grant FASD Research Centre of Research</p>	2019-current	First Nations adolescents	Aim: help with the rollout of the NDIS, provide training in how to use the FASD guidelines to diagnose adolescents and adults, and determine whether the assessment criteria for FASD children needs to be adapted for adolescents and adults.	Alcohol use in pregnancy causes harm	<p>A: discusses alcohol-related harms and FASD</p> <p>B: conveys no amount of alcohol is safe</p> <p>C: increases support and decreases stigma</p>	<p>Fitzroy valley</p> <ul style="list-style-type: none"> - In person workshops and training 	<p>Workshops for young people, training for health professionals</p> <p>Radio broadcast available Link</p>

Campaign name	Who launched it/who funded it?	Timeline	Target population	Overview and aim of campaign	Key messages of campaign	Detail whether the campaign aligns with advice in the SAP (see notes for what A-C stands for)	Setting/method of promotion	Resources included with the campaign
	Excellence Australian Rotary Health, Ian Potter Foundation, University of Sydney			Overview: as of 2021, the study has been seeking the concerns and opinions of parents and carers involved in the study and assisting them with finding support (Link)				
Alcohol. Think Again 'One Drink' campaign	Launched: Mental Health Commission (MHC) and Cancer Council Western Australia as a part of the Preventing Foetal Alcohol Spectrum Disorder (FASD) Project led by MHC Funded: NA	2021-2022	Women and men within Western Australia (18 to 44 years)	Aim: increase the proportion of the Western Australian community who are aware that there is no safe amount or time to drink alcohol when pregnant (Link)	Women who are pregnant or planning pregnancy should not drink alcohol	A: discusses alcohol harms but not FASD B: no amount of alcohol is safe C: may not increase support and may increase stigma	Media (tv commercials, catch up tv, cinema, radio online, mainstream and social media) Within the community (outdoor advertising, GPs)	Community toolkit, posters, flyers, tv commercials, radio commercials, factsheet TV commercials and radio commercials (Link)
Fetal Alcohol Spectrum Disorder (FASD) training	Launched: Government of Western Australia Mental Health Commission Funded: Government of Western Australia Mental Health Commission	2022	Health professionals and service providers	Aim: to provide an overview of the complexities of alcohol use during pregnancy Overview: covers reflective practice, trauma informed care and practice, motivational interviewing, FASD prevention in context of	There is no safe amount of alcohol- use during pregnancy	A: discusses FASD and alcohol-related harms B: cannot be determined from available info C: cannot be determined from available info	Government of Western Australia Mental Health Commission online First Nations focused training offered in Perth	Virtual training Face-to-face training (can register online)

Campaign name	Who launched it/who funded it?	Timeline	Target population	Overview and aim of campaign	Key messages of campaign	Detail whether the campaign aligns with advice in the SAP (see notes for what A-C stands for)	Setting/method of promotion	Resources included with the campaign
				the National Strategic Action Plan, and brief interventions using the AUDITC-C and Five AS, useful resources for ease in recalling training info (Link)				

Notes. NA refers to information that was not publicly available. A = Raising awareness about the risk of drinking in pregnancy and FASD; B = Belief that not drinking is the safest choice and intention to not drink whilst pregnant; C = Increase support for women not drinking in pregnancy while minimising stigmatising the individual

5.4 Has the national Strategic Action Plan supported or influenced improved data on prevalence, evaluation of new therapies and novel diagnostics, improved outcome measurement for individuals with FASD and their families, evaluation of FASD guidelines and tools targeting professionals, the conduct of health economic modelling of the impact of FASD, and new interventions for prevention and management of FASD?

To answer this question, an analysis of documents, survey responses from FASD researchers ($n = 4$), and stakeholder interviews with representatives from the DOHAC, National FASD Advisory Group, and state and territory health departments were conducted. In addition, an overview of the funding provided to support FASD research and activities in Australia since the Strategic Action Plan was launched will be provided to demonstrate how the Australian Government is supporting advancements in FASD research in Australia.

5.4.1 Improved data on prevalence

Overview of response:

The prevalence of FASD is difficult to determine, however funding to expand diagnostic services and the ability of professionals conducting accurate diagnoses is a good first step. Further, the FASD register is a key initiative to help monitor FASD prevalence trends in Australia.

Details:

The Strategic Action Plan identifies the continuation of national surveillance and maintenance of the FASD register to monitor trends and outcomes of FASD as a priority. Specifically, the Strategic Action Plan states that this will enable the collection of epidemiological data and the monitoring of prevalence trends and prognosis. The Australian Government has committed funding to support the FASD register until 2025, which has supported the ability of researchers to obtain improved data on FASD prevalence. Further information about the FASD register can be found in question 6.2.7. Of note, additional funding has been provided to support the running and expansion of FASD diagnostic services, which also assists in improving prevalence data in Australia. An overview of the funding provided since the launch of the Strategic Action Plan is detailed in Table 7 below.

Online surveys

Of the four FASD researchers who completed the online survey two (ACT and WA) specified that the Strategic Action Plan has supported them to acquire better, or more accurate, FASD prevalence data in their research. Specifically, one researcher (WA) discussed using the Strategic Action Plan to create a National FASD prevalence study with a particular focus on co-design, collaborating with First Nations peoples and culturally and linguistically diverse groups. The other researcher (ACT) specified that the tools and methods noted in the Strategic Action Plan have helped specify how to gain better data, which can then be applied to their work.

Stakeholder interviews

One interviewee noted that they were not aware of any formal evaluations concerning FASD prevalence as a result of the Strategic Action Plan. However, the difficulty of being able to obtain accurate prevalence data was also discussed. Factors such as improved diagnosis across healthcare services and a FASD register that is utilised by all relevant practitioners were mentioned as essential steps to being able to obtain improved data on prevalence in the future.

... until you've got a really robust diagnosis happening from primary care through to specialist services and a register that's operating everywhere, you're never going to really be able to pick up everything.

Further, another interviewee highlighted that FASD funding requires recipients to report the number of people with FASD assessed (i.e., to the FASD registry), which helps to improve data on the prevalence of FASD in Australia.

A positive thing about receiving a government grant is that there are requirements in there for you to report on your number of cases assessed, the number of diagnoses made ... so I think it's been a sensible and effective approach to improving our data on prevalence.

5.4.2 Evaluation of new therapies and novel diagnostics

Overview of response:

There is limited detail about novel therapies for FASD to date, however some research has been examining the role of executive functioning and parenting programs. More has been done in terms of novel ways to diagnose FASD, with research examining culturally sensitive approaches that can be used in remote and First Nations communities. This is important, as such settings typically have limited access to specialists and health professionals.

Details:

New therapies

Of the four FASD researchers who completed the online survey, one (ACT) noted that the Strategic Action Plan has supported their evaluation and use of new FASD therapies. However, detail was not provided from this respondent regarding how the Strategic Action Plan has specifically influenced such.

Further, one interviewee mentioned that there has been some research into therapies involving executive functioning and parenting programs, including the Alert Program. However, progress in this area seems to be limited. This was reiterated by another interviewee, who noted that there were not any new therapies or novel ways to diagnose FASD as a result of the Strategic Action Plan that they were aware of.

Novel diagnostics/tools targeting professionals

Of the four FASD researchers who completed the online survey, two (ACT and WA) noted that the Strategic Action Plan has supported them to evaluate novel FASD diagnostic ideas or tools. One researcher (WA) explained this in more detail, noting that they are *"looking at the use of epigenetic changes as a biomarker of PAE [prenatal alcohol exposure] to help with the much-needed screening and diagnosis of FASD"*. This is especially important in situations where alcohol exposure during pregnancy is difficult to establish. For example, in cases where parents are reluctant to disclose alcohol use, in foster care where a child's birth parents cannot be contacted, or in juvenile justice settings. They did not, however, specify that this was being researched differently for different demographic or population groups.

In addition, there has been funding provided through the National Health and Medical Research Council (NHMRC) to researchers from Griffith University (Queensland) to test a less time-intensive and culturally sensitive assessment of FASD in remote First Nations communities. This involves

examination of a tiered approach to diagnosing FASD and allows researchers to improve health care in remote Australian communities. Further information about this funding is provided in Table 7 below.

Another example of a novel way to diagnose FASD can be seen through the Yapatjarrathati Project (<https://www.griffith.edu.au/menzies-health-institute-queensland/our-institute/epic-health-systems/yapatjarrathati-project>). This Queensland-based research study aims to reduce the wait times for families in rural and remote areas to receive assessments and possible diagnosis for FASD, by providing primary healthcare workers a structured, culturally sensitive FASD assessment tool. The project also provides tele-mentoring to support practitioners when assessing and managing child neurodevelopmental problems. The approach taken in this project demonstrates a novel way to diagnose FASD and upskill professionals working in rural and remote areas due to its focus on collaborating with the community and integrating cultural protocols into the diagnostic approach. The Yapatjarrathati project is co-designed to conduct holistic assessment which considers all aspects of the children's and families' social, emotional, spiritual, and cultural wellbeing. This process resulted in six diagnostic tiers, including:

1. *Informed consent*: involves providing all necessary information about the assessment journey in a culturally sensitive, child-friendly way.
2. *Developmental interview*: involves obtaining the essential background information that a doctor needs to diagnose a neurodevelopmental problem.
3. *Developmental screening*: screening is very time-consuming and requires multidisciplinary teams. As such, engagement of required professionals can take a long time in rural and remote areas. Here, the Rapid Neurodevelopmental Assessment is used to provide a quick overview of a child's abilities across nine neurodevelopmental domains, which allows practitioners to quickly identify children with the most severe symptoms and start these children on an early pathway of support.
4. *Collateral information*: involves collecting information about a child's functioning at home and at school. Anyone (e.g., a parent or teacher) can administer these questionnaires and return them to the doctor.
5. *Summary and feedback*: the doctor will bring the information together and identify whether a diagnosis can be made within primary care, or whether more specialist assessment is required. A plan will be co-developed to best support the child, regardless of whether a diagnosis is present or absent.
6. *Specialist assessment*: specialist allied health or medical practitioners will continue the assessment journey and report back to the doctor, where needed.

The Yapatjarrathati project received funding from the Australian Government Department of Health and Aged Care Drug and Alcohol Program in 2017, however, began work the following year and published a protocol article in 2019 detailing the proposed work to be done on this project (Shanley et al., 2019).

The two aforementioned projects address a need for innovative approaches to diagnosis in rural and remote settings. This is essential, as such settings typically have limited numbers of health professionals, limited capacity and experience of local health professionals, and long wait times for

infrequently visiting specialists (Dossetor et al., 2019). Smaller diagnostic collaborations may therefore be more suited to rural and remote settings, where access to multidisciplinary clinics is often not possible.

While unlikely influenced by the Strategic Action Plan, overseas research has begun investigating other technologies to assist with the diagnosis of FASD that may be beneficial to use in Australia in the future. These include facial recognition software (Valentine et al., 2017), eye-tracking (Zhang et al., 2019), and telehealth (Whittingham & Coons-Harding, 2021).

5.4.3 Improved outcome measurement for individuals with FASD and their families

Overview of response:

Improved outcomes for individuals with FASD and their families is difficult to determine without speaking to such people directly. Research projects have reported the following improved outcomes for people impacted by FASD as a result of their research:

- Greater access to required support services
- Access to parenting programs to assist in FASD management
- Increased monitoring of developmental outcomes
- Access to family planning and education

Details:

Of the four FASD researchers who completed the online survey, one (ACT) noted that the Strategic Action Plan has supported them to improve the outcomes and measurement of outcomes for individuals with FASD and their families. However, detail was not provided from this respondent regarding how the Strategic Action Plan has specifically influenced such.

Interviews with key stakeholders noted that improved outcomes for individuals with FASD and their families is a more longer-term goal of the Strategic Action Plan, wherein improvements in other areas of the plan can be used as an indicator of success in this domain. However, to gain a proper understanding of how outcomes have improved for individuals with FASD and their families, direct discussion with these people needs to occur. While this was outside the scope of the current review, this could be something future evaluations endeavour to consider.

A review and analysis of relevant documents revealed that research projects funded through the Australian Government are having an impact by improving outcome measurements for individuals with FASD and their families. However, it is not clear whether the Strategic Action Plan is specifically supporting such.

One example of this is the Bigiswun Kid Project, funded through the Australian Government (via a NHMRC grant; 2018-2020), Australian Rotary Health (2018-2020), the Ian Potter Foundation (2020-2023), and the University of Sydney (2020-2023), which aims to improve understanding of which prenatal and childhood factors predict positive and negative outcomes for people with FASD. As detailed in the impact report written by the FASD Research Australia Centre of Research Excellence (2020), the Bigiswun Kid Project aims to hear about the experiences of young people with FASD as they move throughout their adolescent years. This allows for the development of sustainable support options and appropriate guidance provided to governments, policymakers, and funding bodies to understand the needs of youth with FASD and inform planning for future resources and services. Throughout the project, improved outcomes for youth with FASD and their families participating in the research have included:

1. Employing youth support officers to assist young people during the project, including connecting young people with local health, mental health, education, and employment services, and running yarning sessions to support families.
2. Providing disability support to ensure young people are aware of, and assisted with, NDIS funding.
3. Developing parenting programs to support individuals with FASD who now have a family of their own.

The Northern Territory (NT) Government has also documented their support in improving outcomes for individuals with FASD and their families in their state-specific FASD Strategic Plan (Northern Territory Department of Health, 2018), which is aligned with the Strategic Action Plan. Below details the relevant programs supported by the NT Government to improve outcome measurements for individuals with FASD and their families.

1. *The Families as First Teachers Program*
The NT government has committed to investing \$10.7 million annually to early learning and family support programs at Families as First Teachers sites. The Families as First Teachers program is an early learning and family support program in remote communities and urban areas which aims to improve the developmental outcomes of First Nations children. Targeting families and their children prior to the child starting school, the program can identify any areas where additional support services are needed and provide referrals to these services. The NT government offer this for all families following residential treatment, with a particular focus on those who received treatment for alcohol use in pregnancy.
2. *The New Directions: Mothers and Babies Services Program*
This is an Australian Government funded program which involves services across selected remote, rural, regional, and urban sites providing First Nations families that have young children access to support, information, education, and advice about antenatal and baby care, parenting and childhood development. Through this program developmental milestones are monitored, and health checks are undertaken prior to the child commencing school.
3. *The Australian Nurse Family Partnership Program*
This is an Australian Government funded program that has a particular focus on maternal health and early childhood development. It aims to improve prenatal health, provide assistance with learning parenting skills, help families with planning future pregnancies, and assists with parents completing education or commencing employment following the birth of a baby and in the child's first two years of life.
4. *Maternal Early Childhood Sustained Home-visiting program*
The NT Government has invested \$8 million over three years to work with the Aboriginal Community Controlled Health Service sector to implement sustained nurse-led home-visiting. The Maternal Early Childhood Sustained Home-visiting (MECSH) program is a structured program of nurse home visits that aims to improve transition to parenting, improve child health and development, and improve child life outcomes.

5. *The Healthy Under 5 Kids – Partnering Families Program*

This program is for families with 0–5-year-old children and aims to standardise care across the NT, with a major focus on improving child health and wellbeing outcomes for this cohort through systematised and timely assessment/reporting and referral as required.

6. *The Healthy School Age Kids Program*

This is a joint program between NT Health and the NT Department of Education and provides health screening for school-aged children in remote communities, supports early intervention, health promotion, and integrates other relevant programs and services to enhance care coordination.

5.4.4 Evaluation of FASD guidelines and tools targeting professionals

Overview of response:

The FASD guidelines are currently being reviewed after last being updated in 2020. The Australian Guide to the Diagnosis of FASD is the main tool for professionals to diagnose FASD, however this may need to be adapted for settings (i.e., rural) that have limited access to services and resources.

Details:

Evaluation of FASD guidelines

The Australian Guide to the Diagnosis of FASD was first published in 2016. This was updated in 2020, and is currently undergoing further revision by researchers at the University of Queensland. This is consistent with recommendations within the Strategic Action Plan to “Review the Australian Guide to the Diagnosis of FASD and associated training” (page 38).

As part of the larger process to review and update the Australian Guide to the Diagnosis of FASD, a recent qualitative study by Hayes et al. (2022) highlights the key review priorities discussed by a broad range of stakeholders involved in the assessment and diagnosis of FASD (i.e., healthcare practitioners, researchers, other specialists, individuals with cultural expertise, lived experience and consumer representatives). This research showed a total of 267 priorities were described by key stakeholders, with most relating to reviewing the diagnostic criteria, guideline content, guideline dissemination, and guideline implementation. The findings from this study will help guide researchers as to the areas of the guidelines that require updating.

A summary of the review priorities discussed in the qualitative paper by Hayes et al. (2022) is outlined below:

- Diagnostic criteria
 - Clarifying the definition of FASD, particularly regarding the causative role of prenatal alcohol exposure.
 - Clarity of the prenatal alcohol exposure criteria and review of the inclusion of a threshold level of exposure.
 - Review of sentinel facial features criteria.
 - Review the conceptualisation and consideration of neurodevelopmental domains of the FASD diagnostic criteria. For example, considering the inclusion of sensory processing, excluding academic achievement, clarifying/justifying the affect

regulation domain, and considering the separation of adaptive and social communication skills domain.

- Review the definition of 'impairment' and the currently recommended cut-off scores.
- Updating the suggested assessment tools, particularly the indirect (self- or parent-report) assessments.
- Considering the requirement for functional assessments to be completed as part of the diagnostic process.
- Aligning the neurodevelopmental criteria with other diagnostic guidelines such as Developmental Language Disorder under the language domain and Developmental Coordination Disorder under the motor domain.
- Guideline content
 - Providing the diagnosis and relevant assessment feedback to individuals and families.
 - Use of consistent and minimum standards for diagnostic reports.
 - Guidance on developing management plans.
 - Guidance for post-assessment support and resources, including increased support and coordination for individuals and families across contexts.
 - Cultural considerations – ensuring the guide is culturally sensitive, safe, and inclusive for populations that experience access barriers (i.e., First Nations peoples and individuals and families with non-English speaking backgrounds). This includes considerations of alternative culturally appropriate assessment tools and clinical decision-making processes.
 - Guidance around considering differential diagnoses in the assessment process. For example, considering the impact of other co-occurring conditions such as sleep disturbances and physical health conditions and the role of external influences on neurodevelopment including trauma and poverty identified in assessments.
 - Lifespan considerations – review how FASD assessments are completed in young children (i.e., < 6 years) and clearer guidelines for assessment and diagnosis in adults.
 - Ethical considerations – guidance on the implications of diagnosis and misdiagnosis and the need for advice to be provided to ensure informed consent for referral and assessment.
- Guideline dissemination
 - The need for widespread dissemination of the revised Guide beyond the health system to include education, justice, child protection, and the general community.
 - The need for targeted dissemination to multidisciplinary health teams, including state-wide child development units and a specific dissemination strategy for primary health professionals through established educational pathways and professional associations.
- Guideline implementation
 - Ensuring validity of the Guide, which includes an up-to-date review with supporting documentation and consideration of international diagnostic approaches to ensure alignment with international best practices.
 - Format – ensuring the Guide is clinically focused, written in a user-friendly manner, and in non-judgmental and patient-centred language.
 - Consideration of user needs and values related to the incorporation of lived experiences and end-users' perceptions.

- Consideration of human resources related to multi-disciplinary assessments and recommended alternatives to expand access when multi-disciplinary assessments are not feasible.
- Recommendations for professional training.
- Review of the prenatal care information and the pathways of care for children with known prenatal alcohol exposure
- Assessing the need for a register of FASD diagnostic clinics and practitioners
- Formal monitoring of the implementation of the Guide.

The impact report written by the FASD Research Australia Centre of Research Excellence (2020) notes that the Australian Guide to the Diagnosis of FASD is the most accessed page on the FASD Hub with over 34,475 views. Further, of the four researchers who completed the online survey, one (ACT) noted that the Strategic Action Plan has supported/influenced them to evaluate and use the FASD guidelines. However, detail was not provided from this respondent regarding how the Strategic Action Plan has specifically influenced such.

Tools targeting professionals

The Australian Guide to the Diagnosis of FASD is the main tool for professionals to diagnose FASD in Australia. As mentioned above, there have been funded projects which have looked at novel ways to diagnose FASD, generally in rural and remote areas where access to health services is limited, however these projects are primarily focused on increasing the capacity of health workers in rural and remote communities to provide adequate support rather than the implementation of new tools. Despite this, it is not clear whether the Strategic Action Plan has specifically supported or influenced the use or evaluation of tools currently recommended by professionals to effectively establish a FASD diagnosis. This is consistent with the findings of the online survey, wherein all four researcher respondents reported not being influenced by the Strategic Action Plan regarding FASD tools.

5.4.5 The conduct of health economic modelling of the impact of FASD

Overview of response:

Economic modelling of the impact of FASD has not been a key priority of research conducted since the launch of the Strategic Action Plan. Some researchers noted that they consider the economic impact of FASD when applying for grants in this space, while others specified that determining the economic impact is challenging with the difficulties associated with determining the prevalence of FASD in Australia.

Details:

Of the four FASD researchers who completed the online survey, two noted that the Strategic Action Plan has supported them to understand (ACT) or contribute toward (WA) the health economic modelling of the impact of FASD. Specifically, the researcher from WA explained that the Strategic Action Plan has made them think more about this issue when applying for research grants. This has resulted in the incorporation of an “*economic evaluation of FASD*” in grant proposals, therefore allowing such to be incorporated into current FASD research activities.

One representative from the DOHAC noted that there has not been any Commonwealth funded projects to determine the economic impact of FASD. However, there was mention that funding for projects that have a more direct impact on individuals with FASD and their families, rather than projects that investigate the economic impact of FASD, are a greater current priority. Further, one

interviewee noted that recent research on the cost of alcohol to society excluded FASD due to the difficulties associated with determining the prevalence of FASD in Australia. However, improvements in FASD awareness and diagnosis could assist researchers to include FASD in such reports in the future.

... just recently there was a cost of alcohol study released by the National Drug Research Institute. But it specifically excluded FASD because of the difficulties in costing it ... that points to the gap. But it's really difficult to identify costs if we don't have an understanding of prevalence. And I know that there is work underway and discussions in having a look at how an equivalent study could be done. But again, it's really hard to have an equivalent study, if there's not, you know, more consistent diagnosis.

5.4.6 New interventions for prevention and management of FASD

Overview of response:

Online survey respondents and interviewees did not suggest that the Strategic Action Plan has influenced new intervention in this space. However, it was noted that there have been advancements/extensions to existing intervention, and increased funding to support development of novel prevention strategies, as a result of the plan. Literature searching revealed a lot of research has been conducted concerning the prevention and management of FASD, mainly focusing on increasing awareness and education (prevention) and the known strategies to support individuals (management). An overview of the funding allocated to projects concerning FASD is provided to demonstrate advancements currently underway in this space.

Details:

This question was addressed through online surveys with FASD researchers, stakeholder interviews with representatives from the DOHAC, National FASD Advisory Group and state/territory health departments, and online literature searching.

Online surveys

Findings from the online survey highlighted that two of the four FASD researcher respondents were supported/influenced by the Strategic Action Plan to consider, create, and design new ways to prevent FASD. The researcher from NSW did not elaborate on this, however the researcher from WA noted that the Strategic Action Plan has “helped with [grant] applications for using co-design to re-design the evaluation of a FASD prevention program with multiple stakeholder groups”. In their response to this question, this researcher expressed the impact that the Strategic Action Plan has had on their focus to work with women at high risk of an AOD exposed pregnancy, which aligns with the fourth priority area in the Strategic Action Plan (Priority Groups).

Only one of the four researcher respondents were influenced by the Strategic Action Plan to consider new ways to support and manage the impacts of FASD. In particular, this researcher (ACT) was influenced to think about people's uniqueness, and to conduct a “diversity assessment” when considering ways to assist with the management of FASD.

Stakeholder interviews

Interviewees from the DOHAC and the NSW, SA, and TAS health departments noted that they were not aware of any new interventions for prevention and/or management of FASD created as a result

of the Strategic Action Plan, however, there have been extensions and upgrades of existing intervention and the FASD guidelines since the launch of the Strategic Action Plan which have aided in the prevention and management of FASD.

State health department representatives commented that education and training opportunities for professionals have increased as a result of the Strategic Action Plan rather than development of new interventions.

It's been a real, probably education and training type focus within the state ... there's definitely been a lot of professional development that's happened in our clinician space to support them with making those decisions in alignment with some of those strategies.

In addition, the national campaign launched by FARE was discussed as a novel way to promote the prevention of FASD in Australia, which is directly supported by the Strategic Action Plan. One interviewee also highlighted that funding for projects to develop novel prevention strategies that are specific to the community they are engaging with represents a key way that the Strategic Action Plan supports interventions for the prevention of FASD. While these examples are not specifically representative of new 'intervention', they were discussed as important initiatives in the prevention space.

... some of the remote community work [in WA and the NT] as well, which was funded, allow community consultation and co-design of prevention strategic in remote communities. So yeah, I think there have been some really, really novel approaches as well as allowing implementation of some of the less novel approaches that we know are likely to work.

Literature searching

Research targeting the prevention of FASD is discussed in question 5.3 above. However, in addition to this there has been a lot of recent, notable research concerning the management of FASD which focuses on the need to provide support in a holistic manner. A review of the literature revealed that researchers have detailed the following strategies to support the effective management of a child with FASD:

1. *Appropriate education and support of caregivers*

This is important as it informs caregivers of positive behaviour approaches rather than contingent behaviour management approaches, and how to create learning environments that are effective for individuals with FASD and reduce caregiver cognitive burden (Reid & Moritz, 2019).

2. *Modifying the environment*

This involves recognition of simplifying and structuring a child's environment (i.e., the schooling and social environment) to best support a child with cognitive difficulties. Intervention to help support a child with FASD should be based on their unique neurocognitive profile that emphasises their strengths (Skorka et al., 2020).

3. *Management of known areas of impairment*

Children with FASD can experience deficits in several areas of life, and research has shown that interventions targeting these areas of impaired functioning can have positive impacts on the management of FASD. Reviews by Adebisi et al. (2019) and Petrenko and Alto (2017) summarise research that examines the management of attention, self-regulation/executive function, gross motor functioning, social-information processing, and adaptive functioning

(i.e., safety awareness, social functioning, academic achievement, and substance use prevention) deficits, highlighting the impact that these targeted interventions can have on the management of FASD-caused impairment.

4. *Medication*

Research concerning FASD and pharmacotherapy is in its infancy, with a recent review by Ritfeld et al. (2021) demonstrating limited and conflicting evidence across different medications and FASD symptoms. This is a challenging topic given an individual with FASD often experiences other conditions, such as mental health concerns and sleep difficulties, which may impact the effectiveness of medication. However, as detailed in the review by Ritfeld et al. (2021), there is some research to suggest that stimulant medication may be helpful to address impairments in attentional control and hyperactivity, while neuroleptic medications may be useful when FASD is associated with social-behaviour deficits. In addition, alpha-2 agonists may be most helpful for emotional dysregulation (with antipsychotics another option for severe emotional dysregulation), however, more research is needed in this space.

Further, NOFASD Australia (2020) have developed FASD information cards for the community and the police to help support the management of FASD. These wallet-sized information cards can be carried by people with FASD and their caregivers and, if needed, handed to police officers or bystanders. The advice cards for the community may be used when a child with FASD experiences a sensory overload in public and can assist parents/caregivers to enlist the support of observers by quietly explaining what is happening and asking for their cooperation, including not staring or becoming involved unless assistance is requested. The information cards for the police explain that the person has a cognitive impairment and cannot knowingly waive legal rights, and who to contact if the person is alone. These cards can be ordered free of charge from the NOFASD website:

<https://www.nofasd.org.au/parents-carers-and-families/resources/>.

Table 7 below details the national research funding provided for research and activities concerning FASD since 2012. Figure 2 further provides a graphical representation of the number of FASD projects funded each year since 2012, as well as the total grant funding awarded each year. The availability of records noting the funding provided through each of the four funding bodies (NHMRC, DOHAC, ARC, MRFF) was available up until 2017. From 2012 – 2017 only records from the NHMRC were publicly available. Due to this, it is difficult to confirm an increase in targeted funding, however, the increase in NHMRC funding from the three years prior to 2018 (2015-2017) of \$4,541,259.80 and the three-year post (2019-2021) of \$6,804,608.05 suggest a 50% increase in FASD focused research project funding. Funding provided to support FASD research and activities from state and territory governments could not be determined; this information is not publicly available, and calls with representatives from relevant departments (i.e., health, grants, finance) within each state and territory confirmed that this information is not readily available.

Table 7.

Overview of funding provided to support FASD research and activities in Australia in chronological order from 2012 – present.

Title of project	Funding term	Recipient	Total funds provided (\$AUD)	Funding body	Description of project
The Lililwan Project: Prevalence of Fetal Alcohol Spectrum Disorders in the Fitzroy Valley	2012 to 2015	University of Sydney	\$777,758.08 ^b	NHMRC	Alcohol use in pregnancy is widespread in Australia. Alcohol may cause physical and developmental problems in the developing child including the FASD . This collaborative project, initiated and led by First Nations leaders in the Fitzroy Valley in the remote East Kimberley, WA, will establish the prevalence of FASD, health and developmental problems in a population of primary school-aged, predominantly First Nations children and develop strategies for service delivery, prevention, and education.
A feasibility study of screening, diagnosis, and workforce development to improve the management of youth with fetal alcohol spectrum disorder in the justice system	Announced 18/02/2014 to 2017	University of Western Australia	\$1,442,637.20 ^b	NHMRC	This research will establish the first Australian estimate of FASD among youth in detention and develop and evaluate a new model of service delivery and clinical management.
Building capacity for FASD screening and diagnosis through a prevalence study: The Cherbourg Project	Announced 18/02/2014 to 2018	University of Sydney	\$693,728.85 ^b	NHMRC	The House of Representatives 2012 Inquiry into FASD noted the particular need for research, training and capacity-building relating to FASD in ATSI communities. This project, in collaboration with Cherbourg community in Queensland and the WHO, addresses several Inquiry recommendations by providing: training to increase local capacity to screen/diagnose FASD; community education; diagnostic service for FASD; FASD prevalence data; and data to inform service provision and prevention programs.

The Alert Program: An evidence based treatment program for Aboriginal children living with FASD (Fetal Alcohol Spectrum Disorder)	Announced 17/10/2014 to 2018	University of Western Australia	\$1,150,278.60 ^b	NHMRC	This study will research the effectiveness of the Alert Program to improve self-regulation and executive functioning skills in primary school aged children in the Fitzroy Valley, a vast area located within the Kimberley region of Western Australia. The project also aims to document a sustainable and culturally appropriate method of implementing a therapeutic intervention that supports the improvement of skills in children living with Fetal Alcohol Spectrum Disorders within these communities.
Developmental programming: mechanisms and interventions	Announced 29/08/2014 to 2019	University of Queensland	\$675,810.00 ^b	NHMRC	Disturbances during pregnancy can impact on developmental processes and result in increased risk of disease in later life. This project will examine the impact of perturbations such as maternal stress or alcohol consumption on the development of the placenta and fetal kidney. By gaining an understanding of how these organs are affected by prenatal insults, we are likely to be able to develop more effective intervention strategies to ensure all babies receive a healthy start to life. " Fetal alcohol syndrome " was mentioned as a key word in this project.
Reducing the Effects of Antenatal Alcohol on Child Health (REAACH)	Announced 09/11/2015 to 2019	University of Western Australia	\$2,497,397.20 ^b	NHMRC	Use of alcohol in pregnancy can affect the developing baby and cause Fetal Alcohol Spectrum Disorders (FASD) . Children with FASD have lifelong brain injury that can lead to poor school performance, poor mental health and trouble with the law. This CRE builds on our strong background in research and community engagement to improve FASD prevention, diagnosis, and treatment across Australia.
Making Fetal Alcohol Spectrum Disorders History in the Pilbara: An evidence-based prevention intervention	2016 to 2020	University of Western Australia	\$1,703,824.20 ^b	NHMRC	This project creates and evaluates a community-oriented Fetal Alcohol Spectrum Disorder prevention program. Based on an internationally recognised model, the program will be delivered through the Pilbara's Aboriginal Health Organisations and WA Country Health Service and will assist First Nations women, partners, community, and health providers. Program success will result in a reduction in alcohol use during pregnancy, and

					increased community and health providers' knowledge, attitudes, and practice.
Implementing and evaluating pragmatic strategies to Prevent Prenatal Alcohol Exposure (PAE), and Treat Fetal Alcohol Spectrum Disorders (FASD)	2017 to 2020	University of Western Australia	\$340,038.40 ^b	NHMRC	Drinking alcohol when pregnant places the unborn child at risk of lifelong brain damage, that we call Fetal Alcohol Spectrum Disorders (FASD) . We can prevent FASD by raising awareness of the harms of drinking in pregnancy and supporting women not to drink. For those with FASD, treatment programs can help reduce learning and behavioural problems. Our research team work with communities and service providers to implement FASD Prevention and Treatment strategies, and raise awareness of FASD.
Improving health outcomes for disadvantaged children	01/01/2018 to 31/12/2022	University of Sydney	\$600,655.62 ^a	MRFF	The focus of this Fellowship is research in three areas: rare childhood diseases, Fetal Alcohol Spectrum Disorder , and vaccine-preventable disease, with attention to diagnosis, treatment, and prevention.
Optimising Neurodevelopmental Outcomes in 'At-Risk' Infants	01/01/2019 to 31/12/2022	Monash University	\$2,228,030.00 ^b	NHMRC	This research aims to learn more about factors that occur during pregnancy, at birth, or shortly after birth contributing to neurodevelopmental problems, and to develop new interventions to reduce these problems. The findings have the potential to transform treatment services for high-risk infants. " Fetal alcohol syndrome " was mentioned as a key word in this project.
What shapes our brain?	02/05/2019 to 02/05/2023	RMIT University	\$903,125.00 ^c	ARC	This project will enhance knowledge of how the cerebral cortex folds and develop novel tools for analysing brain development. The project will provide significant benefits including the generation of fundamental knowledge with implications for future understanding of cortical folding abnormalities in babies born preterm, following fetal growth retardation in utero, or when exposed to maternal alcohol . In the longer term, the project will contribute to improvements to human neurodevelopment and brain health.

N/A	26/04/2019 to 30/04/2019	University of Sydney	\$164,125.00 ^c	DOHAC	Funding provided to an organisation rather than a specific research project
N/A	04/06/2019 to 31/12/2021	Russell Family Fetal Alcohol Disorders Association	\$75,000.00 ^c	DOHAC	Funding provided to an organisation rather than a specific research project
N/A	18/06/2019 to 30/06/2020	Monash Health	\$357,500.00 ^c	DOHAC	Funding provided to an organisation rather than a specific research project
A tiered approach to the diagnosis of Fetal Alcohol Spectrum Disorder in remote Indigenous primary care settings	01/10/2019 to 30/09/2024	Griffith University	\$1,070,760.80 ^b	NHMRC	The aim of this project is to test a less time-intensive and culturally sensitive assessment for FASD that general practitioners can use in remote First Nations communities. The outcome will be quality, local services, improved health care and cost savings for families.
The Marurra-U Partnership Study: Supporting children with FASD in the Fitzroy Valley, WA	01/10/2019 to 30/09/2024	University of Sydney	\$1,071,217.25 ^b	NHMRC	This Marurra-U Partnership study will evaluate the ability of in-person and telehealth wrap-around support services in meeting the needs of children with FASD in the Fitzroy Valley, WA. This study is a collaboration between Marninwarntikura, Royal Far West and University of Sydney who have worked together for over ten years supporting children with FASD in the Valley.
Developmental programming: mechanisms and interventions	2020 1-year extension to previously funded grant	University of Queensland	\$145,607.00 ^b	NHMRC	This project will examine the impact of maternal stress and alcohol consumption on the development of the placenta and fetal kidney. By gaining an understanding of how these organs are affected by prenatal insults, this project will be able to assist in the development of more effective intervention strategies to ensure all babies receive a healthy start to life. " Fetal alcohol syndrome " was mentioned as a key word in this project.

Fetal Alcohol Spectrum Disorder prevention and coordination of support for urban Aboriginal and Torres Strait Islander people and communities	01/01/2020 to 31/12/2023	University of Queensland	\$726,743.00 ^b	NHMRC	In partnership with two South-East Queensland urban First Nations primary health care services and the communities they service, this project will co-create holistic, culturally responsive approaches to FASD prevention and coordination of support for urban First Nations people affected by FASD.
N/A	28/02/2020 to 30/09/2023	NOFASD Australia	\$660,000.00 ^c	DOHAC	Funding provided to an organisation rather than a specific research project
Fetal Alcohol Spectrum Disorder (FASD) Teacher and Educational Setting Resources	26/04/2020 to 30/09/2022	University of Sydney	\$660,000.00 ^c	DOHAC	The purpose of this grant is to develop a suite of resources to raise Fetal Alcohol Spectrum Disorder (FASD) awareness, and train educators and mentors to recognise/manage and support students with FASD in the education sector. This will provide educators and mentors with useful guidance materials, tools, and templates to assist students with FASD.
Fetal Alcohol Spectrum Disorder Hub Australia	29/04/2020 to 31/07/2026	Telethon Kids Institute	\$1,155,000.00 ^c	DOHAC	This grant aims to support the continuation of the Fetal Alcohol Spectrum Disorder Hub Australia, and to expand activities under this program.
N/A	01/06/2020 to 30/09/2022	Small and Up Pty Ltd (Patches)	\$660,000.00 ^c	DOHAC	Funding provided to an organisation rather than a specific research project

N/A	04/06/2020 to 30/09/2022	NOFASD Australia	\$660,000.00 ^c	DOHAC	Funding provided to an organisation rather than a specific research project
Fetal Alcohol Spectrum Disorder (FASD) - Australian Register	19/06/2020 to 30/06/2025	University of Sydney	\$715,000.00 ^c	DOHAC	This grant aims to support the continuation and ongoing maintenance of the FASD Register. The maintenance and continuation of the FASD Register contributes to the objectives of the Program through providing drug and alcohol data to support evidence-based treatment, national policy and service delivery.
National Awareness Campaign for Pregnancy and Breastfeeding Women	24/06/2020 to 30/09/2024	Foundation for Alcohol Research and Education (FARE)	\$27,400,000.00 ^d	DOHAC	This grant aims to support the implementation of the FASD National Awareness Campaign for Pregnancy and Breastfeeding Women across Australia. The campaign aims to increase the proportion of Australians who are aware of the risks associated with alcohol consumption, raise awareness of alcohol related conditions including FASD and reduce the incidence of FASD in Australia by supporting and informing women so they can make healthy choices while planning and during pregnancy.
Review and dissemination of the Australian Fetal Alcohol Spectrum Disorder (FASD) Diagnostic Tool	26/06/2020 to 31/07/2023	University of Queensland	\$660,000.00 ^c	DOHAC	The purpose of this grant opportunity is to undertake a comprehensive review and consequent update of the FASD Diagnostic Tool, and to conduct dissemination activities for the updated version. This update will ensure that the tool is in line with clinical and international best practice.
Fetal Alcohol Spectrum Disorder (FASD) Expansion of Diagnostic Services and Models of Care in Victoria	30/06/2020 to 31/07/2023	Monash Health	\$2,200,000.00 ^c	DOHAC	This grant aims to expand the range of diagnostic services and models of FASD care throughout the state of Victoria.

Improving the neurological and mental health of vulnerable children: Through implementation and health services research to close treatment gaps	01/01/2021 to 31/12/2025	University of Sydney	\$1,562,250.00 ^b	NHMRC	This Emerging Leader fellowship will support research to improve child neurodevelopmental and mental health. The program of research will answer several of the crucial research questions expressed in the October 2019 Productivity Commission Mental Health Report, the 2018 National FASD Strategy , the 2018 Senate Mental Health Inquiry Report, the 2018 Lancet Commission for Mental Health, the 2018 MRFF Strategic Priorities, and 2018 WHO National Strategy for Australian Telehealth Discussion paper. " Fetal alcohol syndrome " was mentioned as a key word in this project.
Expansion of diagnostic services	Announced 30/11/2021	University of Sydney	\$4,846,976.67 ^d	DOHAC	Funding will support the FASD diagnostic service, which will operate as a hub-and-spoke model based out of the Sydney Children's Hospital Network with sites in multiple rural and regional communities across New South Wales.
Expansion of diagnostic services	Announced 30/11/2021	Patches Assessment Services, NSW	\$2,148,163.44 ^d	DOHAC	Funding will support FASD diagnostic services within the youth justice system in Newcastle, with outreach services to Port Macquarie, Lismore and Ballina.
Expansion of diagnostic services	Announced 30/11/2021	University of Queensland	\$1,566,640.00 ^d	DOHAC	Funding will support the expansion of the existing University of Queensland and Children's Health Queensland Neurodevelopmental Clinic to reduce the current 3-year waitlist for access to services. Services will be delivered in locations across southern and central Queensland via a tiered model including telehealth support and upskilling of regional practitioners.

Expansion of diagnostic services	Announced 30/11/2021	Victorian Fetal Alcohol Service (Monash Health)	\$1,249,218.41 ^d	DOHAC	Funding will support expansion of the existing Commonwealth-funded Victorian Fetal Alcohol Service into more regional communities across Victoria. Services will be delivered through a tiered model including upskilling of regional practitioners to diagnose FASD independently.
Fetal Alcohol Spectrum Disorder (FASD) - Telephone, Online and Other Supports	28/04/2021 to 30/06/2024	NOFASD Australia	\$1,980,000.00 ^c	DOHAC	<p>The purpose of this grant is to provide evidence-based telephone and online information and support services to individuals, families and carers affected by FASD. This includes the delivery of up-to-date, evidence-based information and resources to the Australian community to raise awareness about the harms caused by consuming alcohol during pregnancy. In addition, this grant opportunity will enhance the capacity of health professionals and support services through professional evidence-based education and training, on raising awareness of FASD and the harms cause by drinking during pregnancy.</p> <p>The FASD Telephone, Online and Other Support Grant directly links to all the key aims of the National FASD Strategic Action Plan 2018-2028.</p>
Fetal Alcohol Spectrum Disorder (FASD) - Diagnostic Services	21/06/2021 to 30/09/2024	Griffith University	\$1,800,000.00 ^c	DOHAC	<p>The purpose of these grants is to ensure continued FASD diagnostic services in established or newly identified locations, targeted high-risk group screening and training of health professionals within agreed geographical locations that would otherwise not have professional FASD expertise.</p>

These grant opportunities were announced as part of the

	09/06/2021 to 30/06/2024	Small and Up Pty Ltd (Patches)	\$4,499,000.00 ^c	DOHAC	Budget Measure Prioritising Mental Health and Preventative Health – Continued in support of the National FASD Strategic Action Plan 2018-2028 .
	21/06/2021 to 30/06/2024	Griffith University	\$1,880,000.00 ^c	DOHAC	Organisations funded under these grant opportunities are required to continue to provide FASD diagnostic services, which links to the overall aims and objectives of the Strategic Action Plan, and directly address priority area Screening and Diagnosis.
Fetal Alcohol Spectrum Disorder (FASD): Expansion of FASD Diagnostic Services	01/02/2022 to 01/02/2025	Small & Up Pty Ltd (Patches)	\$2,362,979.78 ^c	DOHAC	The purpose of these grants is to provide for an expansion of FASD diagnostic services to ensure availability across Australia, with a particular focus on communities with a demonstrated need for FASD Diagnostic Services.
	17/02/2022 to 01/02/2025	University of Sydney	\$5,331,674.34 ^c	DOHAC	These grant opportunities were announced as part of the 2020-21 Budget Measure FASD Diagnostic and Support Services 2020-24 in support of the National FASD Strategic Action Plan 2018-2028 .
	17/02/2022 to 01/02/2025	Monash Health	\$1,374,140.25 ^c	DOHAC	The Expansion of FASD Diagnostic Services grant directly links to the overall aims and objectives of the Strategic Action Plan and aligns with the priority area of Screening and Diagnosis.
	01/03/2022 to 01/02/2025	University of Queensland	\$1,723,304.00 ^c	DOHAC	
Alcohol use during pregnancy: Understanding and improving health outcomes in offspring	01/01/2022 to 31/12/2026	University of Sydney	\$650,740.00 ^b	NHMRC	The aim of this research is to gain understanding of how small amounts of alcohol during pregnancy can impact child development across the first two decades of life and to test the effectiveness of a program that aims to reduce some of this burden. The world's largest datasets for examining prenatal alcohol exposure will be used to provide concrete evidence of

the impacts. "**Fetal alcohol syndrome**" was mentioned as a key word in this project.

Note. ARC = Australian Research Council, DOHAC = Australian Government Department of Health and Aged Care, MRFF = Medical Research Future Fund, NHMRC = National Health and Medical Research Council.

^a Total value from the MRFF funding body representing the full grant amount awarded, however it is not clear whether GST or other post award funding variations have been accounted for in the total amount.

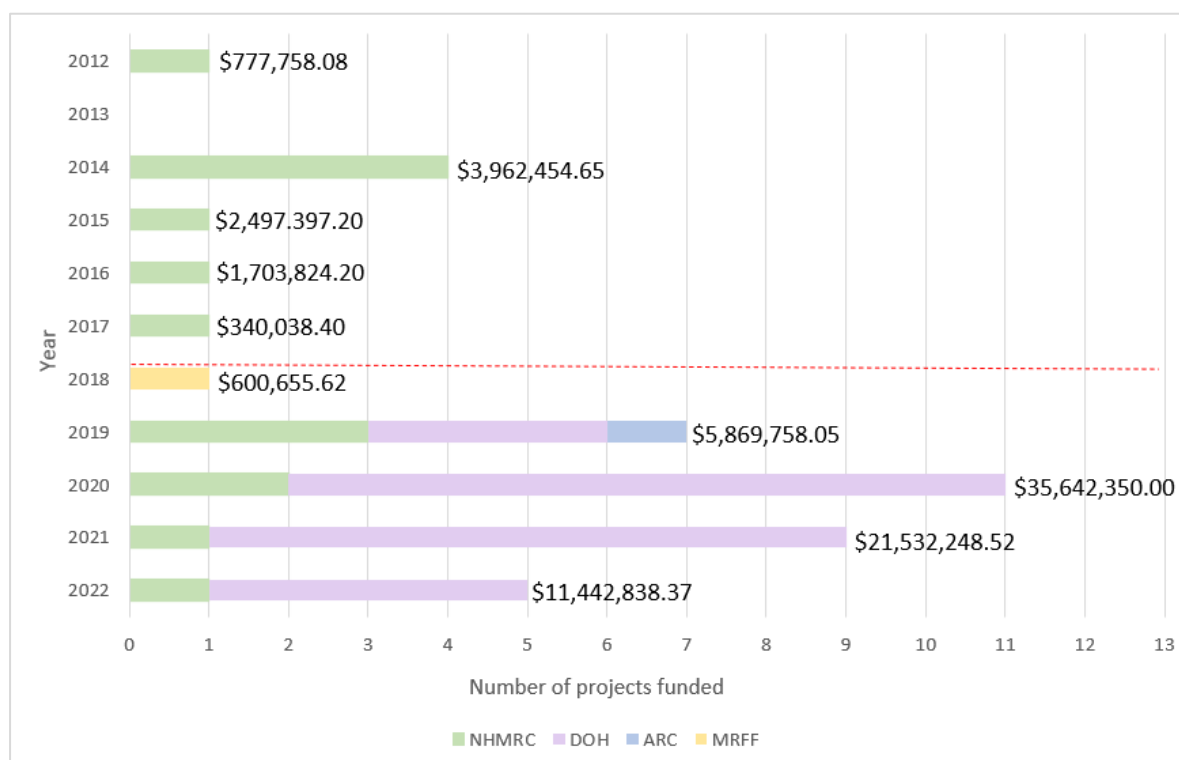
^b Total values from the NHMRC funding body representing the full grant amount awarded, however actual amounts paid to recipients may vary from the approved total due to indexation of payments and other post award funding variations.

^c Total values from the DOHAC and ARC funding bodies representing the full grant amount awarded with GST included.

^d Total values from the DOHAC funding body representing the full grant amount awarded with GST excluded.

Figure 2.

Number of FASD Projects Funded and Total Funding Awarded Since 2012



Notes. The amount of funding awarded to FASD projects is displayed for each year, and represents the total amount (sum) awarded across the projects funded in each respective year.

The red dotted line demonstrates when the current Strategic Action Plan was launched.

NHMRC = National Health and Medical Research Council, DOHAC = Australian Government Department of Health and Aged Care, ARC = Australian Research Council, MRFF = Medical Research Future Fund.

6 EVALUATION OF PRIORITY OBJECTIVES BY PRIORITY AREA

The following section will specifically review the priority objectives by each of the four priority areas, as outlined in the Strategic Action Plan (pages 16-32).

For each question a summary will be provided, followed by a more in-depth analysis of the evidence for that question. This will be presented as 'Overview of response' and 'Details', respectively.

6.1 Priority Area: Prevention

This priority area highlights the importance of preventing FASD from occurring, and as such focusses on preventing the consumption of alcohol during pregnancy and when planning for pregnancy.

Objective: Reduce access and consumption of alcohol in the Australian Community

6.1.1 To what extent has there been a change in pricing and promotion, reduction to access, and consumption of alcohol?

Overview of response:

There have been many efforts to reduce alcohol consumption and related harm on a broad level. This includes changes in alcohol promotion, such as the introduction of mandatory pregnancy warning labels on alcohol products, changes in alcohol price, such as the minimum unit price initiative in the NT, changes in alcohol access, such as legislative change to stop a Dan Murphy's store in Darwin, and changes to alcohol consumption, as evidenced through national data trends. While this is expected to have a positive impact on the prevention of FASD, it should be noted that these efforts were not necessarily in response to, or a direct result of, the Strategic Action Plan.

Details:

To answer this question, interviews with representatives from state/territory health departments and a review of the literature was conducted.

Interviewees were in agreement that there have not been changes to the pricing and promotion, reduction to access, and consumption of alcohol as a result of the Strategic Action Plan. However, interviewees were aware of changes to alcohol access and consumption that have recently happened throughout Australia, including the minimum unit price initiative in the NT and the national mandatory pregnancy warning labelling on alcohol products. Further, one health department representative mentioned current national discussions concerning alcohol pricing, advertisement, and home delivery, noting that this is a topic of current concern and consideration. However, these changes and discussions were not specifically related to the result of the current Strategic Action Plan. It was noted by one interviewee that the Strategic Action Plan may support other initiatives surrounding the reduction of access and consumption of alcohol, but it is unlikely to be the main influencer to such.

A review of the literature and relevant Government documents and policies revealed there has been successful and recent legislative and policy changes regarding alcohol in Australia. These are discussed below:

6.1.1.1 Alcohol promotion

In July 2020, new requirements for mandatory pregnancy warning labels on alcoholic beverages sold in Australia and New Zealand were introduced. Mandatory pregnancy warning labels will help ensure women are appropriately informed about advice to not consume alcohol while pregnant to prevent development of FASD in the developing fetus. Below provides details of this legislative change under the Australia New Zealand Food Standards Code, as well as other state specific changes that have recently occurred concerning the pricing, promotion, access, and consumption of alcohol.

Pregnancy warning labels

The introduction of pregnancy warning labels on packaged alcoholic beverages to adequately inform pregnant women of the risks of alcohol consumption has been a topic of discussion for over two decades. Since 2011, the alcohol industry implemented a voluntary pregnancy warning labelling scheme, however, following evaluation and consideration of evidence Food Ministers agreed that based on the evidence mandatory pregnancy warning labels should be required on alcoholic beverages. Below details the changes made that have led to this recent change, as well as details regarding what mandatory pregnancy warning labels on packaged alcoholic beverages entails.

- Background leading to this change

In response to a recommendation made by an Independent Expert Panel for the Review of Food Labelling Law and Policy (Blewett et al., 2011), The Legislative and Governance Forum on Food

Regulation (2011) provided the alcohol industry with a two-year period, commencing December 2011, to adopt the voluntary initiative to place pregnancy health warning labels on alcohol products. This voluntary pregnancy health warning labelling initiative was reviewed in 2014 in Australia and New Zealand. The New Zealand report outlined that approximately half of all beer, wine, cider and ready to drink beverages available in New Zealand had pregnancy labelling (Ministry for Primary Industries, 2014), while the Australian report outlined the proportion of company product lines with a pregnancy health label ranged from 0-100%, with an average of 71% (Siggins Miller, 2014). Overall, the percentage of products with a pregnancy health warning label was encouraging, but there was particularly low uptake in the mixed alcoholic beverages or ready to drink category. As a result of these reports a decision was made to extend the existing trial on voluntary uptake of pregnancy health warnings on alcohol product labels for a further two-years.

In 2017, the Ministry for Primary Industries (New Zealand) and Siggins Miller (Australia) re-reviewed the voluntary label initiative, outlining that there had been further increases of voluntary pregnancy warning labels on packaged alcohol products since the previous evaluation (Ministry for Primary Industries, 2017; Siggins Miller, 2017). However, it was also noted that there was great variation in what this warning label looked like, and that there was still some non-compliance due to this warning not being mandatory, and imported products not being subject to this voluntary arrangement. In 2018, the Food Regulation Standing Committee prepared the Decision Regulation Impact Statement (DRIS) to provide a recommendation to the Australia and New Zealand Ministerial Forum on Food Regulation regarding regulatory and non-regulatory options for pregnancy warning labels on packaged alcoholic beverages. The key recommendation made within the DRIS was that a mandatory labelling standard for pregnancy warning labels on packaged alcoholic beverages should be developed and should include a pictogram and relevant warning statement (Food Regulation Standing Committee, 2018). This change has been supported by people across Australia; for a signed open letter containing more than 4,000 community leaders and advocates, and more than 180 organisations supporting mandatory pregnancy warning labels, see here: <https://fare.org.au/labelling-open-letter/>

- *Current change*

On July 17, 2020, Food Ministers agreed to mandatory warning labels on alcoholic beverages. These requirements were gazetted in the Code on July 31, 2020, and it was announced that there is a three-year transition period from this gazettal date during which time businesses can choose to adopt the new requirements. Businesses will, however, need to comply with the requirements after the transition period.

This change, outlined in the code, will require all packaged alcoholic beverages with more than 1.15% alcohol by volume for retail sale in Australia and New Zealand to display a pregnancy warning label. There are two types of pregnancy warning labels within this legislation change:

- The pregnancy warning pictogram, which must be displayed on a prescribed alcoholic beverage with a volume under 200 ml and the outer package of a single individual unit with a volume under 200 ml. The pregnancy warning pictogram refers to the silhouette of a pregnant woman holding a wine glass within a circle with a strikethrough.



- The pregnancy warning mark, which must be displayed on a prescribed alcoholic beverage with a volume over 200 ml and the outer package of a single individual unit with a volume over 200 ml. The pregnancy warning mark includes the pregnancy warning pictogram, the signal words 'Pregnancy Warning', and the statement 'Alcohol can cause lifelong harm to your baby' all within a border.



Whilst the direct link between this legislative change and the Strategic Action Plan cannot be determined, the Strategic Action Plan may have assisted in making this topic a priority (see page 35 of the Strategic Action Plan for the recommendation concerning health warning labels on alcohol containers).

Alcohol advertising

It should also be noted that the alcohol promotion industry is self-regulated in Australia. The ABAC Responsible Alcohol Marketing Code (see here for more details: <https://www.abac.org.au/about/thecode/>) aims to protect vulnerable groups from exposure to alcohol advertising and the promotion of harmful messaging through a series of standards concerning the responsible promotion of alcoholic beverages, including prohibiting advertisements that have strong or evident appeal to (or specific targeting toward) minors, prohibiting advertisements that encourage excessive drinking or irresponsible/offensive behaviour, and prohibiting advertisements that display irresponsible depictions of the effects of alcohol (e.g., suggesting that the consumption of alcohol caused/contributed to some success or achievement). However, ultimately alcohol advertising is still a self-regulatory scheme in Australia. An examination of the regulation of alcohol advertising in Australia (Reeve, 2018) revealed many significant issues with the ABAC Code, including a lack of independent administration, systematic monitoring, meaningful sanctions for responding to non-compliance, and loopholes that impact adherence to the Code, such as a failure to adequately restrict the placement of alcohol promotions and to regulate alcohol industry sponsorship. Furthermore, a report written by the Foundation for Alcohol Research and Education (2020) highlights concern with the marketing messages used throughout the COVID-19 pandemic to promote alcohol use. Specifically, the Foundation for Alcohol Research and Education (2020) reported many online advertisements as referring to the ease of alcohol delivery, buying more, or receiving discounts, drinking to cope, drinking daily, and drinking alone in the home. This shows how the self-regulation system can be easily breached.

6.1.1.2 Alcohol Price

Minimum unit price

The minimum unit price (MUP) policy targets the cheapest alcohol and increases the price of those beverages under the minimum price (Taylor et al., 2021). MUP for alcohol came into effect in the Northern Territory (NT) on October 1st, 2018. This is the first and only MUP in Australia, and is set at a minimum cost of \$1.30 per standard drink (10 g pure alcohol) (Taylor et al., 2021). The NT MUP was particularly aimed at reducing the consumption of cheap wine products, with the NT government specifying that the MUP will likely change the price of beer, ciders and spirits very minimally (if at all), while it will substantially increase the price of cheap high alcohol content wine (Taylor et al., 2021). The effects of the MUP were examined via per capita alcohol consumption across the NT and in the Darwin/Palmerston region. Compared to the previous year, Taylor et al.

(2021) found significant per capita alcohol consumption decreases for cask wine (decrease of 48.8% in Darwin/Palmerston; decrease of 50.6% in the NT overall) and total wine (decrease of 13.0% in Darwin/Palmerston; decrease of 21.4% in the NT overall). Per capita alcohol consumption for other alcoholic products, such as beer, ciders, and spirits, were unaffected by the MUP, however due to the minimal change the MUP policy had on the price of such products this was unsurprising.

Alcohol tax

Currently, there is pressure from the alcohol industry to reduce alcohol taxes. The Australian Hotels Association, Clubs Australia, and the Brewers Association have launched a national campaign to cut the twice-yearly beer tax increase, with the Brewers Association also making a submission to the Government (September, 2020) to “support the Australian brewing industry and hospitality businesses by cutting beer excise, or at the very least, freezing it”. The submission can be found here: <https://www.brewers.org.au/policy-issues/submissions-to-government/>. In response to this, 40 organisations and 91 advocates have signed an open letter addressed to the Treasurer (The Hon Josh Frydenberg MP) strongly opposing any moves to reduce the price of alcohol through reductions in the beer and spirit excise in the next Budget or as an election commitment, stating that this would increase alcohol harms. This open letter, which was released on February 21, 2022, can be found here: <https://fare.org.au/taxopenletter/>

Despite the pressure to reduce alcohol taxes, no legislative changes have been made to date and there were no announcements of changes to the rate of alcohol taxation in the 2022–23 Budget.

6.1.1.3 Alcohol Access

Banned Drinker Register

The Banned Drinker Register (BDR) is a policy initiative that aims to reduce alcohol accessibility, and has been introduced in parts of WA and the NT. The BDR targets individuals that consume alcohol at harmful levels by placing them on a register that bans them from purchasing alcohol, and is enforced by scanning the person’s identification at point of sale (Clifford et al., 2021). A two-year trial of the BDR was initiated in WA in the Pilbara region in December 2020 (Birch & Miolin, 2020), following significant pressure on the government from the alcohol industry to trial a BDR instead of other measures (Jackson, 2020). Trials were later added in the Kimberly region in May 2021 (Government of Western Australia, 2021a), followed by the Northern Goldfields region in December 2021, and the broader Goldfields region in February 2022 (Government of Western Australia, 2021b). There are plans for this trial to be evaluated by the University of Western Australia. A BDR was trialled in NT from 2011 to 2012, and reintroduced as a mandatory measure on 1 September 2017 (Clifford et al., 2021). There is currently no clear evidence of the effectiveness of BDRs in reducing consumption and harms, nor unintended consequences that may counter their effectiveness (e.g., secondary supply) (Adamson et al., 2021). The BDR in the NT was followed by the formalisation of police monitoring takeaway alcohol outlets through the establishment of Police Auxiliary Liquor Inspectors (PALIs).

Police Auxiliary Liquor Inspectors (PALIs)

PALIs are a legislative intervention involving uniformed inspectors who are present at takeaway alcohol outlets and seek to prevent the consumption of alcohol in public and restricted areas. PALIs request a form of identification and ask patrons questions regarding their intended drinking location, and the purchase of alcohol is prevented if a valid address cannot be provided. The first cohort of PALIs graduated in August 2018, with full coverage of PALIs in three areas in the NT; Katherine, Tennant Creek, and Alice Springs; achieved by January 2019 (Clifford et al., 2021). PALIs are yet to be

evaluated, however, it is notable to mention that they are a legalised extension of the Temporary Beat Locations (TBLs) initiative; subsequently renamed Point of Sale Interventions (POSIs); which have been operating on a part-time basis since 2012 (Clifford et al., 2021).

Lockout Laws

Lockout legislation attempts to restrict access to alcohol by not allowing new patrons into a venue after a certain time (Taylor et al., 2018). Lockouts have been trialled in Australia for more than 15 years in an effort to respond to alcohol-related violence and injuries (de Andrade et al., 2016). However, there is mixed evidence concerning the effectiveness of lockout laws in reducing alcohol access and alcohol harms. For example, a review by Taylor et al. (2018) found that some studies examining the impact of lockouts showed decreased violence inside the venues (but not outside of the venues) while other studies found no long-term reductions in assault or injury. However, it was noted that most lockouts introduced in Australia were included as part of a multi-pronged strategy, making it difficult to determine the unique impact of lockouts (Taylor et al., 2018).

In March 2021, lockout legislation in the Kings Cross entertainment precinct (Sydney, NSW), which came into effect in 2014, was repealed. Changes as a result of this include the removal of the 1:30am 'lock out' so patrons can continue to enter venues at any time during the night, the 3am 'last drinks' time increased to 3:30am, restrictions on certain drinks, shots, discounted cocktails and use of glass after midnight removed, and requirements for RSA marshals and CCTV no longer apply (NSW Government, 2021).

Dan Murphy's

Many legislative changes arose during Woolworths' bid to build a Dan Murphy's store in Darwin, NT. After a five-year battle, Woolworths abandoned their plan to build Darwin's first Dan Murphy's store. Examples of legislation change during this period include:

- December 2016: The NT government amended the Liquor Regulations to make it a condition of a store licence that the retail floor space was limited to a maximum of 400 square metres.
- February 2018: The NT Government announced legislation to re-establish a NT Liquor Commission.
- October 2019: The NT Liquor Act 2019 came into effect.
- February 2020: The Legislative Assembly introduced the Liquor Amendment Bill 2020 to modify the Liquor Act 2019 to remove the barriers identified by NT Civil and Administrative Tribunal (and appealed by Woolworths).
- November 2020: The NT Government introduced the Liquor Further Amendment Bill 2020, giving power to the Director of Liquor Licensing to decide on the Woolworths' Dan Murphy's application within 30 days.

A complete overview of the timeline associated with Woolworths' plan to build a Dan Murphy's in Darwin can be seen here: <https://fare.org.au/darwin/>

Liquor licensing during the COVID-19 pandemic

During the COVID-19 pandemic temporary laws were put in place in the ACT, NSW, QLD, SA, VIC, and WA to relax liquor licensing restrictions to allow licensed premises, including restaurants, cafes and small bars (which do not usually have the authorisation to sell alcohol for off-premise consumption) to sell alcohol for takeaway and home delivery (Colbert et al., 2020). For most states, this temporary law was only in effect during the COVID-19 lockdown period. However, the Parliament of

Queensland (2021) has made these temporary laws permanent, which include amendments to the Queensland Liquor Act (see chapter 5; <https://www.legislation.qld.gov.au/view/html/bill.first/bill-2021-025#>). These changes, which centre around cafes and restaurants also selling takeaway alcohol, will increase takeaway alcohol density and the availability of alcohol (and the risk of alcohol harm) in the home. A submission to the Queensland Justice Legislation (COVID-19 Emergency Response – Permanency) Amendment Bill 2021 inquiry by the Foundation for Alcohol Research and Education (2021b) notes the following issues with this legislation change:

- Alcohol deliveries are not restricted in known high-risk times (between 10pm and 10am), which increases the risk of family violence.
- Alcohol deliveries are immediate (no delay between order and delivery), therefore supporting the rapid supply of alcohol products.
- There needs to be clear and consistent measures put in place to ensure alcohol is not sold or delivered to children, or to people who are already intoxicated.

6.1.1.4 Alcohol Consumption

Data from the National Drug Strategy Household Survey (NDSHS) and the Australian Bureau of Statistics (ABS) National Health Survey provide an overview of alcohol consumption trends throughout Australia. Whilst such population data is often used to determine changes in alcohol consumption over time, it should be noted that there are significant limitations associated with survey data that may impact the validity of such findings. These limitations should be considered when interpreting the data from the NDSHS and ABS concerning alcohol consumption in Australia.

National data – NDSHS

The most recent NDSHS report was published in 2019. This NDSHS was completed by 22,274 people aged 14 years and older across Australia. The report of the findings can be found here: <https://www.aihw.gov.au/reports/illicit-use-of-drugs/national-drug-strategy-household-survey-2019/contents/summary>.

Before discussing the key findings from this survey, it should be noted that reductions in alcohol consumption do not necessarily mean reductions in alcohol-related harm (i.e., injury or illness) due to the population also increasing between the compared years (2001 to 2019). For example, while there has been a decline in the percentage of people drinking at levels that put their health at risk between 2001 and 2019, it should be noted that in 2001 approximately 3.3 million Australians reported consuming alcohol at levels that exceeded the lifetime risk guideline, while in 2019 3.5 million people had done so.

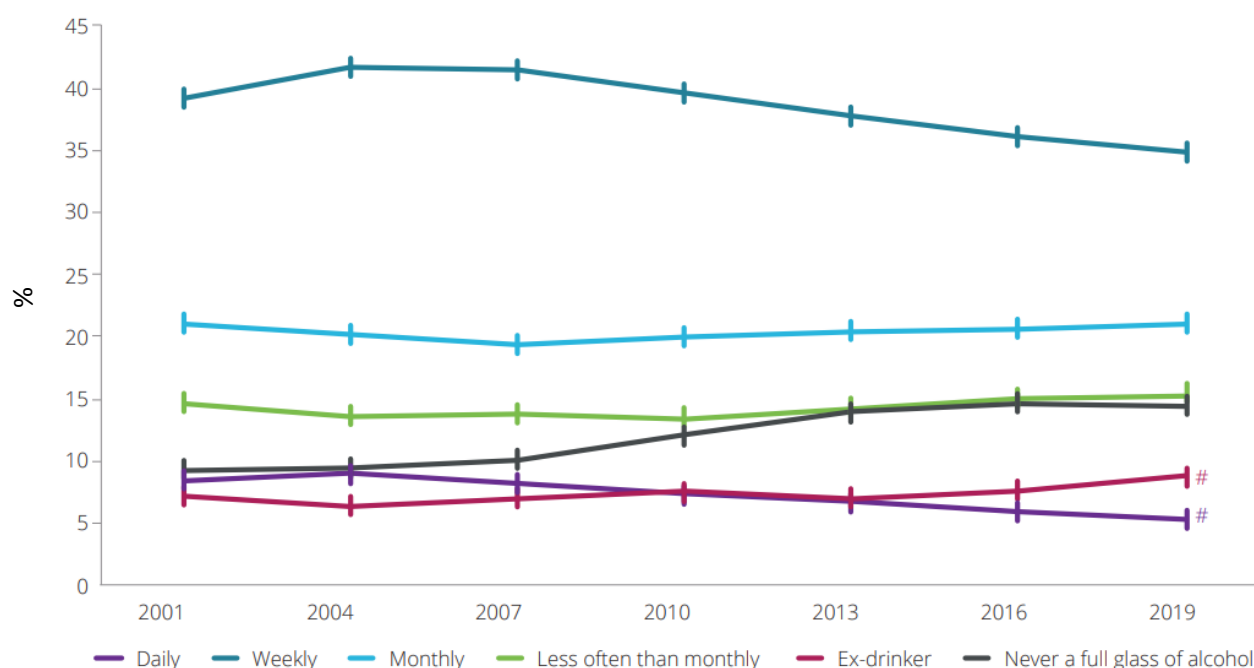
Key findings, as they relate to changes in alcohol consumption in Australia, include:

- The proportion of ex-drinkers increased between 2016 and 2019, from 7.6% (approximately 1.5 million) to 8.9% (approximately 1.9 million) Australians (Figure 3).
- The proportion of people consuming alcohol daily and weekly has been falling since 2004, and is now at the lowest point since 2001 (Figure 3).
- The proportion of people aged 18+ abstaining from alcohol increased from 19.5% (2016) to 21% (2019). The proportion of young adults (18-29 years) abstaining from alcohol has been gradually increasing since 2001.
- Consistent with previous years, the proportion of adults consuming alcohol daily increased with age. People aged 70+ were most likely to drink daily.
- The number of people drinking at levels that put their health at risk has been declining since 2001, however this has remained stable since 2016; 17.2% of people in 2016

- (approximately 3.4 million people) and 16.8% of people in 2019 (approximately 3.5 million people) drank more than two drinks per day (Figure 4).
- The proportion of people drinking more than four drinks in one sitting at least monthly has been declining since 2001, however this has remained stable since 2016 at about 1 in 4 people, which represents approximately 5.1 million people in 2016 and 5.2 million people in 2019 (Figure 4).
 - There was a decline among the adult population drinking 11 or more drinks in a single session at least once a month, from 7.4% in 2016 to 6.7% in 2019.

Figure 3.

Findings from the NDSHS (2019) Concerning Drinking Frequency Among People aged 14+ between 2001–2019.

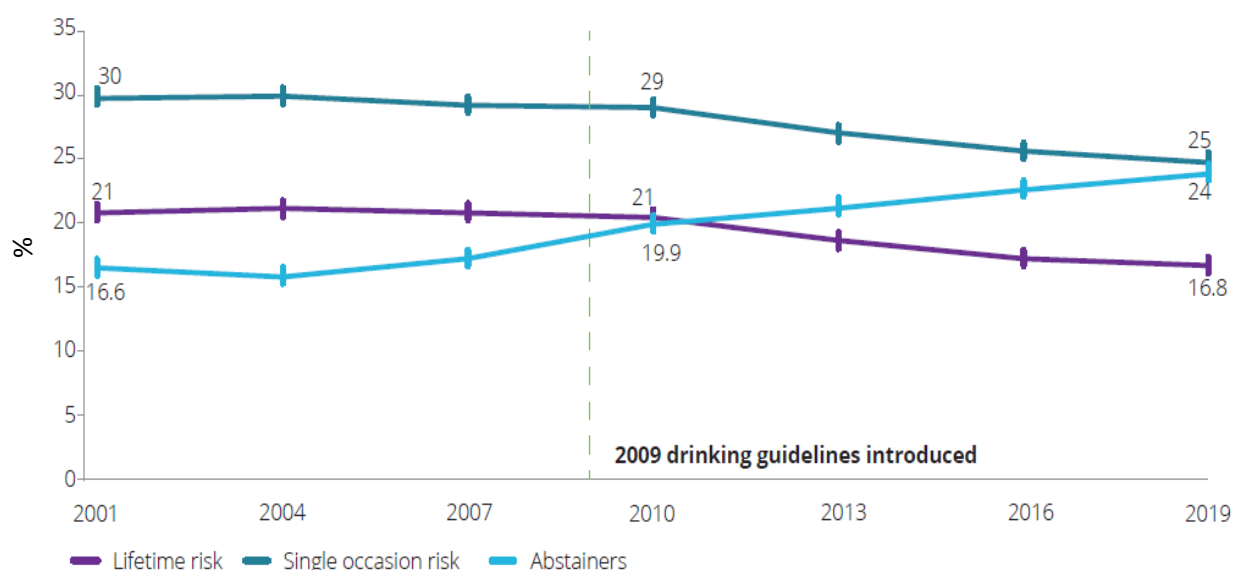


Statistically significant change between 2016 and 2019.

Note. This figure was taken from the NDSHS 2019 report.

Figure 4.

Findings from the NDSHS (2019) Concerning the Proportion of Abstainers and People Exceeding the National Alcohol Guidelines between 2001–2019.



Note. This figure was taken from the NDSHS 2019 report.

National data – ABS National Health Survey

The ABS publishes key statistics and information from survey data about alcohol consumption and its prevalence within Australia each financial year. The 2020-21 National Health Survey collected data from approximately 11,000 households around Australia.

It is noted, however, that the most recent data (2020-21 period) was collected differently to previous years due to the COVID-19 pandemic. For this reason, the ABS has recommended that comparison between the 2020-21 data and previous years not be made. The findings from the 2020-21 National Health Survey can be found here: <https://www.abs.gov.au/statistics/health/health-conditions-and-risks/alcohol-consumption/latest-release>

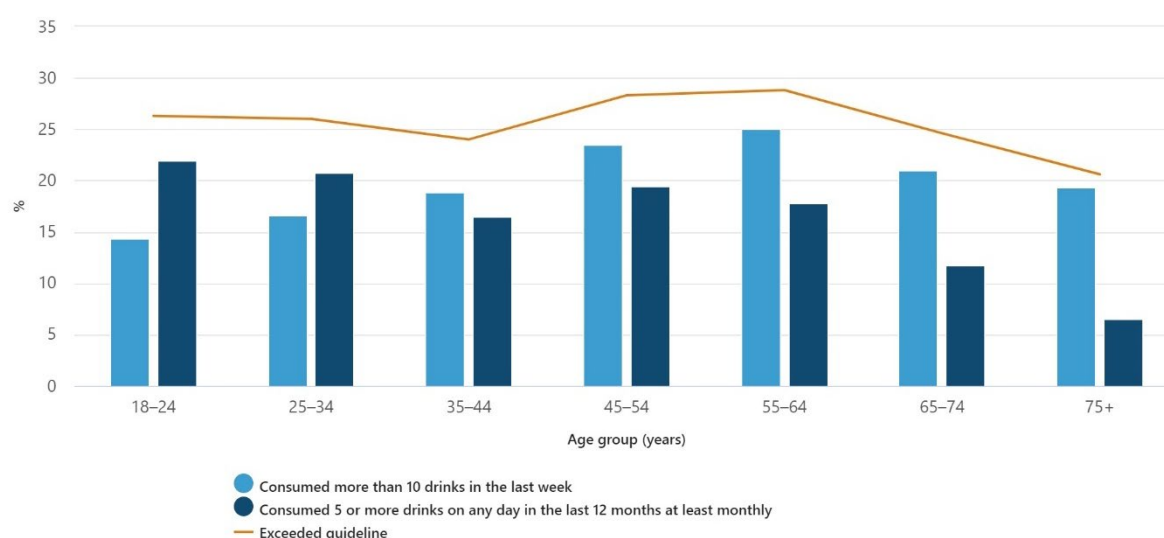
Key findings, as they relate to changes in alcohol consumption in Australia, include:

- Two thirds (66.4%) of people reported their alcohol consumption had stayed about the same in the last 12-months, while nearly 1-in-4 (23.9%) reported decreased alcohol consumption and 1-in-10 (9.8%) reported increased alcohol consumption.
- 1-in-4 (5 million) people aged 18+ years exceeded the Australian Adult Alcohol Guideline in 2020-21 (Figure 5).
- Characteristics of people exceeding the guideline:
 - o Men were more likely than women (33.6% compared to 18.5%).
 - o Adults born in Australia were more likely than those born overseas (30% compared to 17.3%).
 - o Adults living in Inner Regional (29.2%) and Outer Regional and Remote (30.3%) locations were twice as likely than those living in Major Cities (24.5%).
 - o Adults employed full time were more likely than adults who were unemployed (32.0% compared to 16.8%).

- Adults living in areas of least disadvantage were more likely than adults living in areas of most disadvantage (30.7% compared to 18.5%).
- 1-in-5 (19.9%) people aged 18+ years consumed more than 10 standard drinks in the last week. Men were twice as likely as women to consume more than 20 standard drinks.
- 1-in-6 (17.2%) people aged 18+ years consumed five or more standard drinks on a single day in the last year at least monthly (12 occasions per year). Men were twice as likely as women to have exceeded five standard drinks at least monthly (23.5% compared to 11.3%).

Figure 5.

Proportion of Australian Adults who Exceeded the Alcohol Guidelines by Age (2020-21)



Source: Australian Bureau of Statistics, Alcohol consumption 2020-21 financial year

Note. This figure was taken from the ABS 2020-21 report, which is available here:

<https://www.abs.gov.au/statistics/health/health-conditions-and-risks/alcohol-consumption>

Limitations of population survey data

A commentary by Chikritzhs (2021) highlights two key considerations when assessing the representativeness of general population surveys for alcohol.

1. **Response rate.** Not all reports discuss their response rates, and if they do, it can be unclear how they calculated such. When it comes to the topic of substance use, response rates for household surveys are often minimal (with past national surveys reporting varying rates from 50% to less than 35%).
2. **Marginalised groups.** Population household surveys often fail to accurately represent marginalised groups, such as First Nations peoples. This can lead to grossly inaccurate conclusions drawn from a small number of people who completed the survey and belong to such marginalised groups, which can consequently impact policy and funding. Further, these surveys often do not capture people who have unstable living environments (i.e., incarcerated, homeless, hospitalised) or those who are heavy substance users.

Further considerations, such as the amount of alcohol being sold change each year and the nature of people joining our society (i.e., whether they drink heavily or not) should also be considered in comparison of alcohol consumption data between years.

NT-specific alcohol consumption measures

In 2019 all public spaces within urban areas were declared restricted in the NT (Clifford et al., 2021). This prohibits the consumption of alcohol in these areas. The policy adds to those already in place around the NT, including alcohol consumption not permitted within 2km of any licensed premises (NT-wide policy), alcohol protected areas (dry communities), purchasing limits of cask and fortified wines, as well as beer in some areas (in effect in most places), and trading hour restrictions (these differ depending on the location, however, some places (e.g., Alice Springs, Tennant Creek, Katherine) cannot sell alcohol before 2pm on weekdays).

6.1.2 To what extent have Commonwealth, state and territory efforts supported at-risk population groups to implement culturally appropriate initiatives to reduce access to and consumption of alcohol

Overview of response:

Supporting at-risk population groups by implementing culturally appropriate initiatives to reduce the access and consumption of alcohol was discussed as predominately a state and territory responsibility, with each state and territory taking a different approach. However, the Commonwealth has a role in influencing states and territories through funding and providing information about effective alcohol policy.

Details:

This question was addressed through stakeholder interviews with representatives from the DOHAC and National FASD Advisory Group.

Interviewees noted that the Commonwealth's levers for supporting at-risk population groups to reduce the access to and consumption of alcohol is mainly funding and educational based (for example, providing states and territories with information about effective alcohol policies).

The influence they [the Commonwealth] have had I think has been at a higher level such as through influencing alcohol advertising legislation, and putting together information about effective alcohol policy such as a minimum floor price or a volumetric tax or banned drinkers' registries and things like that. I think the Commonwealth have been able to support putting together a synthesis of information, and also having a national alcohol plan. Those levels of intervention I think have then influenced what States and Territories have done.

It was also noted that there are governance systems in place to help the Commonwealth engage with states and territories and ensure appropriate monitoring and reporting of activities relating to efforts to reduce access and consumption of alcohol.

Regarding state and territory efforts to support at-risk groups to implement initiatives to reduce access to and consumption of alcohol, interviewees noted that this differs between the states and territories, with some (e.g., NT and WA) employing more initiatives than others.

However, it was noted that the alcohol industry, Governments, and the communities themselves can act as barriers to states and territories implementing appropriate initiatives to reduce alcohol harms.

Obviously they [the alcohol industry] are a very powerful lobbying group and they have a strong vested interest in the status quo.

... a lot of the people living out there who don't see themselves as having a problem with alcohol don't want to be restricted.

Objective: Increase community knowledge and awareness about the harms and consequences of drinking during pregnancy or when planning a pregnancy

6.1.3 To what extent have evidence-based public education campaigns about the harms and consequences of drinking during pregnancy been implemented?

6.1.4 To what extent have evidence-based public education campaigns for high risks groups been implemented and evaluated?

Overview of response:

Since the launch of the Strategic Action Plan in 2018 there have been 8 national and 21 state/territory-specific public education campaigns about the harms and consequences of drinking during pregnancy. It is difficult to determine whether these campaigns were launched as a direct response to the plan, however, they do all align with the national alcohol guidelines and thus support the actions specified within the Strategic Action Plan regarding the consumption of alcohol during pregnancy. There was limited publicly available information about whether these campaigns have been formally evaluated, therefore the effectiveness of such campaigns cannot be determined.

Details:

To answer questions 7.1.3 and 7.1.4 a review of the literature was conducted to examine what public education campaigns exist that focus on alcohol consumption during pregnancy (Table 8 and Table 9), as well as what information and resources are available to pregnant women and those planning pregnancy about alcohol use in pregnancy (Table 10). Examination of public education campaigns for the general Australian community, as well as those targeting high risk groups, was conducted.

As shown in Table 8 (national) and Table 9 (state/territory), campaigns were summarised according to whether they have been evaluated, the source of the information, and whether the information aligns with national alcohol guidelines and the national alcohol strategy. It was found that many of the campaigns have not been evaluated, while several also did not specify where the information featured in the campaign was sourced. For the campaigns that did include references, information was mainly sourced from the NHMRC alcohol guidelines, peer-reviewed journals, and expert opinion. Most campaigns clearly aligned with national alcohol guidelines; however, some campaigns did not feature information regarding breastfeeding and alcohol consumption.

Table 10 details the websites and services that specifically provide information and resources to pregnant women and those planning a pregnancy regarding alcohol consumption during pregnancy.

Further, it is notable to also mention the impact that pregnancy warning labels have on increasing community knowledge and awareness about the harms and consequences of drinking during pregnancy or when planning a pregnancy. Pregnancy warning labels on packaged alcoholic beverages help to raise awareness about not drinking during pregnancy, and prompt discussions about the risks of consuming alcohol during pregnancy. In addition, pregnancy warning labels may also support the establishment of cultural norms in relation to pregnant women not drinking alcohol. More information about the history of pregnancy warning labels can be found in question 6.1.1.1 Alcohol promotion above.

Table 8.

Review of National Public Education Campaigns Focused on Alcohol Consumption During Pregnancy (n = 8) by launch date

Name of campaign	Launch date	Format	Has the campaign been evaluated/is there a planned evaluation?	Source of information	Alignment with the national alcohol guidelines (See notes for what 3A and 3B stand for)	Alignment with the national alcohol strategy (Priority 3)
Pregnancy and alcohol poster	2018	Poster	No	Mentions expert opinion but does not include any specific references	Aligns with 3A Key messages align with NHMRC guidelines and National Alcohol Strategy - No alcohol is the safest choice when planning a pregnancy or pregnant	- Supporting women to avoid alcohol - Providing alcohol-related harm and risk information
DrinkWise FASD Awareness Program	2018-2020	TV advertisements	No	References the NHMRC guidelines. One of the TV ads features an expert opinion (doctor). No further references	Aligns with 3A and 3B - Abstaining from alcohol during pregnancy, and breastfeeding is important	- Highlights that FASD occurs as a result of drinking during pregnancy and those effects include developmental defect - Raise awareness of alcohol-related harms - Provides evidence-based reasons to support the recommendation that women who are pregnant, breastfeeding or planning a pregnancy should not drink - Discusses support options and improves access to

						<p>support</p> <ul style="list-style-type: none"> - Emphasises the importance of partner, family, and community support
Pregnancy and Alcohol: The Surprising Reality	2019-2021	Podcasts	No	Podcasts feature a range of experts such as doctors and professors involved in FASD, psychology etc.	<p>Aligns with 3A and 3B</p> <p>Consistent with NHMRC guidelines that there is no safe amount or time to drink alcohol, the placenta does not protect the baby from alcohol, any amount the mother drinks is also consumed by the baby, and women should not drink during pregnancy or breastfeeding</p>	<ul style="list-style-type: none"> - Raising awareness of FASD including prevalence, debunking myths, and the impacts of alcohol during pregnancy - Aims to support women by dismantling stigma and highlighting misinformation
Information You Might Not Know About Pregnancy and Alcohol	2020	Brochure	No	NA	<p>Aligns with 3A and 3B</p> <p>Consistent with NHMRC guidelines that there is no safe amount or time to drink alcohol, any amount the mother drinks is also consumed by the baby, and women should not drink during pregnancy or breastfeeding</p>	<ul style="list-style-type: none"> - Supporting women to avoid alcohol: acknowledges the challenges of stopping alcohol consumption - Providing alcohol-related harm and risk information
FASD Awareness Day	(Last date was 9/9/2021)	Nationwide campaign	No	NOFASD Australia provides educational material for the general public and health professionals based on Australian Guidelines -refers to NHMRC and DOHAC	<p>Aligns with 3A and 3B</p> <ul style="list-style-type: none"> - Information contained in FASD awareness day educational packs and social media posts are based on NHMRC guidelines 	<ul style="list-style-type: none"> - Improves FASD prevention through community awareness - Promotes awareness of alcohol-related harms

The Alcohol and Drug Foundation Fetal Alcohol Spectrum Disorder Mini bulletin	2021	Videos, mini bulletin	No	References to the Australian Guide to the Diagnosis of FASD and the governments National FASD Strategic Action Plan, peer-reviewed literature	Aligns with 3A - Alcohol must be avoided entirely	-raises awareness of FASD - Addresses stigma - Enhances the capacity of generalist healthcare, community, and support services
Women Want to Know	2021	Brochures, posters, and videos	No	Information was developed by FARE in collaboration with health professionals	Aligns with 3A and 3B - No amount of alcohol is safe	- Raises awareness about FASD and the importance of not drinking alcohol during pregnancy, - Encourages health professionals to discuss a patient's drinking habits in a non-confrontational and non-judgemental way to support women - Provides alcohol-related risk information - Encourages partners, families, communities and health professionals to provide support for pregnant women - Enhances the capacity of health professionals - Increases awareness of available treatment

Every Moment Matters	2021	Video	Yes (planned)	Developed by FARE	<p>Aligns with 3A and 3B</p> <p>Information delivered is in line with NHMRC guidelines including</p> <ul style="list-style-type: none"> - Alcohol should be avoided entirely during pregnancy - Any alcohol consumed when pregnant passes directly to the developing baby and can damage their brain, body, and organs - Can lead to FASD 	<ul style="list-style-type: none"> - Provides alcohol-related harm and risk information - Raises awareness of FASD
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Notes. All campaigns are summarised in more detail in Q6.**Error! Reference source not found.** above. 3A = to prevent harm from alcohol to their unborn child, women who are pregnant or planning a pregnancy should not drink alcohol. 3B = for women who are breastfeeding, not drinking alcohol is the safest for their baby.

Table 9.

Review of State and Territory Public Education Campaigns Focused on Alcohol Consumption During Pregnancy (n = 21) by launch date

Name of campaign (state/territory of where it was launched)	Launch date	Format	Has the campaign been evaluated/is there a planned evaluation?	Source of information	Alignment with the national alcohol guidelines (See notes for what 3A and 3B stand for)	Alignment with the national alcohol strategy (Priority 3)
FASD Prevention Program (WA)	2011-current	Community education programs and resources	No	No references	Aligns with 3A	<ul style="list-style-type: none"> - Aims to promote awareness of the long-term effects of drinking during pregnancy - Encourages supporting women during pregnancy and breastfeeding - Improves FASD prevention through community awareness
Pregnant Pause Campaign (ACT)	2016-2021	TV, social media, radio	No	Campaign refers directly to national guidelines that indicate that it is safest to go alcohol free when planning a pregnancy or pregnant	Aligns with 3A It is an initiative by FARE designed to promote NHMRC guidelines - There is no safe amount of alcohol consumption during pregnancy	<ul style="list-style-type: none"> - Encourages women who are pregnant to go alcohol free in addition to encouraging people to support the pregnancy of a loved one by going alcohol free - Emphasises creating a village of support
No Safe Amount-the Growing Brain (NT)	2018	Video posted on Indigenous Community Television	No	No reference to where the information came from, it is portrayed in an anecdotal way	Aligns with 3A and 3B Conveys the message that women who are pregnant or planning a pregnancy, and women who are breastfeeding should not drink alcohol	<ul style="list-style-type: none"> - Supporting women to avoid alcohol - Providing alcohol-related harm and risk information - Addressing the role of family and peers for reducing risky alcohol consumption

NT Health social media (NT)	2018	Facebook posts	No	No references for the information	Aligns with 3A Includes information that when a pregnant woman drinks her baby consumes the same amount - Mentions FASD	- Raises awareness of FASD and its relation to alcohol-related harms - Emphasises that everyone has a responsibility to support women and does not just place responsibility on women
Making FASD History: A multisite prevention program (NT)	2018-2020	TV, radio, posters, booklets, information sheets, workshops	Some elements have been evaluated (training sessions) however the whole project has not	Training sessions have been developed by NOFASD Australia Other resources reference peer-reviewed literature	Aligns with 3A - Risks associated with alcohol consumption for pregnant women - No safe amount Placenta does not protect the baby - The amount the mother drinks is the same amount the baby drinks	- Improves FASD prevention through community awareness - Improves FASD prevention through community awareness - Improves diagnosis and enhances the capacity of generalist healthcare, community, and support services
NT Health FASD Social Media Video (NT)	2019	Video posted on NT Health Facebook page	No	No references	Aligns with 3A and 3B	- Raises awareness of FASD - Everyone is responsible for supporting women not to drink alcohol when pregnant, planning a pregnancy or breastfeeding
Addressing Fetal Alcohol Spectrum Disorder (FASD) in the Northern Territory 2018-2024 (NT)	2019	NT Health Strategy Document, Facebook posts	Evaluation is ongoing - The Alcohol Harm Minimisation Working Group was appointed to facilitate cross-agency coordination of the initiatives and	There are references to peer reviewed journal articles and information from the NHMRC	Aligns with 3A - It is recommended that women who are planning a pregnancy or pregnant should not drink as the safest option	- Improves access to support services including through NDIA - Improves FASD prevention through community awareness, improved FASD detection, diagnosis and access to therapy

			<p>monitor the activities There are 3 key measurements of success</p> <p>. Reduced rates of women consuming alcohol during pregnancy Reduced wait times for assessments Increase in neurodevelopmental assessments: during early childhood, during middle school, of youth in the juvenile justice system, of children in out of home care.</p>			<ul style="list-style-type: none"> - Promotes training to support the use of established resources - Increases awareness of the full range of treatment options for women at risk
Strong Babies (WA)	2019	Brochure	No	No references	<p>Aligns with 3A</p> <p>Consistent with NHMRC guidelines that not drinking alcohol at any time during pregnancy is the safest option</p>	<ul style="list-style-type: none"> - Does not make explicit reference to FASD but mentions that alcohol consumed during pregnancy can lead to brain damage and birth defects - Encourages support from partners
What our Women Need to Know About Alcohol Strong Spirit Strong Mind (WA)	2019	Brochure	No	There is no reference to where the information was sourced from	<p>Aligns with 3A and 3B</p> <p>Consistent with NHMRC guidelines that there is no safe amount or time to drink alcohol, the placenta does not</p>	<ul style="list-style-type: none"> - Provides information about the harms of alcohol such as affecting physical development and the development of the baby's spirit

					protect the baby from alcohol, any amount the mother drinks is also consumed by the baby, and women should not drink during pregnancy or breastfeeding	- Encourages partners and other family members to make healthy choices to support a woman who is pregnant. In addition to emphasising the role of First Nations support systems
Yarning about Alcohol in Pregnancy (NT & NSW)	2019	Pamphlet available online or can be ordered	No	Resourced was developed using information from the Menzies School of Health Research and the Northern Territory Department of Health	Aligns with 3A and 3B Conveys the message that women who are pregnant or planning a pregnancy, and women who are breastfeeding should not drink alcohol - When a woman drinks so does her baby - When a woman drinks alcohol goes into her breastmilk	- Supporting women to avoid alcohol - Providing alcohol-related harm and risk information - Addressing the role of family and peers for reducing risky alcohol consumption
Making FASD History (WA)	2019-2021	Education/awareness video. Community delivery	Pilot study was evaluated There is reference to the campaign leading to a 50% reduction of women drinking alcohol during pregnancy and the approach has since been utilised in other areas and several	Developed by Dr James Fitzpatrick (a paediatrician) in collaboration with First Nations peoples in the Fitzroy valley	Aligns with 3A and 3B Consistent with NHMRC guidelines that there is no safe amount or time to drink alcohol, the placenta does not protect the baby from alcohol, any amount the mother drinks is also consumed by the baby, and women should not drink during pregnancy or breastfeeding	- Directly aimed at reducing the occurrence of FASD through prevention

			initiatives are in place			
NT Health No alcohol is safe during pregnancy (NT)	2020	Video posted on NT Health Facebook page	No	Provides a link to obtain further information from the FARE website Provides a link for information	Aligns with 3A	<ul style="list-style-type: none"> - Raises awareness of FASD and its relation to alcohol-related harms - Emphasises that everyone has a responsibility to support women and does not just place responsibility on women
FORWAARD Aboriginal Corporation Pregnancy Program (NT)	2020-2021	Residential alcohol treatment for pregnant women in central Australia	<p>Yes</p> <ul style="list-style-type: none"> - FORWAARD website mentions that the pregnancy program was successful and became the Women's Support Program <p>The results of the pregnancy program are discussed in the 2021 FORWAARD Aboriginal Corporation Annual Report</p>	No references	Cannot determine from available information	<ul style="list-style-type: none"> - Aims to support women by providing support for going alcohol free - Implementation of tailored intervention
Grog in Pregnancy videos (NT)	2021	TV/Online	No	There is no reference to where the information in the videos was sourced	<p>Aligns with 3A and 3B</p> <p>Conveys the message that women who are pregnant or planning a pregnancy, and women who are</p>	<ul style="list-style-type: none"> - Supporting women to avoid alcohol - Providing alcohol-related harm and risk information - Addressing the role of family and peers for reducing risky alcohol consumption

					breastfeeding should not drink alcohol - Information delivered by health professionals in the video that if a woman drinks alcohol the alcohol passes from the mother to the fetus via the placenta	
Alcohol Think Again 'One Drink' Campaign (WA)	2021-2022	TV, cinema, online, social media, community	No	Information was developed by the WA Mental Health Commission and the Cancer Council Australia, there is reference to the NHMRC guidelines but there is no reference to peer-reviewed literature	Aligns with 3A The campaign's call to action is consistent with the NHMRC's revised drinking guidelines (2020), which is women who are pregnant or planning a pregnancy should not drink alcohol, The placenta does not protect a baby from alcohol, any amount of alcohol a mother drinks, the baby drinks, there is no safe amount or time to drink alcohol during pregnancy	- Supporting women to avoid alcohol through reference to available supports such as the Alcohol and Drug Support Line - Providing alcohol-related harm and risk information in a variety of formats from toolkits to posters and factsheets, and social media campaigns - Somewhat addresses the role of family and peers for reducing risky alcohol
Stay Strong and Healthy Facebook Campaigns (NSW)	2021	Facebook posts	No	Some posts feature links to further information on the Strong Spirit Strong Mind webpage	Aligns with 3A - Advice is to have no alcohol when planning a pregnancy or pregnant	- Posts aim to raise awareness of FASD and describe the impact of alcohol - Information is educational and non-judgemental way with a focus on promoting health and reducing
Alcohol. The Facts. (NSW)	2021	Website	This resource was originally developed in 2014 and was evaluated and updated in 2021, but	Developed by NSW Ministry of Health and St Vincent's Alcohol and Drug	Aligns with 3A and 3B - Direct message is that no amount of alcohol is safe	- Highlights that FASD occurs as a result of drinking during pregnancy and those effects include developmental defect

			this has not been evaluated since	Information Service	<ul style="list-style-type: none"> - Section on pregnancy and breastfeeding is developed in reference to the NHMRC -drinking alcohol during pregnancy increases the risk of miscarriage, stillbirth, and perinatal death and may also cause FASD 	<ul style="list-style-type: none"> - Provides evidence-based reasons to support the recommendation that women who are pregnant, breastfeeding or planning a pregnancy should not drink and does not use stigmatising language, but does not discuss support
Vision, future, cycle and effect: A community life course approach to prevent prenatal alcohol exposure in central (NT)	2021	Journal article, TV, and radio commercials	<p>Yes</p> <ul style="list-style-type: none"> - The project has been initially evaluated in the journal article - Commercials were piloted and revised through expert panels and yarning reviews - Further evaluation of the commercials has been recommended 	The information comes from peer-reviewed literature, government statistics (Census data), experts, and local community members	<p>Aligns with 3A and 3B</p> <ul style="list-style-type: none"> - The key tagline of the commercials is “Drinking grog when pregnant can cause Foetal Alcohol Spectrum Disorder (FASD). Grog during and after pregnancy is No Good for Dad, Mum and Bub” 	<ul style="list-style-type: none"> - Uses evidence-based information to raise awareness of alcohol-related harms with a focus on FASD - Recommends that women who are planning a pregnancy or pregnant, or breastfeeding should not drink alcohol - Emphasises the importance of partner, family, and community support for helping women to stop drinking - Yarning reviews of pilot videos were used to ensure the language was not stigmatising
Drug Education Network: Fetal Alcohol Spectrum Disorder Prevention (TAS)	2021	Postcards and Posters	2017 version was evaluated, and the designs and messages of campaign materials were updated and released in 2021. The updated version has not been evaluated	No references	<p>Aligns with 3A</p> <ul style="list-style-type: none"> - Any amount of alcohol can harm your baby while you are pregnant 	<ul style="list-style-type: none"> - Raise awareness of alcohol-related harms - Emphasises the importance of partner, family, and community support for helping women to stop drinking

Using Alcohol During Pregnancy and Breastfeeding (VIC)	2021	Factsheet	No	References the NHMRC, does not reference anything else	Aligns with 3A and 3B - There is no safe amount or time to drink alcohol, the placenta does not protect the baby from alcohol, any amount the mother drinks is also consumed by the baby, and women should not drink during pregnancy or breastfeeding	- Raise awareness of alcohol-related harms - Provides evidence-based reasons to support the recommendation that women who are pregnant, breastfeeding or planning a pregnancy should not drink and does not use stigmatising language - Discusses support options and improves access to support
NT Health social media: Every Moment Matters (NT)	2022	Facebook posts	No	Resource is obtained through FARE	Aligns with 3A References Australian guidelines which advise that alcohol should not be consumed when planning a pregnancy or during pregnancy and that consuming alcohol at any stage can damage a baby's developing brain body and organs, and may lead to FASD	- Provides alcohol-related harm and risk information - Raises awareness of FASD

Notes. All campaigns are summarised in more detail in Q6.**Error! Reference source not found.** above. 3A = to prevent harm from alcohol to their unborn child, women who are pregnant or planning a pregnancy should not drink alcohol. 3B = for women who are breastfeeding, not drinking alcohol is the safest for their baby.

Table 10.*Review of Information Provided to Women About Pregnancy and Alcohol Use*

Website/service	National or State/Territory specific?	Documents/information provided
1. FASD Hub (website)	National	https://www.fasdhub.org.au/ <ul style="list-style-type: none"> • Information about what FASD is and preventing FASD • Evidence-based reasons to help support women to not drink during pregnancy • Services directory of health professionals and services with FASD expertise and experience • Training and education opportunities for health professionals and FASD eLearning modules • Link to NHMRC Guidelines • Link to Australian Guide to the diagnosis of FASD
2. NOFASD (website)	National	https://www.nofasd.org.au/ <ul style="list-style-type: none"> • Confidential online chat or phone for people to ask questions about FASD • Information and resources about FASD, including FASD management, interventions, and strategies • Videos to raise awareness and provide education • Alcohol and pregnancy resources, including the NHMRC guidelines • Webinars and online courses
3. Alcohol. Think Again (website)	National	https://alcoholthinkagain.com.au/alcohol-your-health/alcohol-during-pregnancy/ <ul style="list-style-type: none"> • Based on NHMRC guidelines • Information about FASD and drinking during pregnancy • Strategies about how to avoid alcohol during pregnancy • Information about general health promotion during pregnancy
4. DrinkWise (website)	National	https://drinkwise.org.au/parents/how-alcohol-consumption-can-affect-your-baby/# <ul style="list-style-type: none"> • The information presented links to other replicable sources (i.e., Australian Breastfeeding Association, FASD Hub, NOFASD Australia, Telethon Kids Institute) for more information. • Videos to increase awareness of FASD. • Of note, DrinkWise is funded by the Alcohol Industry.
5. Australian Government Department of Health and Aged Care (website)	National	https://www.health.gov.au/health-topics/alcohol/alcohol-throughout-life/alcohol-during-pregnancy-and-breastfeeding <ul style="list-style-type: none"> • Information about alcohol consumption during pregnancy and its effects during pregnancy and breastfeeding • Strategies for how to stop drinking • Links to the Pregnant Pause campaign • General tips for how to reduce or cease alcohol consumption • Links to FASD Hub contacts and National Alcohol and Other Drug Hotline contacts

Website/service	National or State/Territory specific?	Documents/information provided
		https://www.health.gov.au/resources/pregnancy-care-guidelines/part-c-lifestyle-considerations/alcohol <ul style="list-style-type: none"> • Pregnancy Care guidelines • Statistics about alcohol use during pregnancy • Risks associated with alcohol consumption during pregnancy • Tips for health professionals for how to discuss alcohol consumption in pregnancy with patients • Alcohol assessment tools • Treatment guidelines
6. The Alcohol and Drug Foundation (website)	National	https://adf.org.au/reducing-risk/alcohol/fasd/ <ul style="list-style-type: none"> • Information about what FASD is and its impact • Educational videos • Information about diagnosis and characteristics • Links to related information from other reputable sources (e.g., NOFASD Australia, Telethon Kids Institute)
7. Synapse - Australia's brain injury organisation (website)	National	https://synapse.org.au/fact-sheet/fetal-alcohol-spectrum-disorder-fasd/ <ul style="list-style-type: none"> • Information about FASD and prevalence • Advises that there is no safe amount of alcohol to consume during pregnancy
8. Australian Indigenous HealthInfoNet: Alcohol and Other Drug Knowledge Centre. (website)	National	<p>This website is more aimed at health professionals, but contains resources that health professionals can use to assist pregnant women.</p> https://aodknowledgecentre.ecu.edu.au/learn/health-impacts/fasd/ <ul style="list-style-type: none"> • Information about FASD, FASD prevention, and treatment options • Encourages the role of partners and the community in supporting women who are pregnant to not consume alcohol • Links to current and past FASD projects • Links to academic literature about FASD
9. Pregnancy Birth and Baby (website)	National	https://www.pregnancybirthbaby.org.au/alcohol-and-pregnancy <ul style="list-style-type: none"> • Overview of alcohol consumption during pregnancy, and its effects on the baby • Advises that there is no safe level of consumption and provides education about FASD • Encourages women to discuss alcohol consumption with their doctor or midwife, or confidentially with NOFASD Australia • Tips to avoid alcohol during pregnancy • Recommendations for where to find support

Website/service	National or State/Territory specific?	Documents/information provided
10. Telethon Kids Institute: Alcohol and Pregnancy & FASD (website)	National	https://alcoholpregnancy.telethonkids.org.au/ <ul style="list-style-type: none"> Provides recordings of FASD awareness virtual events Outlines information about standard drinks and how alcohol crosses the placenta, including the effects this can have on a developing baby Discusses why alcohol is harmful in pregnancy Includes information about alcohol in breastmilk and links to further information from the Australian Breastfeeding association Information about current and past FASD projects run through the institute
11. Every Moment Matters (website)	National	https://everymomentmatters.org.au/ <ul style="list-style-type: none"> Guidance for having and supporting alcohol-free pregnancies Outlines how alcohol can affect fertility, and the developing babies' brain, body, and organs Links to relevant Australian Alcohol Guidelines, including the Alcohol guidelines and the Pregnancy and Breastfeeding guidelines Links to suggested services and a directory to find local GPs Outlines the importance of not consuming alcohol when pregnant or planning a pregnancy Includes an educational/awareness video
12. Murdoch Children's Research Institute Victorian FASD Special Interest Group (website)	VIC	https://www.mcric.edu.au/vicfasdsig <ul style="list-style-type: none"> Events, seminars and courses International FASD Awareness Day information Links to resources from reputable sources such as FASD Hub Australia
13. FARE Pregnant Pause (website)	National	https://www.pregnantpause.com.au/ <ul style="list-style-type: none"> Resources for organisations or other community settings Resources for women who are pregnant, planning a pregnancy or anyone who is supporting a woman who is pregnant or planning a pregnancy Interviews about FASD and the campaign
14. Better Health Channel Alcohol and Pregnancy (website)	National	https://www.betterhealth.vic.gov.au/health/healthyliving/alcohol-and-pregnancy <ul style="list-style-type: none"> Summary information about the importance of not drinking alcohol during pregnancy Discusses the risks of alcohol consumption References NHMRC guidelines Outlines the risks of alcohol consumed by men on fertility, conception, and the developing baby Evidence-based reasons to encourage men to support their partners to achieve alcohol-free pregnancies

Website/service	National or State/Territory specific?	Documents/information provided
		<ul style="list-style-type: none"> Links for individuals who may be having difficulties stopping alcohol consumption such as DirectLine, Women's Alcohol and Drug Service, NOFASD, Family Drug Help, and DrugInfo
15. Get Healthy NSW (website)	NSW	https://www.gethealthynsw.com.au/program/get-healthy-in-pregnancy/support-to-stop-drinking-in-pregnancy/ <ul style="list-style-type: none"> Free personal health coach to support women who are pregnant to stop drinking Summary of evidence-based reasons concerning why it is important to stop drinking
16. ACT Pregnancy, pre-pregnancy and breastfeeding (website)	ACT	https://www.health.act.gov.au/about-our-health-system/population-health/drug-and-alcohol-safety/pregnancy-pre-pregnancy-and <ul style="list-style-type: none"> Summary of NHMRC guidelines Pregnant Pause video presentation Outlines the impacts and harms associated with alcohol use during pregnancy Advice for alcohol-free pregnancies Discusses breastfeeding and alcohol Links to further support
17. The Royal Women's Hospital (website)	VIC	https://www.thewomens.org.au/health-information/pregnancy-and-birth/pregnancy-drugs-alcohol <ul style="list-style-type: none"> Provides information about alcohol and other drug use during pregnancy Advises women on the steps they can take to improve health outcomes for their baby Alcohol specific section that lists current NHMRC guidelines Outlines the impacts of alcohol during pregnancy and breastfeeding Provides links to Alcohol and Drug Foundation fact sheets
18. Marinwarntikura Fitzroy Womens Resource Centre (website)	NT	https://mwrc.com.au/search?q=FASD <ul style="list-style-type: none"> Artwork competitions to raise FASD awareness Resources for educators to support young people with FASD FASD annual reports https://mwrc.com.au/pages/about-the-marulu-strategy? pos=3& sid=5b556d9d2& ss=r <ul style="list-style-type: none"> Marulu Strategy (community plan part of the Make FASD History campaign)
19. Substance Use in Pregnancy and Parenting Service (SUPPS) (service)	NSW	https://www.islhd.health.nsw.gov.au/services-clinics/supps-substance-use-pregnancy-and-parenting-service <ul style="list-style-type: none"> Provides an overview about the harms of alcohol during pregnancy, including information about FASD Discusses intervention and services, Links to further resources and support

Website/service	National or State/Territory specific?	Documents/information provided
Women and Newborn Drug and Alcohol Service (service)	WA	https://www.healthywa.wa.gov.au/Articles/U_Z/Women-and-Newborn-Drug-and-Alcohol-Service-WANDAS <ul style="list-style-type: none"> • Service that cares for women who are pregnant and experiencing alcohol and drug issues (based at King Edward Memorial Hospital) • Encourages women to ask for help (specific reassurance that women can seek help without being reported to DCP) • Listed services offered by WANDAS
21. FORWAARD Aboriginal Corporation Pregnancy Program (service)	NT	http://www.forwaard.com.au/family-circles <ul style="list-style-type: none"> • Drug and alcohol counselling service • Drug and alcohol information service • Culturally appropriate support programs

Notes. All information provided through websites and services contained within this table align with the National Alcohol Strategy and the National Alcohol Guidelines except for reference 21, wherein alignment with the National Alcohol Guidelines cannot be determined.

6.2 Priority Area: Screening and Diagnosis

This priority area highlights the importance of universal and targeted screening for FASD, including as newborns, during early childhood, or at the point of enrolment at school. It further emphasises the importance of accurate diagnosis of FASD to ensure appropriate support and management can be provided.

Objective: Increasing screening, diagnostic skills and knowledge in frontline professionals

6.2.1 To what extent have opportunities to improve access to appropriate and evidence-based diagnosis and support services through existing programs been maximised?

Overview of response:

The 2021 report written by the Senate Community Affairs References Committee notes three key areas of focus for improving FASD diagnosis and support services. This includes:

- 1) The improvement of the FASD Register, wherein the Australian Government has committed funding to support the maintenance of the FASD Register until 2025.
- 2) Additional support provided through Medicare, wherein it is noted that there are currently no item codes specifically addressing FASD.
- 3) The improvement of access pathways to the NDIS, wherein it is noted that the NDIS can be accessed by people with FASD, however this may be challenging for some depending on their ability to obtain a formal diagnosis and assistance in accessing appropriate supports.

Interview responses also discussed an increase in funding and FASD education for professionals has helped improve access to FASD screening and diagnostic services. However, it was noted that better communication between the states and territories would ensure funding in this space is more effective nation-wide, and greater emphasis on screening and diagnosis in rural and remote communities is needed.

Details:

To answer this question, a review of the literature and interviews with key stakeholders from the DOHAC, National FASD Advisory Group, and state and territory health departments was conducted.

Literature search

In 2019, a call for submissions to the Senate Community Affairs References Committee regarding effective approaches to the prevention and diagnosis of FASD and strategies for optimising life outcomes for people with FASD was made. The final report, which was released on March 17, 2021 (The Senate Community Affairs References Committee, 2021) detailed the findings from the inquiry, which included 69 public submissions (for a list of the submissions made, see here:

https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/FetalAlcoholSpectrumDi/Submissions).

The report includes 32 recommendations which aim to significantly improve the prevention, diagnosis, and management of FASD in Australia. Of particular note, recommendations were made regarding the improvement of existing programs targeting FASD diagnosis and support, including:

1. The improvement of the National FASD Register through long-term funding (recommendation 1)
2. Additional support for people with FASD provided through Medicare (recommendation 14)

3. The improvement of access to funding support through the National Disability Insurance Agency (NDIA) and the NDIS (recommendations 19, 20, and 31)

6.2.1.1 National FASD Australian Register (FASDAR)

The FASDAR is a national database containing health information about children (less than 15 years of age) in Australia that have been diagnosed with FASD. The aim of the register is to increase the availability of national FASD epidemiological data to support the development of evidence-based treatment, research, national policy, and service delivery. The first recommendation of The Senate report outlines the importance of maintaining the FASDAR, stating: “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.” (The Senate Community Affairs References Committee, 2021, p. 34). In line with this recommendation, the Australian Government has committed to funding the FASDAR until 2025. More information about the FASDAR, including how the coverage and quality of the FASDAR has improved, can be found in question 6.2.7.

6.2.1.2 Medicare

Medicare is a government-funded scheme that gives Australian residents access to healthcare at no or limited cost. Medicare also provides support for services required by people with disabilities, however, there are currently no Medicare item codes specific to FASD, demonstrating a lack of recognition of this disorder.

There are Medicare item codes (e.g., item 135; M10 items) which are specific to other neurodevelopmental conditions, such as autism spectrum disorder, with recent recommendations made to the Senate Community Affairs References Committee to amend these item codes to 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” (The Senate Community Affairs References Committee, 2021, p. 72). Recommendation 14 of The Senate report directly relates to the issues raised concerning the inclusion of FASD in the Medicare Benefits Schedule (MBS), stating “The committee recommends that the MBS Review Taskforce recommends including MBS Items that cover the range of clinical practices involved in FASD assessments, diagnoses and treatments” (The Senate Community Affairs References Committee, 2021, p. 84).

In response to the inquiries submitted to the Senate Community Affairs References Committee, the DOHAC has advised that the MBS Review Taskforce is considering the recommendations to include FASD on the list of neurodevelopmental disorders under Medicare item code 135, as well as ways to improve access to paediatric allied health assessments, including by amending the list of eligible disabilities by M10 items to include FASD.

Further, adding FASD to the list of eligible disabilities for M10 items directly aligns with the recommendation made to the MBS Taskforce by the Allied Health Reference Group (2019), which was developed in 2018 and endorsed by relevant stakeholder feedback prior to final publication to the MBS Taskforce. The Allied Health Reference Group (2019) also made recommendations surrounding the amendment of the item descriptor for M10 items from *Autism, Pervasive Developmental Disorder and Disability Services* to *Autism Spectrum Disorder (ASD), Complex Neurodevelopmental Disorder (CND) and Disability*. These recommendations were later supported by the Medicare Benefits Schedule (MBS) Review Taskforce (2020), however, it is noted that this

does not constitute the final position on these items, which is subject to consideration by the Minister for Health and the Federal Government.

In sum, the recommendations made by the Senate Community Affairs References Committee would support an increase in diagnosis and support/management of FASD. This aligns with recommendations made within the Strategic Action Plan, stating that improving access to appropriate and evidence-based diagnosis and support services through existing programs, such as the MBS, will assist in ensuring appropriate communication and training to professionals engaged in these programs (page 23).

6.2.1.3 The National Disability Insurance Agency (NDIA) and National Disability Insurance Scheme (NDIS)

The NDIS provides support to eligible people who were either born with or acquire a permanent and significant intellectual, physical, sensory, cognitive, and/or psychosocial disability, or those who are caring for a person with an eligible disability. Eligibility for NDIS support is based on evidence that a person has substantially reduced functional capacity because of their disability, or would benefit from the provision of early intervention supports. People with FASD can become NDIS participants if they meet the requirements set out in the NDIS Act, however, not all people with FASD will meet these requirements. The disability requirements are outlined in Section 24 of the NDIS Act 2013 (see here: <https://www.legislation.gov.au/Details/C2013A00020>) and are as follows:

- a. The person has a disability that is caused by an impairment (intellectual, cognitive, neurological, sensory, or physical)
- b. The impairment is, or is likely to be, permanent
- c. The impairment results in significant functional impacts to everyday life in one or more of the following areas: communication, social interaction, learning, mobility, self-care, and/or self-management
- d. The impairment impacts social and economic participation
- e. The person is likely to require NDIS support for their lifetime.

FASD is recognised as an eligible disability in the NDIS under List B (Permanent conditions for which functional capacity are variable and further assessment of functional capacity generally is required) and List D (Permanent impairment/early intervention, under 7 years - no further assessment required). Recognition of FASD within these lists was added in May, 2022; prior to this only 'Fetal Alcohol Syndrome' (FAS) was recognised, which has been described internationally as being at the more severe end of the FASD spectrum, requiring the presence of facial anomalies, evidence of growth deficiency (height and weight), abnormal brain growth (small head circumference) and neuro-behavioural impairments (cognitive and/or behavioural) (Mattson et al., 2019).

Despite this, meeting the eligibility requirements set out in the NDIS Act can be challenging for people with FASD. Obtaining a FASD diagnosis can be a lengthy process and is not always possible depending on resources and the availability of services provided near the individual (a diagnosis requires access to a specialist paediatrician and a skilled team of occupational therapists, psychologists, and speech therapists to carry out in-depth assessments). Subsequently, without a FASD diagnosis, evidence of permanent impairment (criterion b) and significant functional impairment (criterion c) can be difficult to provide, which can ultimately make accessing NDIS support difficult. This is acknowledged by the NDIA, who have subsequently supported/funded several programs to improve the accessibility of NDIS support for those impacted by FASD. These include:

1. *The NDIS Portal*

The NDIS Portal (www.nofasd.org.au/ndis/) is a project in collaboration with NOFASD Australia which is proposed to be an information resource for parents and carers of children with FASD, adults with FASD, and for other family members and support people with FASD. The NDIS Portal was created to help people navigate the NDIS processes, whereby there is a fact sheet and/or example template for each step of the NDIS journey.

2. *The National Information Program*

In October 2019, the National Information Program grant (funded through the NDIS) supported 37 organisations Australia-wide with three-years funding for activities to increase the accessibility, quality, and consistency of information available for people with disability, their families and carers, and for relevant supports and services (see here for details: www.ndis.gov.au/community/information-linkages-and-capacity-building-ilc/funded-projects). NOFASD Australia obtained \$825,000 of this funding to expand the existing NOFASD website to include a designated NDIS section, an interactive online learning platform, webinars, and a communications and promotion plan. The project, titled 'FASD-informed Australia', has resulted in several helpful resources, including sample NDIS documents (e.g., letter template, letter of support, NDIS plans), factsheets, and a booklet aimed at adults living with FASD.

3. *The National Community Connectors Program (NCCP)*

The NCCP, jointly funded by the NDIS, Federation of Ethnic Communities' Councils of Australia and the National Ethnic Disability Alliance, is a free program designed to help Australian people better understand and navigate the NDIS processes and requirements. Community Connectors support participants, potential participants, carers, and families to better understand the NDIS to ensure that people with disability, and their families and carers, have all the information and support needed to successfully engage with the NDIS. The NDIS has identified four communities that might benefit from Community Connectors' assistance: including First Nations peoples, culturally and linguistically diverse communities, people experiencing psychosocial disability, and ageing parents and carers of people with disability. The NDIS committed to a \$20 million expansion of the NCCP in November 2019 (see media release here: <https://www.ndis.gov.au/news/4913-delivering-ndis-20-million-expansion-national-community-connector-program>). However, the funding for this ceased at the end of June, 2021.

4. *The Remote Community Connectors (RCCs) program (WA-specific)*

In April 2019, the Australian Government announced a \$4.6 million investment to Aboriginal Medical Services to improve people's access to the NDIS in remote areas of WA through the RCCs program (see media release here: <https://www.ndis.gov.au/news/2080-new-ndis-arrangements-remote-western-australia-helping-australians-access-disability-supports>). The RCCs program aims to provide a culturally appropriate connection between the NDIA and remote First Nations communities in WA by helping to enhance engagement and access of information about the NDIS, and support people to complete NDIS plans. RCCs also identify potential NDIS eligible First Nations people living in the community with disability, and assist with providing information and support around obtaining assistance through the NDIS. It was noted in the submission to the Senate Community Affairs References Committee by the National Aboriginal Community Controlled Health Organisation (2019) that people with

FASD and their families across Australia would be given greater support if the RCCs program in WA was implemented in other jurisdictions.

Further, submissions to the Senate Community Affairs References Committee detailed concerns that medical professionals are often unable to adequately describe the functional impact of FASD and have a limited understanding of the NDIS, which further contributes to the difficulties that individuals experience in gaining access to NDIS supports. In response to these concerns, the National Disability Insurance Agency (2019) has noted, in their submission to the Senate Community Affairs References Committee, that they will:

“Review the early intervention evidence requirements in acknowledgment that many people with FASD will not have the means or diagnostic/assessment services available to meet the current stated requirements. This will include collaboration between NDIS and Health services to identify possible solutions to this identified barrier” (p. 4).

A representative from the NDIA also noted that the NDIA has committed to two actions to further support children and families requiring the support of the NDIS:

1. Ongoing training and support of Early Childhood Partners and Planners in recognising and understanding signs of FASD and responding/supporting children and families with FASD or suspected FAS/FASD.
2. A focus on system development between the NDIS and Health at the local/regional level, with stronger collaboration, support, and information for families impacted by FASD and the broader community. The emphasis of this work will be on early identification, intervention, and support to improve future outcomes.

The following recommendations were made by The Senate Community Affairs References Committee (2021) in response to the submissions made:

“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” (p. 109; Recommendation 19).

“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” (p. 109-110; Recommendation 20).

“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” (p. 129-130; Recommendation 31).

In sum, people with FASD can obtain support through the NDIS if they meet the requirements set out in the NDIS Act. Appropriate recognition of FASD as a disability is noted as a key enabler to the implementation of the priority areas identified in the Strategic Action Plan (DOHAC, 2018), with NDIS support contributing to the improvement in the support and management of FASD in Australia. However, it is unclear whether the Strategic Action Plan directly informed the direct discussion made to the Senate Community Affairs References Committee regarding the NDIS and FASD. It should be noted, however, that members of the National FASD Advisory Group were involved in several submissions (including the submission by NOFASD Australia, FASD Research Australia, and FARE) to the Senate Community Affairs References Committee, which helped shape the recommendations concerning the NDIS in The Senate report.

Stakeholder interviews

Interviewees discussed the extra funding provided through the Strategic Action Plan and other budget measures, noting that this has increased existing services' capacity to screen and diagnose FASD. However, limited improvements in accessing diagnosis and support services in rural and remote communities and among First Nations communities was raised as an ongoing issue. It was suggested that this issue could be addressed through modifying the diagnostic tool (which is currently under review) to account for ways to screen and diagnose individuals in remote and rural locations with limited resources. Greater communication in terms of what is working and what is not working in this space was also proposed as an effective approach that could be used to allocate limited funding and ensure that it is being used in an effective and efficient manner.

Not all representatives from state and territory health departments were able to comment on progress made in this area. However, one interviewee noted that there has been an increase in FASD training opportunities for clinicians in SA which has improved screening and diagnostic efforts. While this discussion did not focus on improving existing programs per se, these training opportunities have recently been made available to professionals outside the health field (i.e., AOD, police, youth justice/corrections) and those in more regional areas through virtual trainings, which may have a positive impact on the recognition of FASD and subsequent screening and diagnostic efforts.

... there's been a lot of training that's occurred within our clinicians around improved knowledge around screening criteria and feeling confident in actually being able to make those diagnostic decisions. So I know that's some work that's been done reasonably recently here.

6.2.2 What coverage of the health and human services workforce has been achieved by training and development efforts?

Overview of response:

Online surveys with health and human services workers revealed less than one-third of respondents had received FASD training in their workplace. Of those who had not received training about FASD, most indicated that they thought this would be beneficial. Specific examples of training activities were discussed in the stakeholder interviews; the FASD Diagnostic Services and Models of Care project offers a practical way to engage and train healthcare staff around best practice for screening, diagnosing, and managing FASD, while the courses run through the University of WA provide an evidence-based upskilling opportunity to professionals.

Details:

To answer this question, online surveys asked health and human services workers who require FASD knowledge for their role (i.e., healthcare practitioners, maternal and child health practitioners, AOD practitioners, and mental health practitioners) about their experiences of training and education related to screening, diagnostic skills, and knowledge about FASD ($n = 43$). Interviews were also conducted with representatives from the DOHAC, National FASD Advisory Group, and state and territory health departments to identify any training and development activities that have occurred to improve frontline professionals' skills and knowledge concerning FASD.

Online surveys

Overall, 13 respondents (30%) reported receiving FASD education and training, while the remaining 30 respondents (70%) noted that they had not received any training or education concerning FASD. A breakdown of how many respondents reported receiving and not receiving FASD training within each of the relevant practitioner groups is shown in Table 11 below.

Table 11.

Number of respondents who have and have not received FASD training and education across the different health occupations.

Type of practitioner	Received FASD training/ education	Has not received FASD training/ education
Healthcare	2	8
Maternal and child health	8	15
AOD	1	5
Mental health	2	2
Total	13	30

Of the 10 healthcare and maternal and child health practitioners that reported receiving training and education about FASD, most noted that this was delivered through their university degree or general medical training. There were a couple of respondents who specified online training as well, specifically noting Queensland Health and the FASD Hub resources.

The AOD worker could not recall where they received their FASD training from, however felt that it was adequate in scope. The two mental health practitioners reported receiving their FASD training through a workshop and via free online modules, both indicating that these resources were sufficient.

Four respondents (one healthcare and three maternal and child health) indicated that the training they received was insufficient, suggesting that more training for FASD screening and how to ask patients about alcohol use would be helpful.

Good for information, but not necessarily how to implement this in practice. (Maternal and child health practitioner, VIC)

Better education on how to discuss alcohol consumption in pregnancy with women and reference more current research about FASD. (Maternal and child health practitioner, QLD)

Of the 30 respondents that had not received any FASD education or training, 27 (90%) indicated that they would benefit from such training in their workplace.

"I work with children on the NDIS early intervention program. Commonly, I write to paediatrician noting difficulties to be investigated. With training, identifying more areas of concern can help narrow down and provide faster and more accurate diagnoses." (maternal and child health practitioner, NSW)

"Many of our adult clients have learning challenges and some report their mother as being a heavy drinker. It would give our team another lens through which to see and assess our clients and perhaps nudge us to find better ways of working with these folk." (Alcohol and other drug practitioner, VIC)

“It would be essential when working with patients as their cognitive capacity influences the success or no success of therapeutic support.” (Mental health practitioner, VIC)

Stakeholder interviews

One interviewee commented that FASD training is provided to professionals working at FASD diagnostic clinics, however training is limited for broader healthcare settings. However, other interviewees discussed specific examples of training and development activities that have occurred throughout Australia to increase screening, diagnostic skills, and knowledge in frontline professionals more broadly. This included:

1. The FASD Diagnostic Services and Models of Care project, wherein clinicians from WA visited clinics in the NT, ACT, VIC, NSW and TAS to educate and train staff to improve FASD screening, diagnostic and management skills.

... they trained up their clinical coordinators, plus the clinicians - so paediatricians, psychologists, speech therapists and OTs - trained them in how to diagnose FASD. They ran a few clinics with them where they would actually be there in the clinic running it alongside them. And then they stepped out and those clinics kept on running with local staff.

Of note, the training provided at each clinic differed to align with the populations likely accessing the clinic/service, therefore ensuring that the education and training provided was relevant and applicable to each clinic.

2. The online graduate certificate course offered at the University of WA, which targets clinicians and provides information on how to better diagnose FASD.

The FASD graduate certificate is open to clinicians who are already working in the field, and they're wanting to skill up and learn how to better diagnose FASD based on the Australian guidelines.

3. The online micro-credentials offered at the University of WA, which allows other professionals that may come into contact with individuals with FASD (e.g., police, corrections, education, child protection, psychology, social work, nursing, and speech pathology) and community members the opportunity to gain greater FASD knowledge and understanding. This course is relatively new (first offered in 2021) and has mainly attracted WA police to date. One interviewee further noted that there are discounts offered to access this course (i.e., for First Nations populations) to assist in making this training more accessible.
4. Professional development opportunities and training courses run by FASD experts for professionals in the field. These professional development and training course opportunities are offered to, and highly recommended for, health professionals to complete; however, they are not mandatory. Interviewees discussed that some of this training is broad (i.e., applicable to all health professionals), while other training is targeted to medical-based professionals (i.e., nurses and midwives). Interviewees noted that training opportunities are available to health professionals working in inner city, regional, and rural areas; however, it was not clear how these opportunities were advertised to health professionals across the states.

There was a specific two-day training course [in SA] that was provided to clinicians and it focused on the identification of FASD. So it was a number of experts from across Australia and they looked at the different neuropsychology tests that were used to actually identify

FASD and then we also still have access to the resources and those webinar recordings available for any new clinicians as they come on, to be able to actually gain information about that.

I know with the Health Education Training Institute, which is our NSW health education service, they have some online e-learning modules around alcohol and pregnancy and how to talk to parents about alcohol and pregnancy, how to screen that type of thing.

One interviewee discussed a lack of training and development activities currently available for health workers to improve FASD screening, diagnostic skills, and knowledge in TAS. However, it was also noted that there are relevant resources available that just need to be made more accessible, including resources through the drug education network and the Alcohol and Drug Foundation Tasmania. Improving access to and knowledge of these resources was noted as a big aspect of the state-specific Strategic Action Plan that they are currently creating.

6.2.3 How effective have efforts to disseminate and train medical and health professionals in the Australian Guide to the Diagnosis of FASD and the Australian FASD Diagnostic Tool and Referral Guidelines been?

Overview of response:

Online surveys revealed very few healthcare practitioners are aware of the FASD diagnostic tool and referral guidelines, which may indicate that allied health workers may not be as knowledgeable in FASD as they could/should be. Stakeholder interviews discussed funding requirements as a facilitator to disseminating and training medical and health professionals in the FASD diagnostic guide, tool, and referral guidelines, while the process of behaviour change and stigma act as barriers. Some interviewees noted that information may be available regarding the FASD guidelines and tool from the state level, but dissemination to local districts within the state and how these local districts use this information to inform relevant healthcare workers is less clear.

Details:

The Australian Guide to the Diagnosis of FASD supports clinicians in the diagnosis, referral, and management of FASD. This was created in 2016 and updated in 2020; it is currently under review by researchers from the University of Queensland.

Of note, there has also been research supporting the possible expansion of FASD criteria to include other clinical issues to assist in the diagnosis of FASD. These include sleep disturbance (Hayes et al., 2020; Mughal et al., 2020), difficulty with sensory processing (i.e., registration and interpretation of sensory input in the environment) (Jirikowic et al., 2020), and lower accuracy and control of saccadic eye movement (which refers to small rapid eye movements that occur when the eyes change from one point of fixation to another; for example, during reading) involving working memory (Maurage et al., 2020). Recent systematic reviews have further indicated health issues commonly seen in individuals with FASD, however further research in these areas is needed. Such health issues include impacted cardiovascular and renal function (Reid, Akison, et al., 2019), poor metabolic health outcomes (Akison, Reid, et al., 2019), reproductive difficulties (Akison, Moritz, et al., 2019), and poor immune functioning (Reid, Moritz, et al., 2019). Overall, this research is promising in terms of better understanding the challenges and comorbid issues faced by individuals with FASD and highlights the potential for such issues to be incorporated in diagnostic guides in the future.

To determine the effectiveness of efforts to train health professionals in Australia in the Australian guide to the diagnosis of FASD and the FASD diagnostic tool and referral guidelines, online surveys with healthcare practitioners ($n = 10$) and interviews with key stakeholders were used.

Online surveys with healthcare practitioners revealed that only two respondents were aware of the FASD diagnostic tool and referral guidelines, with only one of these respondents indicating that they had been trained in using the tool/guidelines through their university degree.

Interviews with key stakeholders from the DOHAC revealed that requirements to funding provided to diagnostic services, which involve the use of the FASD diagnostic guides and tool, help improve efforts to disseminate such. However, it was noted by one National FASD Advisory Group representative that there has been limited done to train and disseminate the FASD diagnostic guidelines/tool despite these requirements through funding, but that the health professional stream through the national campaign (launched by FARE) may be a good way to promote this in the near future.

Regarding use of the diagnostic tool and guidelines across different populations, interviewees from the DOHAC and National FASD Advisory Group noted that they are purposefully broad to allow health professionals to apply it differently depending on the situation and/or needs of the service/clinic. This is important given that not all diagnostic services/clinics have access to a multidisciplinary team, and thus may need to apply to tool differently to be appropriate to the people they are seeing.

The tool recognises that it's spectrum disorder and the nature of disabilities will vary from one child to the next.

Representatives from the SA and NSW health departments commented that efforts to disseminate and train medical and health professionals in the Australian guide to the diagnosis of FASD and the diagnostic tool and referral guidelines is driven more at a local rather than state level. Specifically, interviewees noted that they support and provide information about the FASD guides/tool, however the degree to which the information is utilised by health workers is dependent on the clinics or clinicians themselves.

... it's not something that we regularly promote out in any particular way ... It would be more on a clinician specific basis to say, look, if you're looking for this information, this is where you would find it.

When we get national documents, we disseminate it on through our networks. What happens at a local level, like a local district level, I couldn't comment on that.

Further, some interviewees noted that trying to facilitate change in terms of how professionals in the health field work and acknowledge FASD is challenging, especially when there is still stigma associated with FASD within the healthcare system. However, it was also noted that the update to the diagnostic tool has had a positive impact on health professionals using such, with one interviewee specifying that it is now easier for professionals to use.

... I think the update to the diagnostic tool made it easier for services that were providing those FASD diagnoses to take a consistent approach, certainly more so than the original release of the diagnostic tool.

6.2.4 To what extent has the general training for assessing child development in a range of health care settings alerted practitioners to the need to identify all forms of neurodevelopment impairment including FASD?

Overview of response:

Most healthcare practitioners who completed the online survey had not received training about FASD in their service setting, and as such, reported limited confidence in identifying and assessing FASD. This perhaps suggests that people working in healthcare settings are in need of general FASD education.

Details:

To answer this question, the online survey asked healthcare practitioners ($n = 10$) to identify the training they have received about identifying FASD, and to assess whether they felt it was appropriate and sufficient to build their understanding. As outlined in section 6.2.2 above, only two of the 10 healthcare practitioners who completed the online survey reported receiving training and education about FASD. Further, only one of these two respondents who had received FASD training, along with one other respondent ($n = 2$ in total) had awareness of the FASD Diagnostic Tool and Referral Guidelines. These findings suggest that general training for assessing neurodevelopmental impairment (such as FASD) in healthcare settings may not be adequate.

Further, healthcare practitioners were also asked (via the online survey) whether they feel confident in their ability to assess child development and identify FASD. Results indicated that only one respondent (who was also aware of the FASD Diagnostic Tool and Referral Guidelines) was confident in identifying FASD. The remaining nine respondents were unsure or partly confident, identifying a lack of formal training or practice as the reason behind their limited confidence.

“Without proper education and knowledge it would be difficult to make a fair assessment under the guidelines. Using clinical thinking and knowledge would be the only factor I could use to assist.” (QLD)

“Unsure what to assess for or what to look out for only know the basics from my university degree.” (SA)

“Haven't been trained in that area so would feel more confident referring.” (SA)

Objective: Improve capacity for screening, diagnosis and surveillance

6.2.5 To what extent has the FASD pre-screening tool been developed for widespread use?

Overview of response:

A FASD pre-screening tool has not yet been developed in Australia, therefore demonstrating an area for future consideration. FAS and FASD pre-screening tools exist in research conducted internationally, with the FAS screening tools shown to be more accurate at recognising FAS risk compared to the FASD tools recognising FASD risk. However, these international screening tools lack in information (e.g., regarding post-screening follow-up procedures) which is necessary to determine the feasibility and scalability of these tools.

Details:

An examination of the literature and discussion with key stakeholders from the DOHAC and National FASD Advisory Group revealed that to date, a pre-screening tool for FASD has not been developed in Australia. In the current version of the Australian Guide to the Diagnosis of FASD (Appendix 9; see here: <https://www.fasdhub.org.au/fasd-information/assessment-and-diagnosis/guide-to-diagnosis/>) it is mentioned that, while there are currently no validated standardised screening tools for FASD, there are two non-validated tools from Canada that may be useful:

- National Screening Tool Kit for Children and Youth Identified and Potentially Affected by FASD (<http://www.fasdn.ca/diagnosis.html>).
- Youth Probation Officers' guide to FASD screening and referral (<https://static1.squarespace.com/static/5afcc5b9e17ba38be3185853/t/5c76fa7a6e9a7f0763056bb1/1551301249598/Youth+Probation+Officers%27+Guide+to+FASD+Screening+and+Referral+%28Booklet+Format%29.pdf>).

Notably, the University of Queensland are currently updating the FASD diagnostic guidelines and have identified a caregiver interview developed in the United States which they are considering testing for use as a pre-screening tool to support referral to diagnostic services.

Further, a recent review of studies utilising FASD screening tools by Lim et al. (2022) details five FAS and seven FASD screening tools in the academic literature which have been developed in the United States and Canada.

The FAS screening tools involved:

- Craniofacial measurements (i.e., sentinel facial features of FAS and head circumference).
- Facial measurements of sentinel facial features of FAS using photographs.
- Examination of prenatal alcohol exposure, growth impairments (heights, weight), hockey-stick palmar creases (crease of the palm close to the fingers), and brain dysfunction.

The FASD screening tools involved:

- Eye movement behaviour tasks (assessing deficits in attention and visual-motor function).
- Neurobehavioural tests (relating to attention, adaptive behaviour, executive functioning, and social skills).
- Examination of language impairment.
- Examination of indicators of FASD risk, including behavioural, historical (including personal and family history), and maternal indicators associated with FASD.
- Examination of education level, employment history, criminal history, and mental health.

This review by Lim et al. (2022) highlights the FAS screening tools performed well in terms of identifying individuals at risk of FAS, however, the FASD screening tools varied in their ability to accurately identify individuals at risk of FASD. Further, the screening tools generally provided clear instructions for administration and interpretation of results, however information regarding the resources required to administer the screening tool and post-screening follow-up procedures were not clear across the examined studies.

6.2.6 Have best practice models been developed and disseminated to child health nurses, child and family services to support their capacity to contribute to the FASD diagnostic process in their service setting?

Overview of response:

Very few maternal and child health workers reported receiving FASD training in or external to their workplace. Irrespective of this, approximately half the survey respondents stated they followed a MOC when treating a person with FASD. The FASD Diagnostic Services and Models of Care project was discussed to have provided a successful on-the-ground approach to supporting child health service workers, however, greater work in areas such as child protection is needed. Finally, there is information targeting child and family service workers regarding best practice for FASD if they choose to seek and engage with such, including government guideline documents and FASD courses held at the University of Western Australia.

Details:

To answer this question, online surveys asked maternal and child health practitioners what information they have received regarding FASD diagnosis at their service, and whether they are aware of best practice models supporting their capacity to contribute to FASD diagnosis in their workplace. In addition, interviews with representatives from the DOHAC and National FASD Advisory Group, and a review of the literature through online searching and documents provided from key stakeholders, was conducted.

Online surveys

Online surveys revealed that of the 23 maternal and child health practitioners who completed the survey, four reported receiving some in-service training about FASD diagnosis. One respondent detailed what this in-service training involved, specifying that it featured how to assess deficiencies in different areas of the brain. Two additional respondents outlined that they did not get any training in their workplace, but did receive external training about FASD. Despite the small number of respondents indicating that they have received some training about FASD diagnosis in their workplace, 11 indicated that they follow a MOC when treating an individual with FASD or suspected FASD, which suggests that there is some knowledge of and processes in place for managing FASD. The MOC discussed by respondents mainly involved referral to specialised services such as paediatrician. The remaining 12 respondents were not aware of any best practice models to support FASD diagnosis in their service setting.

Stakeholder interviews

Interviewees from the DOHAC commented that they were not aware of any specific practice models developed and disseminated to child health nurses or child and family services to support FASD diagnoses. However, it was also noted that this is not information they are generally advised on in their role.

National FASD Advisory Group representatives discussed examples of best practice information being disseminated to child and health service workers to support FASD diagnosis. This included the FASD Diagnostic Services and Models of Care project, wherein it was noted that much of the education provided through this project was to midwives and nurses due to their pivotal role in referring individuals for FASD assessment. In addition, one interviewee noted that there are now resources available online through NOFASD Australia which provide support for other professionals

that may have a role in supporting an individual with FASD, including occupational therapists and social workers. However, the lack of support for child protection workers in was highlighted as a concern; given the high likelihood of young people with FASD entering out of home care, developing and implementing best practice models to support child protection workers in seeking support for FASD diagnoses should be actioned.

Literature search

A review of the literature identified the following resources that have been developed and disseminated to relevant healthcare workers to support best practice in the FASD diagnostic process. It should be noted that many of these resources are targeted toward health professionals/practitioners more generally, which is inclusive of child health and family services.

1. In the NT, an education package has been developed by the Northern Territory Department of Health (2018) in conjunction with Charles Darwin University to provide remote area health providers with the knowledge and skills on childhood development and assessment. This resource complements another program implemented by the NT Government to standardise care throughout the NT through systematised and timely assessment/reporting and referral as required (The Healthy Under 5 Kids – Partnering Families program).
2. The Pregnancy Care Guidelines (DOHAC, 2020) provide best practice guidelines for Australian maternity services, including midwives, obstetricians, general practitioners, practice nurses, maternal and child health nurses, First Nations health workers and allied health professionals, to enable them to provide high-quality evidence-based antenatal care to pregnant women. Section 13 of this guide provides information about alcohol use in pregnancy and supports healthcare professionals to discuss alcohol consumption in pregnancy, to assess alcohol use, and how to advise against alcohol consumption. The guidelines can be found here:
<https://www.health.gov.au/resources/publications/pregnancy-care-guidelines>
3. The Health Workers Guide to Yarning about Alcohol and Pregnancy is a guide produced by the NSW Ministry of Health (2019) This guide has been adapted from a resource by the NT Department of Health in conjunction with Menzies School of Health Research. This guide is aimed at health professionals working with First Nations women, including health care practitioners, educators, drug and alcohol workers, and Aboriginal Health Practitioners, and provides guidance regarding best practice in assessing and providing intervention for alcohol use in pregnant women. This guide can be found here:
<https://yourroom.health.nsw.gov.au/resources/publications/Pages/Health-Workers-Guide-to-Yarning-about-alcohol-and-pregnancy.aspx>
4. In WA, the Mental Health Commission's Workforce Development have launched a suite of FASD training for health professionals and service providers. This training informs health professionals of best practice concerning FASD and alcohol use during pregnancy. The three trainings offered are listed below, with 'Valuable Conversations' created in alignment with the Strategic Action Plan.
 - Promoting healthy women and pregnancies.
This two-hour virtual training event provides an overview of the complexities of alcohol use

during pregnancy, defines FASD, and discusses FASD prevention. The training is offered once a year or upon request where there are sufficient numbers.

- Valuable conversations.

This two-day face-to-face event provides training to reduce the impact of alcohol use during child-bearing years. The training covers topics such as reflective practice, trauma informed care and practice, motivational interviewing, FASD prevention in the context of the Strategic Action Plan, and brief interventions to combine course content with skills practice using the AUDIT-C and 'Five As'. This training is delivered regionally and has a planned rollout throughout 2021 and 2022.

- Healthy women and pregnancies.

This two-day face-to-face workshop provides knowledge, skills, and strategies to support FASD prevention for service providers who work with First Nations clients of childbearing age, their families and community.

These trainings can be found here: <https://www.mhc.wa.gov.au/training-and-events/training-for-professionals/fetal-alcohol-spectrum-disorder-fasd-training/>

5. The Treating Alcohol and Drugs in Primary Care (TADPole) program, funded by the Western Australia Primary Health Care Alliance, aims to increase the capacity of the WA primary care workforce to provide alcohol and drug treatment and support. The TADPole program includes a series of education activities covering general and specific alcohol and drug topics and skill-based techniques delivered in face-to-face education sessions, short video lectures, and webinars. While this program was initially launched in 2017, there have been two topics of relevance added for health professionals to choose: one concerning alcohol use in pregnancy (added in 2019) and another about prevention of FASD (added in late 2020). There are currently 14 topics that practices can choose from, however, generally they choose two topics per session that they book in. In the first half of 2021, funding from the WA Primary Care Alliance supported the launch of the FASD topic, which resulted in the topic being presented at eight practices. Discussion with the project manager has confirmed that since 2018 more than 100 sessions have been conducted, however the alcohol in pregnancy topic has never been chosen. More information about this program can be found here: <https://www.ecu.edu.au/schools/medical-and-health-sciences/training-for-health-professionals-and-teachers/treating-alcohol-and-drugs-in-primary-care-tadpole/overview>
6. The Graduate Certificate in the Diagnosis and Assessment of FASD is a postgraduate course run by the University of Western Australia to provide clinicians trained in psychology, speech pathology, social work, occupational therapy, and medicine (including paediatrics and psychiatry) with further specialised knowledge of FASD, including features of FASD and how to diagnose and assess for FASD. Created in collaboration with key stakeholders, this is the world's first Graduate Certificate in the Diagnosis and Assessment of FASD and was launched in 2019. This course provides information about the national and international diagnostic criteria, diagnoses, assessment tools and how to engage with multidisciplinary team assessment, as well as practical training in FASD diagnostic assessments. Course materials are updated annually to keep up with current clinical and research developments. This course provides professionals the opportunity to work and/or support the assessment and diagnosis of FASD based on best practice in the area. More information about this course can be found here: <https://www.uwa.edu.au/study/courses/graduate-certificate-in-the->

7. The University of Western Australia also offers two FASD short courses (micro-credentials), which are suitable for a range of community members and professionals with an interest in FASD, including family members of an individual with FASD; people trained in relevant health fields, including psychology, speech pathology, social work, occupational therapy, physiotherapy, nursing, and medicine; people working in the criminal justice sector, such as police officers, justice workers, and lawyers; and those people working with youth, including teachers and child protection workers. These micro-credentials may assist in supporting the capacity of child and family service workers to contribute to the FASD diagnostic process by increasing their knowledge and understanding of FASD, as well as the assessment process. Below details a summary of each of the short courses offered:

- *History and Basic Characteristics of FASD*
This course explores the historical and social context of FASD, differential diagnoses, common comorbidities, and common outcomes. See here for more information: <https://www.uwa.edu.au/study/courses-and-careers/short-courses/uwa-plus/micro-credential-history-and-basic-characteristics-of-fasd>
- *Considerations for FASD Diagnosis*
This course explores the relevant ethical issues in the assessment and diagnosis of FASD, how to deliver a diagnosis in a culturally sensitive manner, and intervention strategies. See here for more information: <https://www.uwa.edu.au/study/courses-and-careers/short-courses/uwa-plus/micro-credential-considerations-for-fasd-diagnosis>

8. The FASD Diagnostic Services and Models of Care Project, which was led by professionals from Patches in WA (<https://patches.com.au/>) and the University of Western Australia, assisted in the development of local MOC for best practice in FASD referral, diagnosis, and therapy/support in all participating sites. The MOC were based on existing and emerging service capacity, service stakeholder engagement, and MOC established in the WA Kimberley, Pilbara (developed and utilised through Patches in WA and the NT). Each site involved in this project was provided training around the Patches model, which was then adapted to fit local needs. Examples of the MOC created for the Pilbara region were used as a guide for developing each site's own local MOC, however, each site was encouraged to meet the following criteria for MOC development:

- Reasons for referral
- Screening (workforce, resources, instruments, and tools)
- Who can refer and/or support, and assessment service providers
- Diagnostic assessment team
- Diagnoses
- Services and funding (for those diagnosed with significant impairment)
- Services and support

Sites from the NT (Alice Springs and Darwin), regional Victoria (Shepparton), Tasmania (Hobart), and South Australia (North Adelaide) were included in this project. This project supported the capacity of a range of healthcare professionals in chosen sites to contribute to the FASD diagnostic process in their service setting by training and developing best practice models specific to each site to inform FASD assessment, diagnosis, and management. Further, this project required each site to deliver a minimum of two community education sessions per reporting period and a minimum of four diagnostic clinics as training opportunities for local clinicians to build capacity within diagnostic teams. This allowed for the upskilling of a range of

healthcare professionals.

A report of the findings (Panton et al., 2020) indicated a marked increase in clinical training through the 200+ training clinics run as a result of the project. In addition, each site except one was able to develop a model of service delivery that best suited their local needs, which they could continue using after the project cessation.

6.2.7 How successful have efforts to improve the coverage and quality of the FASD Australian Register been?

Overview of response:

From 2015-2021 reports made to the registry were de-identified. However, from 2021 parents/carers also have the opportunity to consent to their personal details being recorded in the registry, which attempts to help with the management of FASD through communications between the registry manager and registry members. Ongoing funding of the registry allows for its maintenance through the appointment of a registry manager, who has improved the coverage and quality of the registry by promoting its existence, working closely with professionals making reports to the registry, and managing data and queries.

Details:

The FASD Australian Register (FASDAR; <https://fasdregistry.org.au/>), funded through the DOHAC, was launched in 2015 and represents a national database that collects health information about children aged less than 15 years in Australia that have been diagnosed with FASD. Data surveillance occurs through the Australian Paediatric Surveillance Unit (APSU), however the FASDAR houses the APSU's national surveillance of de-identified cases of FASD. From 2015 to January 2022, there has been 839 reported cases (de-identified) of FASD documented.

The FASDAR has two arms; the de-identified and the identified. The de-identified arm relies on health professionals reporting new cases of FASD to the registry. The identified arm, which only begun in January 2021, involves the same information as the de-identified arm to be reported in addition to the parent/guardian providing written consent for their details and their child's details being recorded. The benefit of this is that participants in the identified arm can receive information regarding new services, peer support, effective treatments, and resources when these become available, as well as invitations to participate in relevant FASD research. The identified arm has not been able to recruit many participants to date; researchers involved with maintaining the registry have attempted to increase uptake, however, such efforts have not been successful. Of note, it has been mentioned that the stigma associated with prenatal alcohol exposure, children not having access to a guardian to provide consent (i.e., in the justice system), and an unstable home life (i.e., foster care), are common barriers to involvement in the identified arm of the FASDAR.

Based on the stakeholder interviews, the main improvement undertaken to enhance the coverage and quality of the FASDAR has been the recruitment of a specific researcher to monitor the registry. This has increased recognition of the registry by health professionals as the registry manager can engage with relevant clinics, assessment centres, and health professionals to discuss and support their involvement in the FASDAR, thus improving the coverage of the registry. This has resulted in greater involvement in the registry throughout Australia. Further, having a dedicated person to manage the registry has improved the quality of the data reported by professionals, as clarification

can be sought and errors in reporting can be amended in a timely manner. Stakeholder interviews revealed that having this more consistent, ongoing relationship with professionals who work in the FASD space and report to the registry has assisted in the improvement of the registry by allowing feedback to be provided about the case report forms and questions asked.

6.3 Priority Area: Support and Management

This priority area highlights the importance of providing multidisciplinary support and management, including tailored intervention, as early as possible in life for those impacted by FASD.

Objective: Implement and evaluate better models of management, support and care

6.3.1 To what extent has the Strategic Action Plan influenced the development and evaluation of evidenced-based multidisciplinary models of care across the lifespan and which align with principles of good practice noted in the Strategic Action Plan?

Overview of response:

Multidisciplinary MOC across the lifespan were utilised in some healthcare services, however this was not usual practice among those surveyed, with a common theme of not having, or not being unaware of, procedures in their service for supporting individuals with FASD. This may suggest a lack of understanding of FASD in some health services, which may have implications for whether ongoing support across the lifespan is provided. Better recognition of FASD within national healthcare schemes, such as Medicare and the NDIS, were also discussed as ways to ensure people with FASD are receiving adequate support in key areas of their life. Finally, there has been a small number of projects conducted to improve the care made available to individuals with FASD throughout the lifespan. More recent projects include the FASD Diagnostic Services and Models of Care project and the Making FASD History project. Notably, much of this research has come out of WA.

Details:

To answer this question, online surveys with healthcare workers, stakeholder interviews with representatives from the DOHAC and National FASD Advisory Group, and a review of the FASD MOC literature was conducted.

Online surveys

Healthcare workers, including maternal and child health, mental health, and AOD practitioners, were surveyed about how their MOC support individuals across the lifespan. A MOC broadly defines the way health services are delivered, outlining best practice care and services for a person or population group. It aims to ensure people get the right care throughout their treatment journey (Agency for Clinical Innovation, 2013).

- Healthcare practitioners

Two of the 10 healthcare practitioners detailed that the MOC used in their service supported the management of the individual across the lifespan. Specifically, one respondent detailed that they would “Refer to family services or disability services” (social work, VIC), while the other respondent specified that they would provide continuous support to the foster carer who is supporting the person with FASD (child protection, QLD). The remaining eight respondents either did not answer

this question or noted that their service does not incorporate MOC to support individuals across the lifespan.

- *Maternal and child health practitioners*

Five maternal and child health practitioners noted that the MOC they use in their service considers support across the lifespan, noting that this involved referral to other healthcare services for continual support.

“... community services such as social supports, occupational, speech and physiotherapy services.”

“Provide continuity of maternity care to support women and their babies and support their transition to other community services.”

However, the remaining 18 maternal and child health practitioners who completed the survey either left this question blank or reported that support across the lifespan was not something they consider in their service.

- *Mental health practitioners*

Three of the four mental health practitioners indicated that they follow traditional MOC for mental health clients, such as a biopsychosocial or stepped care approach. All respondents said that they would individualise their MOC depending on the client, which may involve working with the clients' support systems and taking a *“long-term and systemic approach”*. Of note, one respondent indicated that knowledge about how to support a client with FASD has come from existing experience in the field rather than training or a specific MOC.

- *AOD practitioners*

All six respondents noted that there were no MOC in their practice that they use for individuals with FASD or suspected FASD. However, one respondent indicated that they assess the individual needs of each client and work with them in a way that suits their current needs.

Stakeholder interviews

Interviewees commented that a key action associated with the Strategic Action Plan is to facilitate better models of management and support for individuals after receiving a FASD diagnosis. Representatives from the DOHAC and National FASD Advisory Group noted that they are pushing for better recognition of FASD within national healthcare schemes (i.e., Medicare and the National Disability Insurance Agency), however, this is still under discussion. Of note, one interviewee further discussed the need to better models of care to support individuals with FASD in education settings, noting that this is essential to ensuring people with FASD are receiving adequate support in key areas of their life.

Literature search

A review of the literature was conducted to examine any reports of FASD MOC, revealing that there has been some research conducted in Australia to specify best practice for FASD care across the lifespan. A brief summary of this research is detailed below.

Initiated after the launch of the Strategic Action Plan

National FASD Diagnostic Services and Models of Care project (Panton et al., 2020)

- This project aimed to develop FASD MOC relevant to each site included in the project for FASD referral, diagnosis, and therapy/support. This was designed to align with actions specifies within the Strategic Action Plan.
- This project replicated a similar project conducted in the WA Kimberly and Pilbara (Fitzpatrick et al., 2020).
- MOC were created to address prevention and women's education (NT and SA), infants/early childhood (0-6 years; TAS, SA and VIC), education (VIC), children up to 12 years (NT and TAS), youth justice (NT, SA, and VIC) and adolescents (TAS and SA).

Making FASD History – Newcastle (Telethon Kids Institute, 2020)

- This project aimed to sustainability build the capacity of local health services to prevent FASD. One aspect of this project was developing a youth justice MOC.
- The aim of this MOC was to improve diagnosis and management of young people with FASD and other neurodevelopmental disorders in contact with the youth justice system in Newcastle, and thus reduce the risk of harm to both themselves and others and break a cycle of reoffending.
- A MOC tool was created and made available to staff across the youth justice space in Newcastle. This included the youth justice MOC (which assists staff to understand the pathway a young person, who may have a FASD or other neurodevelopmental impairment, travels in their journey through the justice system), information about warning signs of FASD across the lifespan, a diagram of FASD impairments and assessments across the lifespan, and the FASD diagnostic guide.

Initiated before the launch of the Strategic Action Plan

Referral pathway framework for FASD in the Pilbara (WA) (Fitzpatrick et al., 2020)

- This project, which was initiated in 2016, involved the development of localised referral pathways to enhance the journey to diagnosis, treatment, and support for FASD. Three referral pathway templates were developed to identify key stages of an individual's interaction with the relevant service providers, including health, education, and justice systems.
- The health system MOC template includes information for the antenatal, newborn/postnatal, and early childhood periods (0–4 years).
- The education system MOC template is intended to provide a guide for children of school age (4–10 years).
- The justice system MOC template is designed for those working in youth justice and adult services and support (10+ years).
- These MOC templates have been used (and adapted) into other areas outside of the Pilbara since this project was conducted.

Practice principles for supporting children living with FASD (McLean et al., 2014)

- Ask about the impact of parental alcohol consumption on children's development.
- Ensure children are supported by ongoing and specialised case management.
- Adapt services to accommodate children with "brain-based" barriers to service use.
- Reframe challenging behaviour as a "brain-based" difficulty.
- Ensure the environment is simplified, structured, and supervised.
- Teach (and re-teach) children missing skills using enhanced methods.

FASD Model of Care Implementation Forum (Government of Western Australia Department of Health, 2012)

- The report contains 33 recommendations across the continuum of care (which includes primary prevention, early detection of risk factors and secondary prevention, and disease management and tertiary prevention) and emphasises holistic prevention strategies to reduce the prevalence of FASD.
- Recommendations focus on preventing people becoming at risk of FASD, preventing progression to established disease and hospitalisation, preventing/delaying progression to complications, and the management of FASD.

6.3.2 To what extent are the models of care used where there is a high prevalence of FASD and limited access to services?

Overview of response:

Online survey responses demonstrated that there were mixed responses regarding the use of MOC for individuals with FASD, with many not knowing if they had a MOC in their practice to support individuals with FASD or suspected FASD. Notably, there were very few practitioners who discussed adapting/modifying their MOC in situations where there is a high prevalence of FASD and/or limited access to services. This may reflect the infancy of this field, which is perhaps trying to promote awareness of FASD more broadly in healthcare settings. Once this is achieved, further work in this space may need to focus on the applicability of FASD support and management in more at-risk populations.

Details:

To answer this question, relevant health professionals and key stakeholders from the DOHAC and National FASD Advisory Group were asked to describe their MOC in more at-risk populations. Of note, the MOC mentioned in question 6.3.1 above also details MOC in populations with high prevalence of FASD (such as the youth justice system).

Online surveys

Healthcare practitioners ($n = 10$), maternal and child health practitioners ($n = 23$), mental health practitioners ($n = 4$) and AOD practitioners ($n = 6$) were asked to discuss the specific MOC, or way of working within their practice, to support individuals with FASD or suspected FASD. In addition, respondents were asked whether they used the same MOC in populations of high prevalence of FASD and in populations that have limited access to health and community services.

- Healthcare practitioners

Only half of the healthcare practitioners indicated that they have a MOC in their workplace. Two respondents discussed a MOC that is more general in nature (i.e., *"Supporting foster carers to support children"*), while the other three respondents detailed a specific MOC for people with FASD or suspected FASD, which typically involved the use of external referrals or support. Two of these respondents also indicated that the current Strategic Action Plan influenced their MOC.

"Referring women on from antenatal appointments to appropriate supports without judgment." (Registered nurse)

“In my recent role, we undertook assessment of young people with complex experiences and behaviours. We were not the FASD team, however, so would refer to that team for formal diagnosis if suspected.” (Tertiary education)

“NDIS support through developmental delays” (Social work)

Only one respondent provided detail about how they adapt their MOC to support individuals with FASD or suspected FASD in populations of high prevalence of FASD, stating that they use a “*broad AOD [alcohol and other drug] CPG [clinical practice guidelines]*”. Two respondents indicated that they used a different MOC for populations that have limited access to health and community. However, neither of these respondents provided additional detail about how they adapt their MOC.

- *Maternal and child health practitioners*

Eighteen maternal and child health practitioners discussed the MOC used in their practice. Of these, 11 detailed that they have a MOC in their workplace, while seven indicated that they did not have a specific MOC for FASD. Referral to or support from other specialised services was the most common MOC identified ($n = 8$), typically involving referral to or support from paediatrician/paediatrics.

“Pregnant women (if identified) can be cared for antenatally in the Drug and Alcohol clinic by the multidisciplinary team (midwives, obstetrics, neonatology, social work, mental health). Postnatally, babies would be reviewed by Paeds.”

“Referral to paediatrician, speech therapy/OT/ physio- support for the family unit and ongoing input.”

Two respondents indicated they followed a continuity of care model to support parents who have, or may deliver, a child with FASD.

“I work in a continuity of care model. This allows us to work closely with pregnant women whom we suspect will deliver a baby with FASD. We have open conversations about what to expect in terms of newborn behaviour as well as hospital protocols around observation and management.”

Finally, one respondent indicated that they followed the “*Midwifery all risk model MGP*”, however, further detail regarding what this is was not provided.

Two respondents indicated that they change their MOC for those in populations of high FASD prevalence, specifying that high-risk women are transferred to a specialised team to monitor symptoms and assist with substance use. All respondents indicated that they did not modify their MOC for populations that have limited access to health and community services.

- *Mental health practitioners*

All respondents discussed their MOC, with three mental health practitioners noting that these typically followed traditional MOC for mental health clients (i.e., the biopsychosocial model, or the stepped care approach). The other respondent indicated that the Strategic Action Plan influenced their way of working to support individuals with FASD or suspected FASD:

“I saw a presentation at the ANDC in Tasmania and it made me more aware of the signs and symptoms, assessment tools, treatment approach and other support services.”

Two respondents indicated that they modify their MOC to support individuals with FASD or suspected FASD in populations of high prevalence of FASD and/or populations who have limited

access to health and community services, however one respondent noted that this was due to experience in the field rather than a MOC to base their practice upon.

"I have different evidence-based intervention approaches for different referral reasons and client presentations."

"I am using 25 years of alcohol and drug nursing with a high input of working in this space in the 1990's... there is NO identifying model of care. You may find it is clinical knowledge."

- AOD practitioners

All AOD respondents were unable to identify any specific MOC or way of working to support individuals with FASD or suspected FASD. As such, all respondents indicated they would use the same MOC to support clients rather than modifying for populations of high prevalence of FASD and/or populations who have limited access to health and community services.

Stakeholder interviews

Representatives from the DOHAC described limited progress in terms of MOC development and use where there is a high prevalence of FASD and limited access to services. Specifically, interviewees noted that states and territories need to play a bigger role in developing and implementing ways to support those who are at a greater risk of being impacted by FASD.

Conversely, representatives from the National FASD Advisory Group described some good examples of progress in this area, noting the national FASD campaign as a key initiative to MOC development and use in at-risk populations that is supported by the Strategic Action Plan. Importantly, it was noted that to facilitate progress in developing targeted strategies and models of care for groups who are at higher risk of FASD than the general population, such efforts need to be tailored to, and heavily influenced by, the local environment. However, it was also noted that more work needs to be done to develop suitable models of care in this area.

What we've heard from NACCHO [The National Aboriginal Community Controlled Health Organisation] is that there is a need for specific models of care. And models of care that might not be as rigid or [that are] a little more flexible and allow them to diagnose and provide supports, even in remote communities.

6.3.3 To what extent have mental health and drug and alcohol services adopted the routine consideration of FASD in their diagnostic and management plans and interventions?

Overview of response:

Some AOD and mental health workers reported that they enquire about FASD diagnoses when admitting/assessing new clients, however, very few screened for FASD when individuals presented without a pre-existing diagnosis. The implications of this are that the challenges an individual may face that are attributable to FASD may not be appropriately considered in their mental health and/or AOD intervention and management plans.

Details:

Online surveys were conducted of AOD practitioners ($n = 6$) and mental health ($n = 4$) practitioners to assess whether a diagnosis of FASD is queried at intake or as part of diagnostic and management

plans, whether there is a formal process for routine screening and referral for FASD diagnosis, and whether interventions within these services are modified to account for diagnosis of FASD.

Two AOD respondents and three mental health respondents indicated that they ask clients about a diagnosis of FASD at their service, with all respondents except one outlining that this occurs during admission or in early assessment. However, if an individual presents without a pre-existing neurodevelopmental or behavioural diagnosis, only one AOD and one mental health practitioner indicated that FASD screening is undertaken as part of their routine examination. If an individual is deemed to be likely impacted by FASD, both practitioners who reported engaging in FASD screening had an understanding of how to support this individual to obtain a formal diagnosis. This involved reviewing past medical history and referring to other relevant health professionals (such as a GP and a neuropsychiatrist) to facilitate the appropriate assessments. Finally, one AOD and one mental health practitioner indicated that interventions are modified in their service to account for a diagnosis of FASD. Specifically, one respondent outlined additional supports are provided where needed, while the other respondent noted that they ensure all interventions are individualised.

These findings suggest that asking about a diagnosis of FASD and screening for FASD when a diagnosis is not yet established may not be common practice in all mental health and drug and alcohol services. As such, FASD may not be a deliberate consideration in interventions and management plans. Of note, the number of responses from those people working within the mental health and AOD space in this survey is low, therefore seeking a more representative sample in future would be beneficial.

6.3.4 To what extent are Commonwealth, state and territory and local government legislation and policy influenced by the Strategic Action Plan to appropriately recognise FASD as a disability, and improve the extent to which individuals' and their families' needs are met?

Overview of response:

FASD is not included on the List of Recognised Disabilities in Australia, however, people with FASD may be eligible for NDIS support. There have been some proposed policy changes surrounding independent assessments and NDIS reforms that could potentially make it more difficult for individuals with FASD to obtain government support, however, it is understood that due to concerns raised by advocates in the field, these changes are not currently being progressed.

Details:

A review of the literature revealed that there has not been any specific legislation or policy change regarding the recognition of FASD as a disability. As detailed above in section 5.2, FASD is currently not included on the List of Recognised Disabilities in Australia, however, this list represents those disabilities that would always be severe enough to qualify a parent or carer for government support. People with FASD may be eligible to receive assistance through the NDIS, wherein FASD is specifically recognised on access list B and D (see question 6.2.1.3 The National Disability Insurance Agency (NDIA) and National Disability Insurance Scheme (NDIS) for more information about FASD and the NDIS).

In November 2019, the intention to implement the use of independent assessments, which would require a participant/prospective participant to undertake assessments for the purposes of access, planning and plan review decisions (Joint Standing Committee on the National Disability Insurance

Scheme, 2021) was announced by the former Australian Government. However, in April 2021 the rollout of independent assessments was paused pending closer consideration of the outcomes of pilot programs (which were run throughout 2018-19 and 2019-20) (Joint Standing Committee on the National Disability Insurance Scheme, 2021). In July 2021 it was announced that independent assessments would not proceed (Ministers for the Department of Social Services, 2021). This presents as a positive decision in terms of FASD recognition, as many submissions were made to the Joint Standing Committee on the National Disability Insurance Scheme (2021) detailing concerns about the proposed assessment tools and assessors used for independent assessments. There were also submissions made detailing concerns from the perspectives of people with disabilities and their families. These included the fear and anxiety of undertaking a further independent assessment after all the assessments they had already done, the possibility of losing their funding based off an assessment from someone who does not know them, and concerns about the accuracy of independent assessments for fluctuating or rare disabilities.

Objective: Support for parents, carers and families in education and employment settings

6.3.5 To what extent have FASD resources been expanded for individuals, their families and carers including information about the diversity of support services available (e.g., suicide prevention programs, sporting programs, peer and family support groups, parent training programs, vocational and training services)?

Overview of response:

The FASD Hub and NOFASD websites offer a suite of FASD educational resources and training opportunities. Both websites tailor their resources to different audiences, including the general population, parents/carers, professionals, and people who are pregnant or trying to conceive. While there is information about support services available through these websites, this more focuses on support clinics for individuals, peer and family support groups, and education/training programs rather than about mental health support or sporting programs.

Details:

To answer this question, a review of FASD resources on two key FASD websites, the FASD Hub (www.fasdhub.org.au) and NOFASD Australia (www.nofasd.org.au/), was conducted to determine coverage of diverse support services. Both the FASD Hub and NOFASD are funded through the DOHAC and provide a wealth of FASD information and resources to the Australian community. These resources have a large focus on awareness, education/training opportunities, and supports and resources concerning FASD, however, do not necessarily focus on supports outside of the FASD-area, such as suicide prevention programs or sporting programs.

6.3.5.1 FASD Hub

In 2016 the DOHAC, under the Substance Abuse Prevention and Service Improvement Grants Fund, funded the University of Sydney to commence the development of a FASD online hub. This was first launched in 2017 and has since received additional funding from the Federal Government, through the Drug and Alcohol Program, for its continuation (2022-23).

The FASD Hub is designed to be a comprehensive (one-stop-shop) online repository that contains information, tools, and resources concerning FASD in Australia. The FASD Hub provides general information about FASD as well as information and resources that are tailored for a variety of

groups; including health professionals, other professionals who may also interact with people with FASD, the general population, parents/carers of individuals with FASD, people planning a pregnancy, currently pregnant, or breastfeeding, policy makers, and governments. In addition, the FASD Hub has a services directory where health professionals and/or health services can register their services, information on the latest FASD training and support resources available, and links to access relevant FASD research and publications.

The FASD Hub has made the information and resources available to individuals, families, carers, and professionals easy to access, including information about what support options are available (ranging from parent and carer support groups, education/training resources for professionals, Government support options, and specific FASD services that can be contacted). Below details the main information available on the FASD Hub for each group.

Health professionals

Information and resources concerning assessment (how to assess maternal alcohol use and FASD), diagnosis (how to make and report a FASD diagnosis, as well as the benefits of diagnosis), and management (how to create a FASD management plan, how to incorporate relevant interventions into the management of FASD, and the use of medication). Fact sheets are also provided for support managing other problems among children with FASD, as well as relevant research and prevention-based resources. www.fasdhub.org.au/help-me-choose/for-health-professionals/

Other professionals (i.e., teachers, justice professionals, and service providers)

Information and resources focus on understanding what FASD is and the role these professionals can play in supporting people with FASD. There is information about how to best manage FASD in different workplaces/settings (e.g., learning strategies to employ in education settings, support available through each state/territory education department for students with additional needs), why a diagnosis is important (including resources for referrals), and how individuals with FASD can be supported by the Government. www.fasdhub.org.au/help-me-choose/for-other-professionals/

Additional specific resources are provided for:

- Teachers regarding management approaches in the classroom, including modules regarding how FASD impacts learning
- Those working in the justice sector, including educational videos about how FASD may impact people who come into contact with the justice system, training that justice professionals can do to better understand FASD, and relevant research/publications/past court proceedings that featured FASD; and
- Service providers (such as those working in child protection, out of home care, disability, mental health, and drug and alcohol organisations), including information about best practice principles to reduce the impact of FASD on children's lives and recommendations for how to ensure best practice is followed when interacting with people with FASD.

The general population

Information and resources about understanding FASD, preventing FASD, dispelling the myths surrounding alcohol and pregnancy, and the diagnostic and assessment process for FASD. www.fasdhub.org.au/fasd-information/

Parents and carers

Information and resources about understanding FASD, why avoiding alcohol whilst planning a pregnancy, pregnant or breastfeeding is the safest choice, the importance of a diagnosis (and where to locate FASD-informed services), managing FASD, and support options. There are also links for training/education, support groups, and Government support options. www.fasdhub.org.au/help-me-choose/for-parents-and-carers/

Pregnant, breastfeeding, or trying to conceive women

Information about the risks associated with drinking alcohol while pregnant and breastfeeding. Resources include access to the Australian guidelines to reduce health risks from drinking alcohol, fact sheets concerning alcohol and pregnancy, frequently asked questions (and answers) disproving common myths about alcohol use during pregnancy, and campaign videos containing the key messages for people regarding the impact of alcohol during pregnancy. www.fasdhub.org.au/alcohol--pregnancy/

Policy makers and government

Information about relevant guidelines, strategies, reports, Commonwealth and State/Territory inquiries, and policies concerning FASD. www.fasdhub.org.au/fasd-information/understanding-fasd/fasd-and-alcohol-policies/

First Nations populations

Information and resources made by First Nations peoples for First Nations peoples regarding alcohol use and pregnancy. Resources include educational videos, research concerning FASD in First Nations populations, First Nations FASD booklets/posters/brochures, and a link to access The Australian Indigenous Health/InfoNet: Alcohol and Other Drugs Knowledge Centre website (which includes additional resources and information on FASD policies and programs). www.fasdhub.org.au/help-me-choose/for-australian-indigenous-research-and-resources/

6.3.5.2 NOFASD

NOFASD Australia was founded in 1999 and run on a volunteer basis. Since 2012, NOFASD has received funding through the DOHAC.

NOFASD aims to provide a link between those with lived experience of FASD and researchers and clinicians in the field. The website contains an abundance of information for the general Australian population, as well as specific resources targeting service providers and parents, carers, and families. NOFASD also has a confidential hotline that people can call for information or support.

NOFASD's has benefitted from funding security and continuity since the commencement of the SAP, allowing the organisation to expand and refine their significant service offering and reach new groups.

Below details the main content presented on the NOFASD website:

Alcohol and pregnancy

Information provided about what FASD is and the current guidelines pertaining to alcohol and pregnancy. This section of the website also includes a pregnancy podcast, containing several episodes which feature a variety of experts and people with lived FASD experience, as well as resources (information cards, booklets, brochures, other websites/campaigns) which relate to alcohol use and pregnancy. www.nofasd.org.au/alcohol-and-pregnancy/

Resources for parents, carers, and families

Information provided about the effects of FASD and how parents, carers and families can support people with FASD. There are many downloadable fact sheets, presenting topics such as behaviours typically associated with FASD and management strategies, as well as advice cards that can be used in public situations wherein community members may not understand what FASD is and how it is impacting a situation. NOFASD has also created a FASD toolkit for parents, carers, and families, which provides a comprehensive guide with links to many resources to help navigate FASD in Australia. Lastly, there is a section concerning support for caregivers, which highlights many different support groups (including specific programs, social media pages, and international support pages) and the National helpline run through NOFASD. www.nofasd.org.au/parents-carers-and-families/

Resources for service providers

Information and downloadable resources provided for an array of community groups and professionals to raise awareness about the risks of drinking alcohol during pregnancy and to provide a better understanding of FASD. There are specific resources directed at those working in the health, education, and criminal justice sector, as well as resources directed at all service providers, such as the inclusive language guide and current FASD research. www.nofasd.org.au/service-providers/

NDIS

Information about how to navigate the NDIS system, including fact sheets and example templates. See question 6.2.1.3 The National Disability Insurance Agency (NDIA) and National Disability Insurance Scheme (NDIS) for an overview of the NDIS. www.nofasd.org.au/ndis/

Frequently asked questions

There is a page dedicated to frequently asked questions (and answers) regarding FASD, living with FASD, alcohol and pregnancy, diagnosis and assessment, and FASD prevalence. www.nofasd.org.au/fasd-faq/

Education and training

There are many virtual workshops available upon request through NOFASD. These focus on general information and strategies, however, there is also the option to request a tailor-made workshop. Further, NOFASD has launched the Australian Foundations in FASD online course (free for people to complete), educational webinars for parents/carers, occupational therapists, and teachers/educators, as well as two three-part webinar series about supporting your child to learn and child to parent violence. Links are also made to other Australian and international educational resources created outside of NOFASD. www.nofasd.org.au/education-training/

- 6.3.6 To what extent are children with FASD receiving specialised school programs to address their particular needs including education and training for teachers about FASD, evidence-based classroom strategies and involvement in the delivery of individualised education plans (IEP)?

Overview of response:

There are many Australian and international resources available for educators to support children with FASD within the schooling environment, including books, education modules, and specific programs. Each state and territory education department have available resources for teachers to assist in supporting students with disabilities, however, not all states and territories contain FASD-

specific information and resources. The resources and training opportunities identified do not appear to be compulsory for educators to have/complete, therefore they may only be accessed by teachers who seek this information/professional development specifically.

Details:

To answer this question a review of the literature was conducted. This revealed an array of resources available for teachers to assist with managing students with FASD in the classroom. A summary of the resources available in Australia and internationally are detailed below.

6.3.6.1 Australian Resources

1. *Fetal alcohol spectrum disorder (FASD) and complex trauma: A resource for educators, 2018*
<https://mwrc.com.au/pages/mwrc-blog>

This book, created by the Marninwarntikura Women's Resource Centre, aims to support schools, educators, and community members to recognise, understand and work effectively in schools with students with FASD and complex trauma. Further, this resource aims to help educators describe the common learning and behavioural characteristics of children with FASD, present evidence-based strategies that may be helpful in meeting the complex needs of these children and young people, and provide links to further resources that will assist teachers with more comprehensive advice and support. While the resource has been written for educators and school communities in WA, the materials are also relevant for all school communities across Australia. This resource encourages educators to:

- Screen children at school and (where necessary) refer them for multidisciplinary assessment
- Implement therapeutic supports within the school
- Focus on building the capacity of families
- Collaborate between teachers and multidisciplinary teams to develop care plans that take into account individual students' learning needs

2. *The Alert Program*
<https://alcoholpregnancy.telethonkids.org.au/our-research/research-projects/alert-program/>

Used worldwide, this is an 8-week (8-lesson) program about self-regulation. The Alert Program was originally developed in the United States to assist children who may face challenges such as autism and ADHD to self-regulate (the ability to attain, change or maintain an appropriate level of alertness for a task or situation).

The Alert Program has been used in Australia (in WA) as a teacher delivered FASD intervention – this was conducted by the Telethon Kids Institute (<https://www.telethonkids.org.au/projects/alert-program/>) and funded through an NHMRC grant. In particular, the program was adapted to meet the cultural and contextual needs of the Fitzroy Valley First Nations community and translation of findings to community stakeholders such as schools and allied health teams across Australia where similar programs exist. The following papers have been written concerning the findings of the Alert Program in Australia:

- The development of a culturally appropriate school-based intervention for Australian Aboriginal children living in remote communities: A formative evaluation of the Alert Program® intervention (2016 publication)

- Improving self-regulation and executive functioning skills in primary school children in a remote Australian Aboriginal community: A pilot study of the Alert Program (2019 publication)
- RE-AIM evaluation of a teacher-delivered programme to improve the self-regulation of children attending Australian Aboriginal community primary schools (2019 publication)

3. *Western Australia Department of Education FASD Module*

<https://www.education.wa.edu.au/fasd>

This is a 4-part module examining how FASD impacts on learning, and is designed for school leadership teams to present to their staff. It demonstrates the importance of providing supportive learning environments, as well as a range of strategies that support all students with diverse learning needs to access the curriculum and to develop personal and social capability. This resource specifically references the Strategic Action Plan and provides an overview of what FASD is, how FASD may impact children in the classroom, and how educators can better support these children to learn.

4. *Supporting School-age Children with Fetal Alcohol Spectrum Disorder (WA), 2019*

<https://ddwa.org.au/resources/supporting-school-age-children-with-fetal-alcohol-spectrum-disorder-fasd/>

This resource is a booklet/guide to support parents and teachers to manage FASD in children. It is written by FASD health professionals and researchers and provides teachers with strategies to assist in the management of FASD in their classroom. Key topics include

- Understanding FASD
- Information about the needs of children with FASD
- Strategies to meet the needs of children with FASD
- Learning and support strategies at school
- Where to get support and information

5. *Education for teachers in SA*

<https://www.education.sa.gov.au/schools-and-educators/health-safety-and-wellbeing/specific-conditions-and-needs/supporting-children-and-students-fetal-alcohol-spectrum-disorder-fasd>

This resource provides information about managing FASD in education settings, including the use of health support plans and agreements, behavioural support strategies such as the regulation scale and templates for understanding student behaviour, and the use of interoception as a teaching method in the classroom (skill for self-management and self-regulation).

6. *NOFASD Introduction to Teachers resource*

<https://www.nofasd.org.au/wp-content/uploads/2021/08/Download-a-version-here.pdf>

Developed in New Zealand and adapted by NOFASD Australia, this resource provides teachers with a template for how to engage with a child with FASD. Parents and caregivers can use this booklet to provide information about their child, their strengths and challenges, and ideas on how to best support their child.

7. *Understanding FASD in Schools: Capacity Building for Educators*

<http://connections.edu.au/projects/understanding-fasd-schools-capacity-building-educators>

This Australia-wide project is led by the Matilda Centre for Research in Mental Health and Substance Use at the University of Sydney, and aims to address the important gap in educator's skills and

knowledge by providing school leaders, teachers, and the broader school community with easy-to-access evidence-based resources and tools to sensitively and effectively recognise and respond to potential indicators of FASD. While there is not much information currently available concerning this project, the project intends to meet the following three phases:

- Review current national and international FASD resources available within the education sector to educate staff and mentor students with FASD
- Develop and/or modify evidence-based information and training resources to assist the education workforce to understand the impact of FASD on classroom behaviour and learning, identify students with potential FASD indicators and facilitate appropriate referral for diagnosis and support, and improve capacity of teachers and support staff to adopt a strengths-based approach to encourage greater participation and work effectively with children with FASD and their parents/carers
- Promote, disseminate, and evaluate the resources nationally to support staff and students with FASD

8. *Guided Growth, 2020*

<https://www.ntiupstream.com/>

This book incorporates the latest research-based information into a guide designed for teachers, parents, physicians, psychologists, and others working with FASD.

9. *Explained by Brain*

<https://www.jumpstartpsychology.com/Explained-by-Brain-Group.html>

Explained by Brain is a suite of FASD resources for parents, carers, educators and professionals. It includes free downloadable workshops and short videos, and a FASD workbook and online course are available for purchase. This resource was created by Dr Vanessa Spiller; a clinical psychologist and parent.

10. *Classroom adjustments: Fetal Alcohol Spectrum Disorder (FASD)*

<https://www.nccd.edu.au/professional-learning/classroom-adjustments-fetal-alcohol-spectrum-disorder-fasd>

This podcast series, found on the Nationally Consistent Collection of Data on School Students with Disability (NCCD) website, discusses a range of classroom adjustments that can be made by teachers to enable students with disability to access and participate in education on the same basis as their peers. These podcasts are classified as professional learning for educators, and there is a 25-minute podcast specific to FASD. Topics discussed include common difficulties experienced by children with FASD in the classroom, strategies that can help to overcome such difficulties, and how to manage the classroom environment to avoid a sensory overload.

11. *State and territory education department resources*

Each state and territory education department has information regarding how to support students with disability at school. All education departments highlight that reasonable adjustments for students with disability are made to ensure that they can access and participate similarly to their peers. Information provided on these websites is of a general nature rather than FASD-specific.

- ACT: <https://www.education.act.gov.au/support-for-our-students/students-with-disability>
- NSW: <https://education.nsw.gov.au/teaching-and-learning/disability-learning-and-support>

- NT: <https://nt.gov.au/learning/special-education>
- QLD: <https://education.qld.gov.au/students/students-with-disability>
- SA: <https://www.sa.gov.au/topics/education-and-learning/disability-and-special-needs>
- TAS: <https://www.education.tas.gov.au/supporting-student-need/support-students-disability/>
- VIC: <https://www2.education.vic.gov.au/pal/students-disability/policy?Redirect=1>
- WA: <https://www.education.wa.edu.au/children-with-special-educational-needs>

In addition, some states/territories provide additional resources to teachers to assist with supporting students with disability. These are outlined below:

- *NSW*. Professional online learning/courses are available for teachers to access through NSW education. These courses help teachers to support students with a range of disabilities or needs. https://education.nsw.gov.au/teaching-and-learning/disability-learning-and-support/personalised-support-for-learning/professional-learning#sidenavigation_auto
- *QLD*. QLD education mentions FASD under neurological conditions, and refers teachers to the NOFASD website (<https://www.nofasd.org.au/>), the FARE website (<https://fare.org.au/>), and a parenting website (<https://raisingchildren.net.au/guides/a-z-health-reference/fasd>) for more information.
- *VIC*. The Victorian Deaf Education Institute provides an array of professional online learning programs that teachers can access for a small fee (\$30-\$100). Programs are not FASD-specific, but there are some programs that are applicable to all disabilities (e.g., Setting up Inclusive Learning Environments, Keeping the Student at the Centre: A Support Planning Approach that Works). <https://www.deafeducation.vic.edu.au/professional-learning/catalogue>.

The Department of Education also provides professional development opportunities: <https://detbehavioursupport.vic.edu.au/>; <https://deecdvic.tech-savvy.com.au/>.

Finally, AllPlay Learn is a program available to support Victorian education and schools. AllPlay Learn helps to create inclusive education environments for children and young people with developmental challenges and disabilities through practical online information, courses, and resources for teachers. Information and resources are available for early childhood education and care settings, primary schools, and secondary schools. <https://allplaylearn.org.au/>

- *WA*. WA offers FASD-specific training through the 'Students with diverse learning needs hub'. <https://www.oneclassroom.wa.edu.au/ssend/online-resources>

12. Reframe training

<https://www.telethonkids.org.au/reframe/>

Developed by researchers at the Telethon Kids Institute, reframe training is an evidence-based program that aims to educate frontline professionals to recognise and understand neuro-disability in young people, reframe associated behaviours, and respond appropriately. The program was initially tailored for the youth justice workforce but is now open to anyone who interacts with individuals with complex needs and behaviours.

13. FASD Hub e-modules

<https://www.fasdhub.org.au/fasd-information/assessment-and-diagnosis/guide-to-diagnosis/eLearning-modules/>

These modules, which were updated in 2019, are designed to provide health professionals (including teachers) with an understanding of the risks and effects of alcohol use in pregnancy and how to assess alcohol use in pregnancy, how to conduct a diagnostic assessment and discuss the diagnosis, how to develop a management plan to supporting families and individuals after a FASD diagnosis, and an understanding of referral and screening criteria for FASD.

14. Learning with FASD

<https://learningwithfasd.org.au/>

The Learning with FASD portal, which is funded by the DOHAC, was launched in April 2022, and provides educators with evidence-based resources to help them understand and support children with FASD in Australian primary schools. This website contains information to assist educators to:

- Understand FASD in general and in a schooling environment
- Understand what to do if there are concerns about a student, including information about the referral and diagnostic process
- Employ classroom strategies to help support teaching and learning and a supportive classroom environment
- Effectively communicate with parents and carers

In addition, the Learning with FASD portal also has a quiz that educators can use to test themselves on each of the core topics presented on the website, along with a list of external resources that may provide additional helpful information about FASD in schooling environments.

6.3.6.2 International Resources

1. *Eight Magic Keys (Canada)*

<https://www.nofasd.org.au/supporting-students/>

Developed in Canada by Deb Evensen and Jan Lutke, this resource by 'WRaP Schools' outlines the guidelines that teachers can use to support young people with FASD in the classroom. The 9 guidelines are:

- Concrete (avoid words with double meaning, abstract terms, sarcasm, and the use of idioms or analogies - this is challenging for concrete thinkers)
- Simplicity (keep instructions short, sweet and clear, the environment decluttered, the directions short)
- Repetition (overcome issues with slow processing, short term memory loss, short attention span)
- Supervision (people with FASD often have difficulties with memory, lack of impulse control, and poor judgment - and therefore benefit from constant supervision and structure, use of gentle reminders, and small steps taken to increase independence)
- Specific (be clear, be exact, tell them all the steps and don't assume anything)
- Consistency (change can lead to a person with FASD becoming very flustered and overwhelmed - need to have a constant, consistent, predictable, structured environment)

- Structure (structure and predictability is key. Have clear routines. Having choices is ok, but offer suggestions to limit choices or pre-warn students about these situations to help students not feel so overwhelmed)
- Routine (eliminates power struggles, increases cooperation, increases sense of mastery/competence)
- Teamwork (collaborating with teachers and peers to ensure they receive the support and guidance needed to thrive)

2. *Supporting Students with Fetal Alcohol Spectrum Disorders (Canada)*

<https://www.engagingalllearners.ca/il/supporting-students-with-fasd/>

This resource (three modules) provides an explanation of FASD and its impact on the brain, as well as exploring behavioural patterns in students with FASD and strategies for designing classroom instruction and routines to support these students.

3. *What Educators Need to Know about FASD Working Together to Educate Children in Manitoba with Fetal Alcohol Spectrum Disorder (2018) (Canada)*

https://www.gov.mb.ca/fs/fasd/pubs/fasdeducators_en.pdf

A guide, developed by Healthy Child Manitoba and Manitoba Education and Training, to assist classroom teachers with strategies to best support a child with FASD in the classroom.

4. *Supporting and Teaching Learners with FASD - Educator Handout (2019) (Canada)*

<https://www.fasdoutreach.ca/resources/all/s/supporting-and-teaching-learners-with-fasd-educator-handout>

This guide provides teachers with information about FASD, what other disabilities are commonly associated with FASD, and strategies to help support children with FASD.

5. *Communication: For Learners with FASD and Other Complex Learning Needs (2018) (Canada)*

<https://www.fasdoutreach.ca/resources/all/c/communication-brochure>

This brochure outlines strategies for teachers to improve communication with learners with FASD and other complex learning needs.

6. *Environment: For Learners with FASD and other Complex Learning Needs (2018) (Canada)*

<https://www.fasdoutreach.ca/resources/all/e/environment-brochure>

This brochure that provides strategies for teachers for setting up a classroom environment to create a supportive environment for learners with FASD and complex learning needs.

7. *POPFASD TalkED (Canada)*

<https://www.fasdoutreach.ca/resources/collections/popfasd-talked>

This 7-part podcast series, created between 2019-2020, discusses research and strategies related to education and FASD.

8. *Teachers Toolbox (US)*

<https://do2learn.com/disabilities/FASDtoolbox/index.htm>

This resource provides guidance and examples of activities that teachers can use in the classroom to assist with classroom management or different learning strategies. The do2learn webpage also details FASD specific strategies that can be used to help support a child with FASD across multiple domains, including cognitive development, motor development, visual/special skills, auditory

processing, and general behaviour management. This can be found here:

https://do2learn.com/disabilities/CharacteristicsAndStrategies/FASD_Strategies.html

9. *Reach to Teach: Educating Elementary and Middle School Children with Fetal Alcohol Spectrum Disorders (US)*

https://www.vitalitenb.ca/sites/default/files/reach_to_teach.pdf

This is a resource for parents and teachers to use when educating elementary and middle school children with FASD. The 60-page booklet provides tools to enhance communication between parents and teachers, including schedules, strategies, and problem-solving. This resource was developed by the Substance Abuse and Mental Health Services Administration, an FASD Center for Excellence.

10. *National Organisation for FASD (UK)*

<https://nationalfasd.org.uk/learn-more/practitioners/educators/>

This website provides a range of downloadable fact sheets and resources which detail ways that educators can support a student with FASD across several domains (e.g., the environment, approach style, how to ensure they understand a task), checklists to help make situations more manageable, information about common strengths and weaknesses, and strategies for primary and secondary aged students.

11. *Understanding Fetal Alcohol Spectrum Disorder (FASD) - What Educators need to know: For education staff working with children and young people with FASD (UK).*

<https://www.nhsaaa.net/services-a-z/fetal-alcohol-spectrum-disorder-fasd/>

https://www.nhsaaa.net/media/8391/fasd_whateducatorsneedtoknow.pdf

This handbook, published in 2019 by the NHS Ayrshire & Arran, aims to provide educators with a clear understanding of the needs of children and young people with FASD. This includes information about brain differences associated with FASD and ways that educators can help children with FASD meet their potential.

6.3.7 To what extent are supportive services for pregnant women and their partners more accessible including brief intervention for alcohol use in pregnancy, contraception and reproductive technology options and specialised treatment for pregnant women who are alcohol dependent?

Overview of response:

There are services available for pregnant women who consume alcohol (rather than just broad AOD services), wherein treatment tends to focus on rehabilitation and counselling-based options. Further, there are guidelines for identifying alcohol risk in pregnant women in Emergency Departments, however the degree to which these guidelines are followed by hospital staff could not be determined through literature searching alone. Online surveys revealed that AOD service workers generally reported referring alcohol-dependent pregnant clients to specialised services and case management and counselling, with referrals to GPs made for contraception.

Details:

To answer this question, online surveys of AOD practitioners ($n = 6$) were conducted to assess the options available to pregnant women who are alcohol dependent. Further, a literature search was conducted to review the available support services for pregnant women regarding alcohol use

during pregnancy. This included contraception and reproductive technology, as well as interventions available through Emergency Department, maternal health services, and AOD treatment services.

Online surveys

Four respondents indicated it was commonplace to refer or recommend clients to a GP for contraception, however, one of these respondents also noted that their service provided condoms. The other two respondents indicated contraceptive support options for women who are alcohol dependent were not available at their service, likely because their service does not target pregnant women.

Four respondents discussed the support, management, and intervention options available at their service for pregnant women. This included referral to chemical/substance use in pregnancy services (CUPS/SUPS), AOD specific programs, case management, counselling, and AOD withdrawal support.

“Attendance to weekly CUPS appointments, and ongoing collaboration with their local CUPS/SUPS services in the community.”

“As well as the usual AOD programs we have an intensive case management program for pregnant women. They continue to work with the woman post birth also. The program supports women to attend and seek all medical and psychological supports during their pregnancy with the view to improve the outcomes of both baby and mother. The program also assists in setting up the home ready for baby and gives ongoing education to the woman and their supports.”

“We offer inpatient detox and withdrawal support, in home counselling, day programs and GP management.”

Literature search

- *Interventions available through Emergency Departments*

The National Drug and Alcohol Research Centre (2014) developed a Guide for Primary Health Care Professionals that provides guidelines, based upon NHMRC recommendations, for identifying the risk of alcohol consumption during pregnancy for women presenting in Emergency Departments (EDs). For women who are not planning a pregnancy, it is recommended to provide contraceptive counselling or provision of contraceptives and to reinforce healthy behaviours. For women who are planning a pregnancy or who are pregnant, it is recommended to administer the Alcohol Use Disorders Identification Test (AUDIT-C) and conduct brief intervention where necessary. The AUDIT-C is a short (3-item) alcohol screening tool that can help identify people who are hazardous drinkers. It is also advised that women who are pregnant and consuming alcohol should be referred to specialist antenatal care, psychological support, and drug and alcohol treatment.

To evaluate the execution of recommendations within EDs, information presented online regarding support services and interventions were investigated in a sample of major hospitals throughout Australia: The Royal Melbourne Hospital (VIC), The Royal Women's Hospital (VIC), The Royal Darwin Hospital (NT), Liverpool Hospital (NSW), The Royal Perth Hospital (WA), The Women and Children's Hospital (SA), and The Royal Hobart Hospital (TAS). It was found that hospital websites provided broad reference to maternity services or women's health problems and pregnancy issues; however, detailed information about targeted support or intervention for alcohol use during pregnancy was unavailable to the public. Without discussion with hospital EDs in each state and territory specifically (which was outside the scope of this evaluation) the extent to which EDs implement the

recommended approaches to pregnant women presenting with alcohol consumption issues cannot be determined due to lack of available information.

- *Interventions available through maternity health services and AOD treatment services*

Table 12 summarises the support services and interventions available through maternity health services and AOD treatment services. In addition, if the services provided treatment option documents for women who use alcohol these were examined and summarised.

Typically, the services are free to access with the exception of some telephone services where calls incur a small fee. Some services require a referral from a GP, midwife, or other specialist service while others accept self-referral and feature over-the-phone or online booking systems. Primary treatment options were typically rehabilitation and counselling rather than preventative measures, such as contraceptive education. The documents available to prospective patients mainly feature general factsheets providing information about healthy pregnancies, including the core message from the current national alcohol guidelines that no amount of alcohol is safe to consume during pregnancy (National Health and Medical Research Council, 2020).

Table 12.

Support Services and Treatment Options Available through Maternity and AOD Services

Name of Service	Location	Description	Dates of availability	Treatment Option Documents	Cost
Pregnancy Help Australia ^a (Link)	Online, National	A range of support services to help women through pregnancy and surrounding problems. This includes: <ul style="list-style-type: none"> - 24-hour phone support - Individual appointments - Maternity supplies - Group workshops - Early parenting support 	Currently running, phone support is available 24/7, individual appointments and group workshop availability depends on the operating hours of the individual clinic	N/A	Free for all
NOFASD ^a (Link)	Online, National	Online or phone chat option available for people to ask staff members at NOFASD, or a family support person, questions about pregnancy and alcohol use, as well as support for parents who have a child with FASD <ul style="list-style-type: none"> - NOFASD provides resources for women who are pregnant including information about alcohol, alcohol free pregnancies, and FASD 	On demand and currently still running, information about commencement N/A	NOFASD features several resources about alcohol use in pregnancy including: <ul style="list-style-type: none"> - Brochures about FASD and supporting alcohol-free pregnancies - Access to the Australian guidelines to reduce health risks - Culturally appropriate information for First Nations populations - Access to relevant campaigns and support - FASD handbook for health professionals 	Free for all
Pregnancy, Birth and Baby ^a (Link)	Online, National	Phone or video call service where people can speak to a maternal child health nurse for advice and support	On demand and still running. Information about commencement of the program N/A	Website provides several documents that can be read or listened to. These include <ul style="list-style-type: none"> - Alcohol and Pregnancy (information about alcohol use during pregnancy, the risk it poses for FASD, and what support options are available) - Foods to Avoid When Pregnant (emphasises that there is no safe amount of alcohol to consume while pregnant) - Having a Healthy Pregnancy (provides a general overview of health recommendations during pregnancy, including those pertaining to alcohol) 	N/A

Name of Service	Location	Description	Dates of availability	Treatment Option Documents	Cost
				<ul style="list-style-type: none"> - Healthy Diet During Pregnancy (provides a general overview of what encompasses a healthy diet during pregnancy, including limiting alcohol use) 	
Substance Use in Pregnancy and Parenting Service (SUPPS) ^{b, c} (Link)	NSW	Variety of services available, including: <ul style="list-style-type: none"> - Detoxification - Links to rehabilitation facilities - Counselling - Specialised midwifery and obstetric care 	Commenced in October 2018 Assessments for treatment available 9:00am-4:30pm Monday to Friday Phone call service is also available	Pamphlet provides an overview of the service (i.e., how they work with women to make changes to alcohol use, treatment options, other relevant services). Factsheet explains how alcohol use in pregnancy can harm the developing baby, emphasises that there is no safe amount of alcohol consumption while pregnant, explains FASD, and provides numbers to local supports in NSW. The following resources are only available to health professionals with a National Drug and Alcohol Research Centre user account: <ul style="list-style-type: none"> - Guide to identifying women at risk of alcohol use during pregnancy - Guide to supporting pregnant women who use alcohol 	Free for all
Get Healthy in Pregnancy ^c (Link)	NSW	Get Healthy NSW features seven programs including a pregnancy program. A personal health coach service is available through pregnancy and early postnatal months that includes support for women to not drink alcohol while pregnant or breastfeeding. This includes: <ul style="list-style-type: none"> - 10 confidential health coaching calls - Information package and booklet 	Commenced in 2009, however the Pregnancy Program commenced in 2017 and is currently still running. Available 8am-8pm Monday to Friday A pilot study of the program was conducted from 2014-2016: see here for more details.	An online factsheet (see here) that supplements the Get Healthy service: <ul style="list-style-type: none"> - Discusses alcohol guidelines and rates of alcohol consumption amongst pregnant women - Explains how alcohol enters the baby's bloodstream via the placenta in the same concentration - Emphasises that there is no safe amount of alcohol or time to drink alcohol during pregnancy - Discusses FASD - Discusses alcohol and breastfeeding 	Free for all

Name of Service	Location	Description	Dates of availability	Treatment Option Documents	Cost
		Women can also re-enrol for free after they have used all their coaching sessions.			
MotherSafe (Link)	NSW	<p>1) A telephone service based at the Royal Hospital for Women that provides counselling for women who are concerned about exposures during pregnancy and breastfeeding^{b, c}</p> <ul style="list-style-type: none"> - Covers alcohol consumption - Face-to-face counselling is offered to some women <p>2) Pregnancy Planning, Lifestyle and Nutrition (PLaN)^a</p> <ul style="list-style-type: none"> - A pre-pregnancy planning clinic that offers education to women and their partners who are considering pregnancy. - Program: Not Pregnant, Just Looking <p>3) Complex Preconception Clinic^b</p> <ul style="list-style-type: none"> - For women and their partners who have complex medical, genetic, or obstetric conditions 	<p>1) Commencement date N/A, however this is still running from 9am-5pm Monday to Friday</p> <p>2) Commencement date N/A. Last ran on the November 16, 2021</p> <p>3) Commencement date N/A. Runs once a month</p>	<p>The website provides an online factsheet about common exposures that can be harmful during pregnancy and breastfeeding</p>	<p>1) Free for all</p> <p>2) \$25 per couple</p> <p>3) Offers Medicare billing</p>
Drug Use in Pregnancy Service (DUPS)	NSW	Clinic for pregnant women who are prescribed certain medication and women who may be using or have recently stopped using alcohol or non-prescribed drugs	Commencement date N/A, however this service is still running from 8am-4pm Monday to Friday	<p>DUPS provides a factsheet produced by the Woman Want to Know project</p> <ul style="list-style-type: none"> - Provides information for women about pregnancy and alcohol - Tips for saying no to alcohol 	N/A

Name of Service	Location	Description	Dates of availability	Treatment Option Documents	Cost
(Link)				<ul style="list-style-type: none"> - Discusses NHMRC guidelines - Encourages women who may be experiencing challenges with alcohol to speak to a doctor, midwife or obstetrician 	
Western Sydney Local Health District: The Drug and Alcohol Network ^a	NSW	Care for the management of alcohol and drug problems for individuals and families <ul style="list-style-type: none"> - Includes pregnancy services - Outpatient individual and group programs - Inpatient detoxification 	N/A	N/A	N/A
(Link) FORWAARD Aboriginal Corporation Pregnancy Program ^a	NT	The pregnancy support program is for expecting women who struggle with substance misuse use. This program provided 11 women with residential AOD care and awareness, and pregnancy support	Commenced in 2020 Ended in 2021	N/A	N/A
(Link) Women and Children's Hospital ^b (Link) (Link)	SA	Hospital provides general information about pregnancy programs recommends women attend the Alcohol and Drug Information Service SA clinic <ul style="list-style-type: none"> - Alcohol and Drug Information Service provides specialised ongoing care and support Telephone counselling, information and referral services also provided	Commencement date NA, however, this service is still running Emergency assessment service is available 24 hours a day, seven days a week and does not require an appointment Telephone service available seven days a week between 8:30am and 10:00pm	Provides a pamphlet to women who are pregnant about the hospital's pregnancy programs and information about healthy pregnancies References NHMRC guidelines that women who are planning a pregnancy, are pregnant, or breastfeeding should not drink alcohol.	Local call fee for Drug and Alcohol Information Service

Name of Service	Location	Description	Dates of availability	Treatment Option Documents	Cost
Turning Point ^{b, c} (Link)	VIC	<p>This is not a pregnancy-specific service, but offers specialist services relevant to alcohol use</p> <ul style="list-style-type: none"> - Turning Point Eastern Treatment Services Intake Service: offers triaging and refers clients onwards to appropriate treatment service - In-patient detox and short-stay rehabilitation - Specialist addiction services - Counselling - Group programs - Telephone and online services 	Commencement date NA, however, this service is still running	<p>Provides a factsheet about alcohol and other drugs</p> <ul style="list-style-type: none"> - Not pregnancy specific - Includes withdrawal support for a range of substances - Discusses harm reduction 	Free for all
Women's Alcohol & Drug Service (WADS) ^b (Link)	VIC	<p>State-wide drug and alcohol service providing specialist clinical services to pregnant women with complex substance use dependence.</p> <p>Women see a triage nurse for screening to determine suitability for admission into the clinic, and whether the women's care could be managed in a maternity hospital where the woman is based.</p> <p>Relevant services offered include:</p> <ul style="list-style-type: none"> - Addiction medicine - Drug and alcohol counselling and assessment - Midwifery and pregnancy care - Paediatric care 	<p>Commencement date NA</p> <p>Available 9:00am-5:30pm Monday to Friday</p> <p>Also includes a 24 hour on-call addiction/obstetric service for patients to contact. Provides a secondary consultation, further information is NA</p>	Factsheet summarises the effect of alcohol use during pregnancy and breastfeeding, including FASD, support/counselling options for women who are pregnant and currently drinking, and withdrawal	N/A

Name of Service	Location	Description	Dates of availability	Treatment Option Documents	Cost
		<ul style="list-style-type: none"> - Assessing and caring for babies with Neonatal Abstinence Syndrome - Infant home-based withdrawal program - Methadone stabilisation program - Mental health assessment - Nutritional care - Pharmaceutical advice and assessment <p>This service includes advice for women regarding contraception.</p>			
Women and Newborn Drug and Alcohol Service (WANDAS) ^{b, c} (Link)	WA	<p>Service for pregnant women experiencing drug and alcohol issues based at Kind Edward Memorial Hospital.</p> <ul style="list-style-type: none"> - Specialist care from a team of allied health professionals, midwifery, and medical professionals - Drug and alcohol support and counselling - Referral for women who are struggling to stop using alcohol or drugs to additional treatment services such as Next Step Drug and Alcohol Service - Services include routine scans, help with diet, social support, parental education, 	Commencement date NA, however, this service is still running	N/A	N/A

Name of Service	Location	Description	Dates of availability	Treatment Option Documents	Cost
		psychiatric support, midwifery support Includes an outreach service for prisoners who are pregnant			

Notes. N/A refers to information that was not available to the public

^a information about referral for this service was not available

^b Referral by a GP or medical professional is required for access to this service

^c Self-referral to this service is an option

6.4 Priority Area: Priority Groups

This priority area recognises that there are some groups within our society who are at a higher risk of being impacted by FASD, including those who consume alcohol at harmful levels during pregnancy, some First Nations communities, young people who engage in binge drinking behaviour, and those in the criminal justice system.

Objective: Continue to support and evaluate targeted risk strategies and models of care for groups who are at higher risk than the general population

6.4.1 To what extent are First Nations communities supported to evaluate and further develop a range of culturally appropriate prevention, treatment, and support programs?

Overview of response:

Literature searches revealed Queensland, Victoria, and Western Australia have specific programs to support First Nations families and youth. Many of these programs are early intervention and prevention focused, with some trying to prevent contact with the justice system, and others focusing on youth development and parental support. Interviews further noted that ensuring prevention and treatment efforts are initiated and run through people within the First Nations communities is essential to their success, however more work needs to occur to develop more appropriate treatment MOC within these communities moving forward.

Details:

This question was answered via a review of the literature and discussions with key stakeholders from the DOHAC and National FASD Advisory Group. Of note, programs to support First Nations communities were examined from Queensland, Victoria, and Western Australia, however such information could not be obtained for the remaining states and territories through online literature searching. Discussion with representatives from local First Nations communities in each state and territory may provide additional information in future evaluations.

Literature search

- *Queensland*

The Gidgee Healing primary health service (<https://gidgeehealing.com/services/primary-health-care/>) provides medical and clinical services to First Nations people who live in Mount Isa or surrounding regions. It is free to access for people who have a valid Medicare card and provides transport to patients. Gidgee Healing also offers a family health service that provides culturally appropriate maternal, child and family health services in addition to support programs. Their goal is to track development and ensure children and families are linked to relevant support. Services include pregnancy care, Mum's and Bub's post-natal assessments, immunisations, child health assessments, clinic appointments, home visits, transport, rheumatic heart disease management, healthy skin program, rapid neurodevelopment assessment, Mum's and Dad's health checks and family support clinic appointments. There are also Family Wellbeing services that work with First Nations families and communities to provide culturally responsive support. These services work across Youth Justice and Child Safety systems to implement early intervention and prevention. They also provide support to families after Child Safety or Youth Justice Interventions. Gidgee is funded by the Queensland Government Department of Health, Headspace, Institute for Urban Indigenous

Health, North West Hospital and Health Service, Queensland Department of Child Safety, Youth and Women, Western Queensland Primary Health Network, Checkup Australia, Griffith University, Queensland Department of Social Services, National Indigenous Australian's Agency, NDIS, Queensland Department of Education. Queensland Aboriginal and Islander Health Council, and Health Workforce Queensland. Gidgee Healing are also partners in Griffith University's Yapatjarrathati project (see section 5.4.2 Evaluation of new therapies and novel diagnostics for an overview of this project), and have implemented the Yapatjarrathati MOC at their service.

- *Victoria*

The following programs have been implemented to reduce the amount of First Nations youth who come into contact with youth justice systems in Victoria: Koori Youth Justice Program, Koori Early School leavers and Youth Employment Program, the Koori Intensive Support Program, Aboriginal Cultural Support Plans, and Youth Justice Units (see here for more information: <https://www.justice.vic.gov.au/justice-system/youth-justice/koori-youth-justice-programs>). The Koori Youth Justice Program (developed in 1992) is delivered through 15 agencies that are funded by Aboriginal Youth Justice with additional funding granted in 2020 that is set to be available until 2024 (Victorian Aboriginal Justice Agreement, 2021). In 2021, all the agencies received an additional \$10,000 one-off payment to support key efforts such as additional Community Based Aboriginal Youth Justice workers, targeted support for First Nations girls, and improving the prevention of youth justice contact (Victorian Aboriginal Justice Agreement, 2021). The additional programs are all run under the Aboriginal Justice Agreement through the Department of Justice and Community Safety however, there is no confirmation about how these programs are funded or evaluated.

- *Western Australia*

Baya Gawiy Buga Yani Jandu Yani U is an initiative ran through Marninwarntikura Fitzroy Women's Resource Centre and consists of early childhood learning, a child and parent centre and partnerships for improving wellbeing of children and families in the Fitzroy Valley (see here for more information: <https://www.marulustrategy.com.au/>). The Baya Gawiy Early Childhood Learning Unit (ECLU) is a program available to families in the Fitzroy valley that uses trauma-informed practice to provide First Nations children with early education. In 2016, Baya Gawiy developed a partnership with Goodstart under the National Partnership Agreement on Indigenous Early Partnership Agreement on Indigenous Early Childhood Development. Whilst the program is not FASD-specific, it focuses on issues in child development and aims to provide culturally appropriate intervention to ensure First Nations children have access to high quality early learning. This program initially received funding from the Government of Western Australia in 2014 to establish the centre and now receives funding partly through donations to the Marninwarntikura Fitzroy Women's Resource Centre.

The Child and Parent Centre aims to improve access to education and health for families in the Fitzroy Valley, specifically targeting children aged 0-7 years and their families. There is a focus on meeting the needs of vulnerable families. There are also community programs to improve health, wellbeing, cultural knowledge and educational outcomes for children and their families. These programs include supported play groups, mothers and babies' groups, young women's empowerment group, dads time, toy making workshops, and women's bush dyeing workshops. There is a focus on improving child development and wellbeing and strengthening the capacity of parents and carers. There is also a mobile playgroup funded by the Department of Education that extends to communities beyond the Fitzroy Valley and focuses on early learning.

Stakeholder interviews

Interviewees revealed that there has been some work done to support culturally appropriate prevention efforts through targeted health promotion in treatment services, funding programs that have an First Nations focus, and developing culturally and linguistically diverse material for First Nations communities. However, it is unclear whether these prevention efforts have been evaluated, and less was known about treatment and support programs within First Nations communities.

Further, one interviewee also discussed the fourth stream of the national FASD prevention campaign launched through FARE, which focuses on First Nations people. It was emphasised that this stream is developed and run by people within First Nations communities to ensure the messages and information presented to First Nations communities is culturally appropriate. However, it was also noted that when considering culturally appropriate treatment and support efforts for FASD within First Nations communities, more work needs to be done to develop suitable models of care.

What we've heard from NACCHO [The National Aboriginal Community Controlled Health Organisation] is that there is a need for specific models of care. And models of care that might not be as rigid or a little more flexible and allow them to diagnose and provide supports, even in remote communities.

6.4.2 To what extent are young people in detention centres and community programs for young offenders screened for FASD, offered post release referral services, and offered treatment?

Overview of response:

A review of the literature revealed that there is research to suggest that screening for FASD in youth offender populations is needed, however, there is limited information available to determine whether such recommendations have been followed.

Details:

In 2018, Elizabeth Kikkert MLA, the ACT Shadow Minister for Families, Youth and Community Services, called for the screening of FASD in Canberra's Bimberi Youth Justice Centre. It was recommended that screening tools should be conducted in accordance with the Australian Guide to the Diagnosis of FASD. Similarly, FARE (2021) put forth an Amendment Bill to the Queensland Government in 2021 which included the recommendation for FASD screening; there is no update available on whether this amendment has been considered.

The Banksia Hill Detention Centre Project (see here:

<https://alcoholpregnancy.telethonkids.org.au/our-research/research-projects/Banksia-hill-detention-centre-project/>) too revealed a need to screen for FASD in the youth justice system and implement management strategies. Within this project a FASD screening tool for use in the justice system was developed. However, since the results of this study were published there has been a lacking improvement for using screening measures in youth detention centres. A key barrier identified is the exclusion of incarcerated youth from the NDIS which means that screening and support is insufficient and the effectiveness of screening/diagnosis is minimised (Pedruzzi et al., 2021). Further barriers include insufficient training of youth detention centre staff, a lack of resources, and questionable relevancy to treatment outcomes reducing staff motivation to conduct assessment (Pedruzzi et al., 2021).

Overall, the implementation of screening processes is insufficient despite recommendations. There is limited information online about referral services offered post-release, however, an overview of stakeholder interview responses regarding treatment and referral options and support through case management is discussed in question 6.4.3 and 6.4.4 below, respectfully.

Objective: Work with the criminal justice system to implement therapeutic justice interventions

6.4.3 To what extent are staff in juvenile justice systems provided FASD education and training including identification processes and referral pathways for further assessment and support?

Overview of response:

FASD education and training provided to staff in juvenile justice systems likely differs between the states and territories in Australia, however, the current evaluation could not ascertain the extent of these differences due to limited uptake of interviews from the justice sector nation-wide for this study. FASD education and training in WA and the NT is of high quality, and may serve as a baseline for other states/territories. Further, there have been some notable advancements in training available for justice workers to independently access, including workshops, online courses, and online modules, to improve their knowledge of FASD in justice settings.

Details:

This question discusses the known opportunities for staff in the justice system to improve their understanding of FASD, which is based on information found through an online literature search and through consultation with limited experts in this field (stakeholder interviews).

Literature search

1. *Reframe training*

<https://www.telethonkids.org.au/reframe/>

Reframe training is a four-hour workshop developed by researchers at the Telethon Kids Institute and is an evidence-based program that aims to educate frontline professionals to recognise and understand neuro-disability in young people (including FASD), reframe associated behaviours, and respond appropriately. Whilst this program was initially tailored for the youth justice workforce, it is now available to anyone who interacts with individuals with complex needs and behaviours.

Reframe Training was developed following an extensive consultation process with young people in detention and professionals in the Western Australian justice and health sectors, with a pilot study in 2018 demonstrating that this training led to improvements in FASD knowledge and attitudes, staff confidence to engage with youth with neuro-disabilities, and staff intent to use recommended practices taught in the training (such as listening and repetition), as well as decreases in staff intent to use undesirable practices (such as aggression or ignoring) (Passmore et al., 2020).

2. *FASD short courses (micro-credentials) through the University of Western Australia*

As described in question 6.2.6 above, these two micro-credential short courses are suitable for people in the community or those who work in sectors that may come into contact with people with FASD to gain knowledge and understanding of FASD and the assessment and diagnostic processes.

There are no entry requirements for these short courses, however they are approximately \$800 each to do.

3. *FASD Hub training*

<https://training.fasdhub.org.au/>

The FASD Hub provides seven free self-paced e-learning modules aimed at health professionals involved in FASD assessment and diagnosis. This would be relevant for staff in juvenile justice systems to complete to gain a greater understanding of FASD (including characteristics and manifestations), how to screen for FASD, the diagnostic criteria, how to support a person with FASD, and referrals.

4. *Understanding FASD: A guide for justice professionals*

<https://alcoholpregnancy.telethonkids.org.au/our-research/research-projects/understanding-fasd-a-guide-for-justice/>

The Telethon Kids Institute have developed a range of resources to benefit people who work in the justice system in better understanding FASD. Such resources include the development of an online Continuing Professional Development (CPD) module for lawyers in Western Australia, six videos about FASD in the justice system (can be accessed nationally), and updated FASD information to the Department of the Attorney General for inclusion in Chapter 4 'People with disabilities' in the Equality before the Law Bench Book. These resources are free for people to access.

5. *Decolonising Justice for Aboriginal youth with Fetal Alcohol Spectrum Disorders*

This book, written by Blagg et al. (2020), provides justice workers with an understanding of the multidisciplinary and cross-jurisdictional analysis of issues surrounding FASD and the criminal justice system, and the impact on Aboriginal children, young people, and their families.

6. *Funding under the 2018-2019 Mid-Year Economic and Fiscal Outlook (MYEFO) measure*

Twelve activities were approved under the Strategic Action Plan program funding (\$7.2m over four years), as detailed in the submission made to the Senate Community Affairs References Committee (Australian Government Department of Health, 2019a). One of these activities involved the Australian Government allocating funds to people working in the criminal justice system to support better recognition of people affected by FASD and improving understanding of the implications of FASD within the criminal justice system. In addition, the resources may also provide information on assessment processes and management strategies to improve the outcomes of people with FASD.

Stakeholder interviews

Interviews were conducted with representatives from the National FASD Advisory Group and the Department of Justice, who were mainly able to comment on the extent to which staff in the WA and NT juvenile justice systems are provided FASD education and training, including identification processes and referral pathways for further assessment and support. Findings from these interviews revealed the following key points:

FASD education and training in the youth justice system

- Youth custodial staff in WA received FASD-specific training after the launch of the FASD diagnostic tool in 2016, however, due to high turnover in this industry this training has not been recently provided to current youth custodial staff.

- There is compulsory FASD training, delivered yearly by NOFASD Australia, for staff within the Department of Justice in WA. There are plans to make this FASD training part of the minimum requirements that are needed for workers in the justice system to complete.
- Research projects have been run in some parts of NSW (Newcastle), Victoria (Shepparton), the NT (Alice Springs) and Tasmania to develop a MOC for FASD assessment in the justice system. This work includes funding to educate youth justice officers and community corrections officers about FASD, and making services to support those impacted by FASD available.

FASD Identification and assessment in the youth justice system

- Courts in WA and the NT are responsible for ordering a FASD assessment if they are concerned about the cognitive capacity of a young person. As such, judges and magistrates are aware of developmental or cognitive impairment, including FASD, and that they can refer the individual for assessment prior to sentencing.
- Funding for FASD assessment in the justice system has been sustained since 2018 in WA, however, this is not the case nation-wide. It was noted that the funding of FASD assessments is a big barrier to obtaining a diagnosis of FASD in many justice systems.

Treatment and referral options

- A diagnosis of FASD is considered by the courts when sentencing a young person. This does not necessarily mean a lighter sentence, but it does facilitate a fairer sentence given the young person's cognitive capacity is considered.
- A diagnosis of FASD impacts the treatment and referral options recommended/provided to a young person. This applies whether they are sentenced or offered a non-custodial option, and may include access to disability support, child protection services, and First Nations liaison services.
- In WA, the courts can release information to relevant professionals about an individual's diagnosis to assist with support and management.

6.4.4 To what extent are individuals suspected of developmental or cognitive impairment accessing appropriate case management, including through the appointment of specialist court-based clinicians and access to diversionary programs in First Nations communities which involve community-controlled processes 'on-country' and provide culturally secure and appropriate environment for stabilising children with FASD?

Overview of response:

Online searching revealed there is evidence of court-based clinicians who can perform assessments and facilitate appropriate supports in most justice systems. However, whether FASD is something that is screened/considered cannot be ascertained from online searching alone. Online searches also identified several diversionary programs targeting First Nations youth; however, these seem to be more about general diversion rather than programs for youth with suspected developmental or cognitive impairment. Finally, interviewees noted that support offered through case management can be challenging due to high caseloads and the geographical location of an individual, which may result in greater reliance on the individuals' community to assist.

Details:

To answer this question, an online literature search was conducted to identify the presence of court-based clinicians and diversionary programs for children with FASD or suspected developmental or cognitive impairment in Australia. In addition, key stakeholder interviews were conducted with representatives from the Department of Justice and the National FASD Advisory Group, who mainly discussed this question in terms of the WA youth justice system.

Literature search

Specialist courts and court-based clinicians

First, the websites of courts in each state and territory in Australia were examined to identify whether they utilised specialised courts and clinicians for youth suspected of developmental or cognitive impairment. Second, a range of different terms were searched to broaden the scope of findings, such as: cognitive disability and courts, cognitive disability and the justice system, cognitive impairment and courts, cognitive impairment and the justice system, and court clinicians.

It was found that not all states and territories provided information online about whether they utilise specialised processes for cases where young people have suspected developmental or cognitive impairment; discussion with each state and territory court system specifically may provide additional detail in future evaluations, however this was beyond the scope of the current evaluation. Below details the information that could be obtained from online searches. It should be noted that for each of the specialised court-based services mentioned (with the exception of the Assessment and Referral Court in Victoria), there was no information about the number of clinicians or the number of people utilising each service.

- New South Wales

The Children's Court Clinic provides experienced clinicians, called Authorised Clinicians, from the fields of psychology, psychiatry, and social work who undertake assessments of children and provide reports to the Children's Court (see here: <https://www.schn.health.nsw.gov.au/find-a-service/network-services/childrens-court-clinic/authorised-clinicians>). Authorised Clinicians are employed on a contractual basis, and referral is determined under the Children and Young Persons (Care and Protection) Act, 1998.

- Victoria

Similarly to NSW, a Children's Court Clinic exists in Victoria where clinicians perform psychological, neuropsychological, and developmental assessments of children (see here: <https://www.childrencourt.vic.gov.au/childrens-court-clinic>). However, these clinicians perform assessments for the Children's Court in relation to child welfare.

- Queensland

The Queensland Court Liaison Service assists in the identification of mental health treatment needs and facilitates referral to services and diversion from the criminal justice system. This is not a FASD-specific service and is available to adults, young people, and children (see here: https://www.health.qld.gov.au/_data/assets/pdf_file/0030/638454/cpp_court_liaison_service.pdf). For children and young people, referrals to services are voluntary and require consent from the child or young person. Further, the Magistrates Court in Queensland gives magistrates specific power relating to people with intellectual disability, mental illness, or other mental conditions, which includes the authority to dismiss charges and refer a person for examination via an authorised mental health service. Under the Examination Authority, a doctor or authorised mental health

practitioner provides an examination and assessment of whether a Recommendation for Assessment should be made. This allows for necessary treatment and care to be provided to a person when they do not have the capacity to consent.

- *Western Australia*

The program 'Links' consists of a clinical mental health team and community support coordinators who provide mental health assessment to young people involved in the Children's Court (see here: <https://www.mhc.wa.gov.au/getting-help/diversion-support-programs/mental-health-court-diversion-program/links/>). Referrals to Links can be made by magistrates, lawyers, welfare agencies, or family members when it is deemed that a young person appearing before the Court may have a mental health issue. Links uses the outcomes of the assessment to guide future management of the court proceedings and care for the young person. If a young person is deemed as having significantly unmet mental health needs, Links may offer case management support or referral to other services for treatment. Notably, this service is targeted towards mental health; from the information provided it could not be determined if FASD is assessed.

- *Tasmania*

The Youth Justice Court in Tasmania assesses cases involving young people under the age of 18. A key feature of this court is the inclusion of a specialist list of cases that involve young people with a variety of issues or impairments. The Youth Justice Court provides greater supervision and appropriate case management to cases on the specialist list.

Diversionary programs in First Nations communities

1. The Koori Youth Justice Program (also discussed in question 6.4.1) was launched in VIC in 1992 and is still running with current funding set to finish in 2024. The aim of this program is to deliver community-based programs for First Nations children and young people who are vulnerable to, or have been involved in, the criminal justice system. To assist at-risk youth, the program addresses and resolves factors that contribute to offending.
2. The Koori Early School Leavers and Youth Employment Program (VIC) aims to divert First Nations youth from the youth justice system. This program focuses on key risk factors that young people experience, however is not specific to FASD.
3. The Koori Intensive Support Program (VIC) aims to reduce the number of First Nations young people who are detained before sentencing. It also aids young people to help them comply with conditions for deferred sentences and with bail conditions. This program is not specific to FASD, however support for youth with FASD may be applicable through this program.

The following diversionary programs have also been identified; however, it is unclear whether these are still currently running.

1. The Tiwi Islands Youth Development and Diversion Unit (NT) was established in 2003 and was delivered as recently as 2014 (Stewart et al., 2014; Tiwi Islands Regional Council, 2013). This voluntary program provided early intervention for at-risk First Nations youth to prevent entry into the criminal justice system (Stewart et al., 2014). Specifically, it offered first-time offenders with an opportunity to avoid obtaining a criminal record. Conditions of agreement typically included apologising to the victim, attending a youth justice conference, attending

school, and completing community service. Youth justice conferences allowed for the development of individualised 12-week case plans that met the conditions of diversion whilst providing the young person with access to relevant supports (Stewart et al., 2014). The number of participants involved in this program is unknown.

2. The Woorabinda Early Intervention Coordination Panel service (QLD) began in 2008 to provide assessment and referral for early intervention and diversion from prison to First Nations youth aged between 10-17 years. A cross-agency panel assessed the needs of youth and their families to develop intervention plans to address specific needs. These interventions were delivered by staff from the cross-agency panel or through agencies involved in the panel, such as psychiatrists or teachers (Stewart et al., 2014). Interventions included counselling, after-school activities, health promotion, and family support.

There is no available information regarding the programs end date, however it was last evaluated in 2014 (Stewart et al., 2014). The evaluation noted that there was limited statistical evidence that the panel was supporting the needs of families involved, and the program only reached a very small number of participants from the eligible population. The average length of time spent participating in the service was 1.4 years, with participants leaving the program after their presenting problems were deemed to be sufficiently addressed. The evaluation report further outlined that there was little data available to evaluate the success of the service, although qualitative accounts did indicate that participation improved the behaviour of the adolescents involved, improved family relationships, and enhanced the parents' capacity to ask for help. However, statistics showed that participants typically continued with offending behaviour after program completion.

3. In QLD, the Aggression Replacement Training program (see here: <https://www.qld.gov.au/law/sentencing-prisons-and-probation/young-offenders-and-the-justice-system/youth-justice-community-programs-and-services/aggression-replacement-training-program>), adapted from a program developed in the United States, was utilised. This began in 2010 and was running as recently as 2021 (Stewart et al., 2014). This program comprises of cognitive-behavioural training for youth, including First Nations youth, who are at risk of offending or re-offending. If a young person demonstrates, or has been found guilty of, violent behaviour they may be referred to this program or it may be included as an additional condition of a court order. A referral from a court, Youth Justice service centre staff member, or youth detention centre staff member is required to access this program. This program is delivered three times per week over 10-weeks in a group setting of 4-6 young people (Stewart et al., 2014). This program targets offending behaviour by teaching anger control, moral reasoning skills (such as learning about how anger can affect other people), and skill streaming (where appropriate ways to respond to different situations are learned).

Stakeholder interviews

Interviewees noted that case management is provided to all young people entering the justice system, whether they are in custody, leaving custody, or diverted to a community-based order. However, one interviewee noted that the capacity for case managers to support individuals is limited, and greater support through the NDIS would be beneficial.

If somebody receives a FASD diagnosis ... and is able to be put into the NDIS and is allocated funding for support coordination ... then there will be a whole range of providers out there falling over themselves to help this person into services and into a job. But at the moment that driver isn't there.

The sustainability of case management plans was noted by interviewees as challenging when the young person did not geographically have access to the services and programs they need. Consequently, this often results in modifying the case management plan to utilise the existing services and supports offered within the community. While it was noted that this may not represent the preferred intervention for the individual, it does represent something that is manageable and achievable given the resources available.

6.4.5 To what extent are non-custodial therapeutic options used by courts to divert FASD-affected offenders away from prisons and into programs and services?

Overview of response:

Most states and territories offer non-custodial options for people with disability or cognitive impairment to divert away from prisons and into programs that address the reason for the offending behaviour. However, a magistrate often needs to refer an individual to these non-custodial options, and given FASD may not always be diagnosed in people entering the criminal justice system, inclusion in such non-custodial opportunities may depend on a magistrates' discretion in the absence of diagnosis. Interviewees highlighted a lack of FASD-specific diversion programs and the issue of geography in people being able to access the support and programs they need as areas for further consideration.

Details:

To answer this question, a review of programs available to courts within each state for persons diagnosed with FASD was conducted. In addition, key stakeholder interviews were conducted with representatives from the Department of Justice and the National FASD Advisory Group, who mainly discussed non-custodial options in the WA and NT justice systems.

- *Victoria*

The Neighbourhood Justice Centre (NJC) was established in 2007 as a part of the Specialist Courts and Programs Division of the Magistrates' Court of Victoria (see here: <https://www.neighbourhoodjustice.vic.gov.au/about-us/our-story/what-we-do>). Whilst the NJC is a court rather than a program, it is accessible to people with disabilities and provides linkage to a range of programs. The NJC provides an alternative for the Magistrates' Court of Victoria, Children's Court, Victorian Civil and Administrative Tribunal, Victims of Crime Assistance Tribunal, and offers a client services team. It utilises a non-adversarial approach, featuring a single Magistrate with an extensive background in restorative justice and therapeutic jurisprudence (Blagg & Tulich, 2018). The NJC avoids using technical and formal language so the proceedings can be better understood by offenders with a range of impairments. It offers services such as counselling, mental health and AOD programs, mediation, legal advice, employment and housing support, First Nations support services, and family violence support. The NJC is a useful diversion tool as it offers needs-based assessment by a clinical service team (Blagg & Tulich, 2018); in-depth case-by-case assessment allows the NJC to identify vulnerable clients and the reasons behind offending. By increasing awareness of how impairments can impact offending behaviour, the NJC promotes appropriate uses of non-custodial

services. However, there is no public record of the number of referrals received by the NJC and the proportion of offenders with a diagnosis of FASD who may be referred to this service is unknown.

Further, the Australian Community Support Organisation (ACSO) provides support to people with a range of intellectual and cognitive disabilities who are in contact with the Criminal Justice System (see here: <https://www.acso.org.au/wp-content/uploads/2022/02/ACSO-2017-18-Annual-Report-PDF-Final-003.pdf>). The ACSO delivers a support program called ReStart that is aimed at short sentence and remand prisoners who have high reintegration needs. It includes three months of outreach support post-release that aims to assist with reintegration into the community and promote sustainable links. Participants in the program receive assistance and support from staff to ease the transition into community settings.

Finally, there is also the Assessment and Referral Court (ARC) in Victoria which may assist adults with cognitive impairments to address contributing factors to their offending behaviour (see here: <https://www.mcv.vic.gov.au/about-us/assessment-and-referral-court-arc>). The ARC is available at the Frankston Magistrates Court, Latrobe Valley Magistrates Court, Korumburra Magistrates, Melbourne Magistrates, and the Moorabbin Magistrates Court. Before a case can be heard in the ARC a referral must be made and an ARC manager is required to conduct an assessment to ensure eligibility criteria are met. For an individual with FASD to access the ARC, they must have a formal diagnosis of FASD and reduced capacity in self-care, self-management, social interaction, or communication. It is also a requirement that the accused person pleads guilty prior to the development of an individual support plan. In the period 2020-2021, across all ARCs, there were 127 referrals of which 58 were accepted and 31 participants completed the Court Integrated Services Program (CISP).

- *New South Wales*

As per Section 32 of the Mental Health ACT 1990, courts in NSW have the power to divert any offender who is cognitively impaired or suffering from a mental illness/mental condition to the treatment of health professionals rather than the criminal justice system (see here: <https://legislation.nsw.gov.au/view/html/inforce/current/act-1990-010>). Evidence of the impairment or condition must be provided and the contributions of the impairment or condition to the offending behaviour must be clearly identified. If the application is successful, charges may be dismissed if the accused person agrees to participate in a treatment plan.

Other diversion programs within NSW (such as the Court Referral of Eligible Defendants into Treatment [CREDIT] program, Drug Court, and the Magistrates Early Referral into Treatment) feature rehabilitation, treatment, or intervention programs; however, to be eligible offenders must present with problems such as AOD dependency, mental illness, homelessness, or extreme poverty.

Further, the Children's Court features diversionary options for young people facing criminal charges where they are referred to intervention and rehabilitation programs to address issues that may have contributed to offending behaviour (see here: <https://childrenscourt.nsw.gov.au/childrens-court/criminal/youth-justice-conferencing.html>). This is available to young people or children who have a cognitive impairment or mental illness. The most common diversionary pathway is a referral to a Youth Justice Conference which is available for less serious offences. Conferences involve discussing the impact upon the victim and require the young person or child to accept responsibility and acknowledge their wrongdoing. This facilitates development of an outcome plan which may include things such as an apology to the victim, participation in an education program, counselling, or a combination of any of these.

- *Queensland*

Court Link is a diversion program that offers integrated court assessment, referral, and support (see here: <https://www.courts.qld.gov.au/services/court-programs/court-link>). The main aim is to connect participants with relevant support services and treatment and provide a level of support that matches a persons' individual needs such as risk of re-offending and ability to receive help. To be eligible for Court Link, a person must require assistance with issues that contribute to their offending, and this includes impaired decision-making capacity.

Queensland police also have a strategy embedded into their work that offers a preventative diversion pathway by connecting at-risk and vulnerable community members to over 450 external support service providers (see here: <https://www.police.qld.gov.au/police-and-the-community/police-referrals>). Now referred to as 'Police Referrals', this strategy aims to promote early intervention to address social and lifestyle issues that may impact future offending to divert vulnerable individuals from engagement with the criminal justice system. Notably, this service refers to a broad range of issues and is not specifically for FASD, but it may be covered.

- *South Australia*

In South Australia there are two diversionary courts available; the Magistrates Court Diversion Program which operates in regional areas (see here: <https://lsc.sa.gov.au/dsh/ch04s10.php#:~:text=The%20Magistrates%20Court%20Diversion%20Program,Australian%20Magistrates%20Courts%20since%201999>), and the Treatment Intervention Court which services metropolitan areas (see here: <https://lsc.sa.gov.au/dsh/ch04s11.php>). The Magistrates Court Diversion Program aids offenders that suffer from mental impairment or mental health issues that are related to offending behaviour. To be eligible for referral a person must be over the age of 18, charged with a summary and/or minor indictable offence, and have impaired intellectual or mental functioning. Further there needs to be a connection between the defendant's impairment and the offending behaviour, and the participant must plead guilty to the most serious offence that they have been charged with. The Treatment Intervention Court also assists people charged with offences who have illicit drug use problems.

- *Northern Territory*

Whilst it is not FASD specific, the Youth Diversion program aims to divert young people away from the criminal justice system. Instead of going to court, there is a pre-court youth diversion option, including written or verbal warnings, youth justice conferencing, or participation in diversionary programs or community service (see here: https://tfhc.nt.gov.au/_data/assets/pdf_file/0005/1073039/territory-families-housing-and-communities-annual-report-2020-21.pdf). These programs aim to address the causes and risk factors of offending behaviour to reduce reoffending. Court-ordered youth justice conferencing is also available in various locations across the NT and is delivered in Community Justice Centres.

- *Western Australia*

The Intellectual Disability Diversion Program Court aims to reduce the number of people with an intellectual disability, cognitive disability, or autism spectrum disorder from engaging with the criminal justice system (see here: https://www.magistratescourt.wa.gov.au/i/intellectual_disability_diversion_program_court.aspx). Whilst FASD is not explicitly mentioned, this may be covered under cognitive disability. Participation is voluntary and referrals are usually made to this court by magistrates. The court aims to reduce

future contact with the criminal justice system, increase access to positive behaviour support, identify undiagnosed impairments, disabilities, and/or mental health challenges, and to achieve fair outcomes relating to an individual's criminal charges that balances the interests of the victim with considerations made for the persons' disability or impairment, and nature of the offence.

The Mental Health Court Diversion and Support Program provides a specialised adult program called 'Start Court' that aims to provide holistic support and a solutions-based approach to offenders with mental illness/mental conditions (see here:

https://www.magistratescourt.wa.gov.au/s/start_court.aspx). The program aims to reduce contact with the criminal justice system and link individuals to appropriate services.

Other available programs include AOD diversion, mental health court diversion, and juvenile court diversion (see here: <https://www.mhc.wa.gov.au/getting-help/diversion-support-programs/>). The focus of these programs is AOD use or diagnosed mental health conditions, so they may be suitable for some offenders with FASD.

- Tasmania

in Tasmania there is a specialised court for adult defendants with mental illness or impaired intellectual functioning called the Diversion List (see here:

https://www.magistratescourt.tas.gov.au/about_us/criminal_division/diversion_list). The Diversion List focuses on treatment and support, and was developed to help understand the reasons behind offending behaviour (Magistrates Court of Tasmania, 2022). To be eligible, an accused person must have been charged with a minor offence, and must have a diagnosed mental illness, intellectual disability, acquired brain injury, or autism spectrum disorder (Magistrates Court of Tasmania, 2022).

- Australian Capital Territory

Diversion service programs are aimed people who have been charged with AOD related offences; eligibility criteria does not include intellectual or cognitive impairment. As per the ACT Corrective Services Disability Action & Inclusion Plan 2021-2023 (see here:

<https://www.correctiveservices.act.gov.au/act-corrective-services-disability-action-and-inclusion-plan-2021-23>) [https://correctiveservices.act.gov.au/sites/default/files/2020-12/ACT Corrective Services Disability Action and Inclusion Plan 2021-23 %281%29.pdf](https://correctiveservices.act.gov.au/sites/default/files/2020-12/ACT%20Corrective%20Services%20Disability%20Action%20and%20Inclusion%20Plan%202021-23%20%281%29.pdf), there are plans to investigate and implement options for offenders with disabilities in typical custodial and community environments. However, these services focus on re-integration rather than non-custodial alternatives.

Stakeholder interviews

One interviewee noted that non-custodial options are preferred by courts (over custodial sentencing), however, this is dependent upon factors such as cognitive capacity/impairment, age, and type of offence committed. Further, frustration was expressed by two interviewees concerning the lack of appropriate diversion programs available to individuals with FASD.

... we don't have diversionary programmes that are robust enough to really help these people on a different pathway. So that's a big gap that I think does need specifically to be addressed, to have therapeutic remedial pathways that are a diversion away from the justice system and away from offending behaviour.

It was also discussed that support through the NDIS would be a good way to make these diversionary programs more sustainable moving forward. However, the issue of geography was raised, which highlighted how some people have limited access to services and programs based on where they live.

As such, increasing access to programs and services to promote non-custodial options is necessary, however, improving the capacity of the communities to which people return to may also be a good way forward – especially for those remote communities where service capacity is limited.

7 DISCUSSION AND FUTURE CONSIDERATIONS

This review has demonstrated that there is a substantial amount of progress being made in the FASD space to increase awareness of FASD and improve the screening, diagnosis, and management of FASD. While there are some key links to the Strategic Action Plan via specific projects and initiatives that have been funded through the plan (e.g., the National Awareness Campaign for Pregnancy and Breastfeeding Women), it is difficult to attribute all advancements in this space directly to the Strategic Action Plan. However, it should be noted that while many current initiatives and advancements in the FASD field may not be directly attributable to the Strategic Action Plan, many projects and initiatives are aligned with the plan and are therefore helping to support the outcomes posed in the Strategic Action Plan. Further, the lack of baseline (pre-2018) data in many areas also makes it challenging to determine the impact of the Strategic Action Plan.

Progression in the priority areas

Prevention

Good progress has been made to increase community knowledge and awareness about the harms and consequences of drinking during pregnancy or when planning a pregnancy. This is evidenced through the number of FASD public education and awareness campaigns launched since 2018 ($n = 42$) that align, either fully or partly, with the advice detailed in the Strategic Action Plan regarding raising awareness about the risk of drinking in pregnancy and FASD, the belief that not drinking is the safest choice and intention to not drink whilst pregnant, and increasing support for women not drinking in pregnancy while minimising stigmatising the individual. In addition, the Strategic Action Plan has funded one of the biggest national FASD campaigns to date (the National Awareness Campaign for Pregnancy and Breastfeeding Women).

Policy change concerning mandatory pregnancy warning labels on alcohol products and the development of FASD short courses run through the University of WA have further improved the opportunity for people to obtain knowledge of the harms/consequences of drinking during pregnancy or when planning a pregnancy, and awareness of FASD.

Screening and diagnosis

Good progress has been made in providing opportunities for frontline professionals to increase their FASD knowledge and screening and diagnosis skills. This is evidenced through the development of the first FASD university course run through the University of WA, targeting health professionals in one of the four streams of the National FASD Campaign, establishing the Australian and New Zealand FASD Clinical Network, and through research projects which have aimed to support clinicians to diagnose and support clients with FASD, such as the FASD Diagnostic Services and Models of Care project. There has also been specific funding allocated to FASD diagnostic services, which has helped to improve capacity for screening, diagnosis, and surveillance.

However, online surveys with health and human service workers highlighted that FASD training in the workplace is not common, and there was a common theme of not having/not being aware of procedures for supporting people with FASD in the workplace.

Notably, there are several available resources (25 were identified) that teachers can use to help support children with FASD in the classroom. However, these are not compulsory resources, and it is unclear how much these are being used in educational settings.

Support and management

There have been projects targeting this priority area that have demonstrated good progression toward improving FASD support and management. First, the FASD Diagnostic Services and Models of Care project has established a good foundation to supporting FASD support and management through developing models of care specific to each service. Second, the Making FASD History project has improved the diagnosis and management of FASD in young people engaged with the justice system. Lastly, there is research currently underway to assist adults in the criminal justice system to obtain supportive employment post-release. In addition, funding to support websites such as the FASD Hub and NOFASD Australia have provided individuals the opportunity to obtain information about FASD management and supports.

Priority groups

There have been some targeted prevention campaigns and resources for First Nations peoples and those in the criminal justice sector, however, co-design has been shown to be essential to successfully engaging with these at-risk populations.

How the Strategic Action Plan and FASD screening/diagnostic tools are used in priority groups may need some adjustment to ensure it is relevant and appropriate to particular communities and the resources they have.

Notably, the recognition of FASD in the criminal justice system is lacking in many jurisdictions. However, the processes undertaken in Western Australia are promising.

Funding

There has also been an increase in funding provided to FASD projects and activities Australia wide since the launch of the Strategic Action Plan, in particular from the DOHAC (who have funded 24 projects between 2019 and 2022). The funding aligns with, and assists in the progression of, the four priority areas detailed in the Strategic Action Plan. Funding from four national funding bodies from 2012 – 2022 were examined (NHMRC, DOHAC, ARC, MRFF), and while it was difficult to confirm an increase in targeted funding, the increase in NHMRC funding from three-years before the launch of the Strategic Action Plan (2015 – 2017) to the three-years after (2019 – 2021) suggests a 50% increase in FASD focused research project funding. Funding has mainly targeted activities to raise FASD awareness (i.e., \$27 million to funding the National Awareness Campaign for Pregnancy and Breastfeeding Women) or to increase diagnostic services.

Caveats

Of note, there are some overarching caveats that should be considered when interpreting the findings of the current evaluation:

- Difficulty attributing initiatives to the Strategic Action Plan
 - It is difficult to quantify the role of the Strategic Action Plan in many current initiatives, however, the Plan should be recognised as aligning and indirectly contributing to current initiatives. The Strategic Action Plan has provided funding to key FASD activities, and has represented a successful policy framework from which many positive developments have evolved.
- Low participation rate

- Participation in the stakeholder interviews and online surveys was low, which means the findings from such may not be generalisable to all relevant peoples nation-wide. This has, however, been considered when explaining findings throughout the report.
- Time to complete the evaluation
 - This evaluation was completed in a short time period (October 2021 to May 2022), therefore there were limits to what groups of individuals could be realistically targeted in the interviews and surveys in the timeframe proposed. As such, the perspectives of all relevant persons could not be included in the proposed methodology, therefore findings need to be viewed in light of this.
- The COVID-19 pandemic
 - The impact of the COVID-19 pandemic likely impacted the ability of health departments and the health workforce to implement the Strategic Action Plan. While progress has still been made, it should be acknowledged that this was likely.

Future considerations

In addition, there are a number of key points arising from this report which require further consideration for future evaluations:

- There has been less emphasis on the support and management priority area of the Strategic Action Plan to date, including the procedures/processes involved in obtaining appropriate support post-diagnosis and what services can assist individuals and families to obtain the support that they need. While there have been recommendations made to increase the supports available through national schemes such as the NDIS and Medicare, greater awareness of health professionals regarding support and management plans for individuals with FASD would be beneficial. Further, discussion with people with lived experience and service providers specifically may provide helpful insight into this area.
- There is a clear need and opportunity to provide professional development for individuals working in the space regarding diagnosis, treatment, and management of FASD. This will assist in the development of more accurate prevalence rates in Australia, and also assist in ensuring that professionals are providing consistent messaging to the community regarding FASD and alcohol use during pregnancy. Training individuals once already in the field may be a challenging task, however incorporating FASD training into university course requirements represents a promising way to improve the FASD knowledge of upcoming health professionals. The University of WA is leading the way with providing such courses specifically targeting FASD diagnosis and treatment, however, this is currently an optional course. Professionals currently in the field would benefit from role specific training to increase their confidence with recognising and addressing FASD in their service setting. Incorporating adequate education and training opportunities is noted in the Strategic Action Plan as an enabler to the activities specified within the Plan, and specifies such training should be extended to relevant professionals outside of the health field, such as educators and those working in corrections. Greater emphasis on training for all healthcare services in recognising the signs of FASD, referral/assessment, diagnosis, models of care, and management strategies is also relevant to the screening and diagnosis and the support and management priority areas.
- There is a clear need for improved awareness and training for those working with at-risk populations (i.e., First Nations communities and corrections). This includes recognition of FASD in department policy and practice guidelines, and is very important given the likely over-representation of FASD in these populations. Training should involve FASD awareness,

screening/assessment, diagnosis, and support/management, and should be specific to the setting. As outlined above, incorporating adequate education and training opportunities is noted in the Strategic Action Plan as an enabler to the activities specified within the Plan, as is the coordination and collaboration of policy across jurisdictions and communities. Having representatives in these at-risk populations who are skilled in assessing and managing FASD will allow for a greater understanding of how to best prevent and manage FASD within these communities.

- The Strategic Action Plan needs to be communicated more effectively to priority (at-risk) populations, including First Nations communities. In addition, alternative ways to assess, diagnose, and manage FASD needs to be considered in situations and environments where access to resources and appropriately trained professionals is limited. More work to develop best practice models for such communities is needed, and should include co-design methodology wherever possible. The use (and effectiveness) of co-design methodology to develop initiatives and resources to assist in the prevention, assessment, diagnosis, and management of FASD has been shown through some work conducted in First Nations communities. This work has demonstrated the need to adapt and modify resources to suit the communities in which they are being used, especially when considering rural and remote areas that have limited access to resources. This aligns with the guiding principle of collaboration, as specified in the Strategic Action Plan, which highlights the need to use linkages and opportunities to cooperate and partner responsibly to achieve greater impacts than can occur in isolation.
- There has been some work conducted in the justice sector regarding FASD assessment, diagnosis, and management, however this does not seem to be consistent across the jurisdictions. Given the high proportion of individuals with FASD entering the justice system, a review of the procedures and processes undertaken by the justice sector is important. Specifically, policy and procedures within corrections need to reflect a stronger position on FASD awareness, screening, and management, and should include appropriate training to support staff to support individuals with FASD in these settings. As outlined in the Strategic Action Plan, coordination and collaboration across jurisdictions and communities is vital to reducing the prevalence of FASD and the impact it has on individuals, families, carers, and communities.
- Appropriate recognition of FASD as a disability is specified as a key enabler in the Strategic Action Plan. While FASD is not currently included on the List of Recognised Disabilities in Australia, FASD is recognised as an eligible disability in the NDIS. However, meeting the disability eligibility criteria, as specified in the NDIS Act, for many will be difficult. This is due to reasons such as not having access to appropriate practitioners to diagnose FASD (i.e., not having the resources to conduct multidisciplinary assessments) and practitioners not having the necessary skills to correctly assess and diagnose FASD.
- We found a number of resources that have been developed for individuals who work with people with FASD, including at risk populations (i.e., First Nations populations, criminal justice populations). However, a system or network to share resources between states and territories needs to be developed and promoted. This would benefit progression in all the priority areas, and also aligns with the policy coordination enabler within the Strategic Action Plan, which recognises that such collaboration between the jurisdictions is essential to reducing the prevalence of FASD and the impact it has on individuals, families, carers, and communities. This will allow researchers, policy makers, and service providers greater opportunity to collaborate and use the learnings of other jurisdictions rather than reinventing the wheel. Facilitating this through somewhere like the FASD Hub might be a

possibility. Promoting a network for shared resources will have a positive impact on policy and practice, and assist in greater communication about how to best approach the topic of FASD throughout Australia.

- There needs to be greater communication between commonwealth agencies and the states and territories concerning the prevention and management of FASD. This would help increase the shared sense of responsibility for action concerning FASD, and give states and territories a greater opportunity to be involved in the discussions around what would best work in their jurisdictions. Similarly to the previous point, this aligns with the advice posed in the Strategic Action Plan regarding policy coordination as a key enabler to reducing FASD in Australia.
- The FASD Diagnostic Services and Models of Care Project is a highly successful project with important implications for moving forward with FASD service delivery Australia. More focus into whether there could be a widespread rollout of this project, or the adoption of elements of this project throughout Australia, should be examined.
- We found a number of programs operating in different states that are targeted for FASD or could potentially be extended to include specific elements for FASD. However, it is not clear whether all of these programs have been evaluated or assessed for quality, so it is difficult to determine the effectiveness of these initiatives. Having this information available, and ensuring that future programs evaluate and publicly disseminate such findings, is important for the continued progression of FASD research. Ensuring appropriate evaluation of research efforts would help support the research and evaluation enabler in the Strategic Action Plan.
- It was difficult to find people to engage in surveys/interviews, which may reflect a lack of knowledge about the Strategic Action Plan.

Additional considerations for future evaluations

There are a number of recommendations for future monitoring activity that could be implemented in future evaluations of the Strategic Action Plan. These activities were not included in the current evaluation due to requiring additional ethics approval and a longer project timeframe.

- The groups of people contacted for the stakeholder interviews should be expanded to also include:
 - At-risk groups, such as women with alcohol dependence and other high risk alcohol consumption behaviour, pregnant women (including those who are alcohol dependent), youth in the justice system, and First Nations representatives. Examining these groups will allow for greater insight into the accessibility of services and any facilitators and barriers to accessing services (this would require high-risk ethics approval).
 - FASD service providers to identify whether there has been improved access to appropriate and evidence-based diagnosis and support services.
 - Aboriginal Community Controlled Health Organisations and First Nations services to identify accessibility of services for pregnant women who use alcohol during pregnancy, as well as opportunities to improve access to diagnosis and support services through existing programs (this would require high-risk ethics approval).
 - Individuals who have been diagnosed with FASD and their families to identify the extent to which they believe their needs are being met by the legislation and policy, and how they are supported to manage their diagnosis (this would require high-risk ethics approval).

- Staff from detention centres and community programs to assess any informal methods for assessing FASD that are not outlined in formal documents/processes, and to identify and map out the post release process for those offenders with FASD (this would require ethics approval from the Department of Justice).
- Court case managers to identify whether those suspected of developmental or cognitive impairment are accessing appropriate services, and the facilitators and barriers of doing so (this will require ethics approval from the Department of Justice).
- Examination of public education and awareness campaigns about drinking during pregnancy and FASD was conducted, however examining community awareness of these campaigns would also be beneficial.
- Online surveys could be expanded to also include education and justice staff (this will require Department of Education and Department of Justice ethics approval). This would provide greater insight into the training and education they receive concerning FASD, what the referral process looks like in these settings, and what considerations need to occur within each setting respectively to appropriately manage individuals with FASD.
- An assessment of the number of young people in detention centres and community programs identified with FASD compared to national/state FASD rates and the number of persons accessing post release and treatment services and/or non-custodial sentencing options (this would require ethics approval from the Department of Justice).

Conclusion

The Strategic Action Plan, at the three-year mark of a 10-year plan, seems to be on track to meeting the actions specified within the plan. The 'prevention' and 'screening and diagnosis' priority areas have obtained more funding and seen greater progression compared to the 'support and management' and 'priority groups' priority areas. However, there has been promising developments in all priority areas to date considering disruptions from the COVID-19 pandemic during this time. Future evaluations would benefit from greater time allocated to evaluate the progress of the Strategic Action Plan, as this would allow for more time to collect data and more relevant persons the opportunity to contribute their data.

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