

Australian Government response to the Senate Community Affairs References Committee report:

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

Overview

Fetal Alcohol Spectrum Disorder (FASD) is the umbrella term used to describe a spectrum of disorders that can occur when a child has been prenatally exposed to alcohol. The spectrum covers physical, neurological, behavioural and learning difficulties from mild through to severe symptoms. Fetal Alcohol Spectrum Disorder is a serious yet preventable disability that has profound and life-long lasting consequences for affected individuals, families, carers and communities across Australia.

On 9 September 2019, the Senate Community Affairs References Committee (the Committee) launched an inquiry into effective approaches to prevention, diagnosis and support for people living with Fetal Alcohol Spectrum Disorder.

The Australian Government recognises the significant impact Fetal Alcohol Spectrum Disorder has on individuals living with the disorder and the spectrum of challenges their carers and families face. It welcomes the Inquiry Report and would like to thank all of those who provided input into the Inquiry.

The Australian Government is committed to addressing Fetal Alcohol Spectrum Disorder in Australia through increasing awareness to assist in reducing the prevalence of Fetal Alcohol Spectrum Disorder and providing the appropriate support to those the impacted by it. This commitment is supported through the *National Fetal Alcohol Spectrum Disorder (FASD)* Strategic Action Plan 2018–2028, which outlines a range of priorities and opportunities to improve the prevention, diagnosis, support and management of Fetal Alcohol Spectrum Disorder.

More broadly, the Australian Government is committed to preventing and minimising the harms of alcohol use on all aspects of the Australian community and recognises the importance of working in partnerships with jurisdictions, community organisations and the sector to reduce these impacts. This commitment is outlined in the *National Alcohol Strategy 2019-2028*, which provides a framework of shared responsibility for focusing and coordinating population-wide and locally appropriate responses to alcohol-related harm, including action in respect to Fetal Alcohol Spectrum Disorder. Implementation of this strategy is a shared responsibility of the Australian Government, state and territory governments and non-government sectors.

A number of the recommendations made in the Report require a collaborative approach between the Australian Government and jurisdictions whilst other recommendations contain actions relevant to the non-government sector, such as health professionals and the education sector. The Australian Government will continue to work with jurisdictions and the non-government sector to encourage action on recommendations to achieve improved Fetal Alcohol Spectrum Disorder awareness, education, services and support.

The Australian Government Department of Health and Aged Care has prepared this Australian Government response in consultation with a range of agencies, including: the Attorney-General's Department, Australian Institute of Health and Welfare; Department of Education, Skills and Employment, Department of Infrastructure, Transport, Regional Development and Communications and the Arts; Department of Social Services; National Disability Insurance Agency; National Health and Medical Research Council; National Indigenous Australians Agency; and The Treasury.

The Australian Government supports 6 recommendations, supports in-principle a further 14 recommendations, and notes 11 of the 32 recommendations. One recommendation is not supported.

Several of the recommendations do not fall within the remit of the Australian Government. Where indicated, the Australian Government will engage further with stakeholders in relation to these recommendations.

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.

Supported-In-Principle

The Australian Government understands the importance of the national Fetal Alcohol Spectrum Disorder case register.

The Australian Government is funding the national Fetal Alcohol Spectrum Disorder Australian Registry (the Registry). Funding has been provided since 2016 with the Registry funded until 2025. Future decisions in relation to the Registry will be considered in the context of the formal reviews of the *National Fetal Alcohol Spectrum Disorder (FASD)* Strategic Action Plan 2018-2028.

The first review, at the third year of the Strategic Action Plan has now been completed. This review found that the recruitment of a researcher to monitor the Registry, supported through the Government funding, has:

- increased recognition of the Registry by health professionals, improving the coverage and uptake of the Registry; and
- improved the quality of the data reported by professionals.

Recommendation 2

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

Supported-In-Principle

The Australian Government acknowledges there is a need to improve national Fetal Alcohol Spectrum Disorder prevalence data, and notes that improving capacity for screening, diagnosis and surveillance is an objective under the *National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018-2028*.

The Australian Government (Department of Health and Aged Care) is engaging with the National Fetal Alcohol Spectrum Disorder Advisory Group to explore this recommendation further. This group was established to monitor and report on the progress of the *National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018-2028*, and advise the Government on any emerging issues, trends, opportunities and gaps regarding Fetal Alcohol Spectrum Disorder within Australia.

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

Supported-in-Principle

The Australian Government notes the importance of reporting on standardised data for maternal alcohol consumption. The Australian Institute of Health and Welfare (AIHW) is undertaking work on this.

Maternal consumption of alcohol during pregnancy is collected as part of the National Perinatal Data Collection. The Australian Institute of Health and Welfare uses the National Perinatal Data Collection to produce reports such as Australia's Mothers and Babies; and the National Core Maternity Indicators. The National Perinatal Data Collection includes data items from the Perinatal National Best Endeavours Data Set (NBEDS) and the Perinatal National Minimum Data Set (NMDS).

From 1 July 2019, six data items relating to maternal consumption of alcohol during pregnancy have been included in the Perinatal National Best Endeavours Data Set. The data items relate to an indicator of alcohol consumption in pregnancy, frequency and number of standard drinks. Data is collected at two time points in pregnancy: before and after 20 weeks of gestation.

The Perinatal National Best Endeavours Data Set is intended as an interim standard while jurisdictions implement data items into their collections and refine data quality. When data items are assessed as being of high quality, it is expected that the data elements will be included as data elements in future Perinatal National Minimum Data Sets.

The Australian Institute of Health and Welfare will continue to monitor and report this data and move to routine reporting once sufficient data quality is available. As at July 2024, seven states and territories provide data on an indicator of alcohol consumption in pregnancy. This information is published in the AIHW's annual Australia's mothers and babies report. Frequency of alcohol consumption during pregnancy is provided by six states and territories, and quantity of alcohol consumption during pregnancy is provided by five states and territories, with varying levels of completeness. This information has not been published to date. The status of Perinatal National Best Endeavours Data Set data elements is reviewed on an annual basis as part of routine development in relation to the Perinatal National Minimum Data Set and National Best Endeavours Data Set.

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

Supported-in-Principle

The Australian Government will consider options to undertake a social and economic study on the costs of Fetal Alcohol Spectrum Disorder, to support ongoing implementation of the *National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan*. The validity of this study will also depend on the availability of Australian prevalence data to provide an accurate estimate of the social and economic cost of Fetal Alcohol Spectrum Disorder (as per Recommendation 2).

The Australian Government currently funds a range of activities to strengthen the alcohol evidence base to help inform responses to alcohol use in Australian communities. This includes high quality research and data analysis to increase awareness and understanding of the health and social impacts from drinking. National Health and Medical Research Council (NHMRC) reviewed and updated the *Australian guidelines to reduce health risks from drinking alcohol*. Updated guidelines were released in 2020 and included recommendations in relation to women who are pregnant or breastfeeding.

The National Health and Medical Research Council is the Australian Government's main health and medical research funding body. Over the last ten years (2014 to 2023), the National Health and Medical Research Council has expended funding of \$16.1 million in new grants for research related to Fetal Alcohol Spectrum Disorder. For example, the Targeted Call for Research in Fetal Alcohol Spectrum Disorder and the establishment of a Centre of Research Excellence in Fetal Alcohol Spectrum Disorder (2016-2020).

The National Health and Medical Research Council continues to welcome research grant applications from Fetal Alcohol Spectrum Disorder researchers through its standard research-funding mechanisms.

Recommendation 5

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

Supported-In-Principle

An objective of the *National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan* 2018-2028 is to 'increase community knowledge and awareness about the harms and consequences of drinking during pregnancy or when planning a pregnancy'.

Consistent with this objective, the Australian Government (Department of Health and Aged Care) is funding the Foundation for Alcohol Research and Education (FARE) to deliver a National Awareness Campaign for Pregnancy and Breastfeeding Women (the Campaign).

The Campaign aims to increase awareness of the risks associated with alcohol consumption during pregnancy, while planning a pregnancy or breastfeeding, based on the National Health and Medical Research Council's 2020 *Australian guidelines to reduce health risks from drinking alcohol*. The Campaign provides information and support so women can make healthy choices during pregnancy, while planning a pregnancy and while breastfeeding. The Campaign is being delivered through four streams: a mainstream campaign to the general public; priority groups such as women at higher risk of alcohol exposed pregnancies; health professionals; and First Nation communities. 'Every Moment Matters', the mainstream component of the Campaign, launched on 30 November 2021, and is being advertised on TV, radio stations and other social media platforms across Australia. Initial feedback has shown that the majority of people surveyed were motivated to not drink alcohol, or to support their partners not to drink alcohol, when pregnant, trying to get pregnant, or breastfeeding.

The Campaign will be subject to a formal evaluation, expected in late 2024. The formal evaluation of the Campaign will help to inform any future decisions regarding national public education campaigns over the term of the *National Fetal Alcohol Spectrum Disorder* (FASD) Strategic Action Plan 2018-2028.

Recommendation 6

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

Noted

The Australian Government recognises the importance of targeted Fetal Alcohol Spectrum Disorder education efforts.

The Australian Government funds the University of Sydney's Matilda Centre to administer the acclaimed Positive Choices website, available at: https://positivechoices.org.au/. This website provides Australian secondary schools and communities, including teachers and parents, with access to evidence-based and peer reviewed alcohol and other drug information and education resources.

Positive Choices was informed by input from teachers, parents and students across Australia, and was developed in collaboration with expert researchers. It links teachers to over 18 evidence-based teaching programs. Positive Choices undertakes ongoing marketing and promotional activities aimed at teachers and school staff across Australia to encourage usage of the portal.

Whilst there is currently limited content in respect to Fetal Alcohol Spectrum Disorder on Positive Choices, the Department of Health and Aged Care will explore options to include additional relevant content, where appropriate. It is important to note that the implementation of content in school curriculums is a decision for State and Territory Governments and school education authorities. Fetal Alcohol Spectrum Disorder is not specifically mentioned in the nationally agreed Australian Curriculum, however drug and alcohol related issues are addressed through the Health and Physical Education Learning Area.

Recommendation 7

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

Supported

The Australian Clinical Practice Guidelines: Pregnancy care (now known as the Australian Pregnancy Care Guidelines) were developed to support health care professionals to provide high quality, evidence-based care to pregnant women. Topics covered include routine physical examinations, screening tests and social and lifestyle advice for pregnant women without complications.

The Pregnancy Care Guidelines are being updated as living guidelines by the Australian Living Evidence Collaboration (Monash University). In May 2022, the alcohol chapter of the Australian Pregnancy Care Guidelines was updated to direct health professionals to Guideline 3 of the Australian guidelines to reduce health risks from drinking alcohol.

In October 2023, a draft recommendation 'Provide advice not to consume alcohol during pregnancy, or around the time of conception, to prevention potential harm to the developing baby' was published. This recommendation, which aligns with the 2020 Australian guidelines to reduce health risks from drinking alcohol, received NHMRC approval in June 2024.

New Australian Postnatal Care Guidelines are also being developed. The recommendation 'Provide advice not to consume alcohol while breastfeeding, to prevent potential harm to the baby' is included and was approved by NHMRC in June 2024.

The updated recommendations are available online to guide clinical practice.

Recommendation 8

The committee recommends that the medical profession, including the various medical colleges, acknowledge the critical role they play in education and awareness-raising of the

dangers of consumption of alcohol for both women and men, particularly as it relates to consumption in relation to pregnancy.

Supported-In-Principle

The Australian Government acknowledges the critical role that medical professionals play in education and awareness-raising of the risks of alcohol consumption for both men and women generally, and particularly in relation to pregnancy.

The Australian Government notes that while medical colleges are autonomous, self-accrediting institutions who are responsible for the content and quality of their courses, the Department of Health and Aged Care regularly engages with medical colleges and the medical profession to raise awareness of alcohol-related harms and the use of relevant guidelines and diagnostic and screening tools.

The Department of Health and Aged Care funds a number of projects that create useful resources for health professionals. This includes the Education Package and Training Grant for GPs in Drug and Alcohol Addiction. This was a time limited program announced as part of the 2018-19 Budget measure: Preventive Health – support for alcohol and drug abuse. Funding of \$8 million was provided to both GP colleges (the Royal Australian College of General Practitioners (RACGP) and the Australian College of Rural and Remote Medicine (ACRRM)) to develop training packages and provide incentive payments to GPs who complete the training, rewarding GPs for upskilling in the treatment of alcohol and other drugs. The program was delivered by the RACGP until February 2023 and will continue to be delivered by ACRRM until February 2024. The Alcohol & Other Drugs (AOD) GP Education Resource Library was also developed by the RACGP as part of this program. It includes the Alcohol and other drugs use in pregnancy online module, which is freely available on the RACGP website and contains practical tips, guidelines and resources relating to the effects of alcohol and other drugs during the childbearing years. The resource library also has a whole of practice focus, with resources tailored to practice nurses, allied health workers, and practice staff.

As part of the health professional stream of the National Awareness Campaign for Pregnancy and Breastfeeding Women, resources, training and tools will be developed for use in clinical and professional settings to encourage and facilitate health professionals to initiate conversations about alcohol consumption and alcohol-related harm during pregnancy, when planning a pregnancy and when breastfeeding.

In addition, the Department of Health and Aged Care provides funding to the FASD Hub Australia, which is a central repository for information regarding Fetal Alcohol Spectrum Disorder. The Hub is aimed at clinicians, researchers and policy makers and includes a series of e-learning modules to support health professionals to understand the risks of maternal alcohol consumption, identify and diagnose Fetal Alcohol Spectrum Disorder, and support families and individuals after a Fetal Alcohol Spectrum Disorder diagnosis. The e-learning modules are available from www.fasdhub.org.au.

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

Supported-In-Principle

The Australian Government (Department of Health and Aged Care) has funded a series of e-learning modules for health professionals as part of the development of the Australian Fetal Alcohol Spectrum Disorder Diagnostic Tool (the Tool). This includes a module on assessing prenatal alcohol exposure, with specific content on assessing alcohol use in pregnancy, using the Alcohol Use Disorders Identification Test – Consumption (AUDIT-C). The AUDIT-C involves 25 questions which provide a standardised method for the assessment of maternal alcohol use. Calculation of the AUDIT-C score, although not essential for diagnosis, allows the clinician to categorise the level of fetal risk associated with maternal drinking. The e-learning modules are available from www.fasdhub.org.au.

In addition, the Australian Government (Department of Health and Aged Care) has funded the University of Queensland to undertake a review and update of the Tool to ensure it is in line with clinical and international best practice. The review will include revised e-learning modules for health professionals on the use of the Tool and the importance of regular discussions with patients on the risks of alcohol consumption during pregnancy, while planning a pregnancy and while breastfeeding. The review is due for completion in late 2024.

The Australian Government will continue to encourage the medical and other relevant professions to embed educational resources and screening tools into routine practice in antenatal care.

Recommendation 10

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

Noted

The Australian Government is committed to preventing and minimising alcohol-related harms through the overarching framework of the *National Alcohol Strategy 2019-2028* (the Strategy). Implementation of the *National Alcohol Strategy 2019-2028* is a shared responsibility between the Australian Government, State and Territory governments and a range of non-government sectors.

One of the priorities in the *National Alcohol Strategy 2019-2028* is 'managing availability, price and promotion', which identifies several policy options to minimise the promotion of

risky drinking behaviours and other inappropriate marketing, and potential pricing and taxation reforms to reduce risky alcohol consumption. The Australian Government continues to actively consider potential policy options to prevent and minimise alcohol-related harms.

In respect to taxation, the Australian Government continues to monitor and assess the suitability of Australia's tax settings to ensure they contribute to balanced economic and social outcomes. It considers the current taxation settings for alcohol are appropriate and is not currently considering large scale changes.

Recommendation 11

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

Supported-In-Principle

The Australian Government recognises the value of increasing community awareness of mandatory pregnancy warning labels on alcoholic beverages. From 31 July 2023, packaged alcoholic beverages in Australia and New Zealand must display a pregnancy warning label with prescribed style, font and colours to advise 'alcohol can cause lifelong harm to your baby'. These labels inform pregnant women and the broader community that the advice for pregnant women is to not consume alcohol during pregnancy.

The Australian Government (Department of Health and Aged Care) has developed 'Your Healthy Pregnancy' resources. These resources were supported by a social media campaign and provide guidance and simple tips for healthy eating and advising not to drink alcohol during pregnancy.

In addition, the Australian Government is providing \$32.4 million over six years (from 2019) to the Foundation for Alcohol Research and Education to deliver the 'Every Moment Matters' Campaign. The Campaign aims to increase Australian's awareness of the risks associated with alcohol consumption during pregnancy and while breastfeeding, including Fetal Alcohol Spectrum Disorder. The Campaign also aims to increase the proportion of Australians who are aware alcohol should not be consumed during pregnancy and that it is safest not to drink alcohol when breastfeeding.

The Australian Government will continue to identify opportunities to include messaging on abstaining from alcohol during pregnancy, while planning a pregnancy and while breastfeeding and for the new mandatory labelling in any future campaigns related to pregnancy and health.

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

Supported-In-Principle

Preventive health is a key priority for the Australian Government. The *National Preventive Health Strategy 2021-2030* focuses on system wide, evidence-based approaches to reducing poor health and improving wellbeing at all stages of life. The *National Preventive Health Strategy 2021-2030* provides the overarching, long-term approach to prevention in Australia and builds on other strategic work that has already been developed, or is currently being drafted, such as the *National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018-2028*. A key focus area of the *National Preventive Health Strategy 2021-2030* is "Reducing alcohol and other drug harm", which aims to build on Australia's long-standing harm minimisation framework. The Australian Government, and state and territory governments, have commenced implementation activities to support the National Preventive Health Strategy 2021-2030.

The Australian Government (Department of Health and Aged Care) in collaboration with States and Territories has developed the *National Alcohol Strategy 2019–2028* and the *National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018–2028,* which both highlight the importance of prevention.

Recommendation 13

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

Supported-In-Principle

The Australian Government acknowledges the complexity and importance of Fetal Alcohol Spectrum Disorder diagnostic services.

A review of the *National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018-2028* was undertaken at the three-year mark after its implementation, with support from the National Fetal Alcohol Spectrum Disorder Advisory Group. The review addressed a range of evaluation questions to inform future decisions about diagnostic service funding models and priority areas.

The review found that progress has been made in providing opportunities for frontline professionals to increase their Fetal Alcohol Spectrum Disorder knowledge, screening and diagnostic skills. This included recent activities to:

- support the development of the first Fetal Alcohol Spectrum Disorder university course, run through the University of Western Australia;
- develop resources to upskill health professionals through the National Awareness
 Campaign for Pregnancy and Breastfeeding Women;
- establish the Australian and New Zealand Fetal Alcohol Spectrum Disorder Clinical Network; and
- research projects aiming to support clinicians to diagnose and support clients with Fetal Alcohol Spectrum Disorder, for example the Fetal Alcohol Spectrum Disorder Diagnostic Services and Models of Care Project.

Through the Australian Government's Fetal Alcohol Spectrum Disorder Diagnostic Services and Models of Care Project, additional funding has been allocated to Fetal Alcohol Spectrum Disorder diagnostic services to improve capacity for screening, diagnosis and surveillance. Available in select sites, the Project has proven to be successful in providing improved access to Fetal Alcohol Spectrum Disorder services in Australia.

In addition, through the 2023-24 Federal Budget, the Australian Government is providing additional funding of more than \$3 million over two years (from 2023-24) to support the delivery of FASD diagnostic services throughout Australia.

Future considerations identified through the implementation review of the *National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018-2028* include:

- greater emphasis on training for all healthcare services in recognising signs of Fetal Alcohol Spectrum Disorder, referral, diagnosis, models of care and management strategies;
- ensuring communities with limited resources still have effective models of care following a Fetal Alcohol Spectrum Disorder diagnosis;
- greater emphasis on screening and diagnosis in education and criminal justice settings.

Recommendation 14

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

Noted

The Australian Government acknowledges the importance of Medicare rebates to support increased diagnostic and treatment activity for Fetal Alcohol Spectrum Disorder.

At present, patients who have been diagnosed with, or are suspected of having, Fetal Alcohol Spectrum Disorder can access a range of Medicare Benefits Schedule items, such as general time-tiered consultation items, used by General Practitioners and specialists to support Fetal Alcohol Spectrum Disorder assessments, diagnoses and treatments.

The Australian Government (Department of Health and Aged Care) Medicare Benefits Schedule Review Taskforce completed its five-year review of the Medicare Benefits Schedule in 2020. The Medicare Benefits Schedule Review Taskforce made several recommendations consistent with this recommendation. Specifically, the Taskforce recommended clarifying the use of existing paediatric and psychiatric Medicare Benefits Schedule items, and associated allied health service items, so that they expressly include the assessment and treatment of Fetal Alcohol Spectrum Disorder and increasing eligibility age limits for these items from under 13 years to under 25 years.

These changes were implemented on 1 March 2023.

Recommendation 15

The committee recommends that the Australian Government fund:

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

Supported-in-Principle

The Australian Government recognises the importance and availability of alternative models for improved utilisation of primary health care services in the assessment and diagnosis of Fetal Alcohol Spectrum Disorder. The Australian Government notes the importance of Fetal Alcohol Spectrum Disorder diagnosis being made more widely available within the community, particularly in rural and remote areas.

The Australian Government (Department of Health and Aged Care) supports a range of research initiatives to improve the health of all Australians. For example, the Health and Medical Research Office administers the Medical Research Future Fund (MRFF). The MRFF offers the opportunity to strategically fund research and address national priorities through its focus on priority-driven research. These priorities are addressed through open and competitive grant opportunities; and the objectives of these grants may align with the priority to strengthen the specialised end of diagnostic services. In particular, the MRFF's Primary Health Care Research Initiative, which will provide \$100 million over 10 years from 2024-25, aims to increase Australia's evidence base in primary health care through research to improve service delivery and patient outcomes and translate this knowledge into action. The funding for this initiative will support projects that enhance equity of access to high quality primary health care through digital health innovation and that help patients to monitor and control their own health care, support continuity of care and enable health care providers and patients to communicate in innovative and timely ways. Funding decisions under this Initiative will be driven by meaningful engagement with end users, such as patients, clinicians and health service providers, to address specific needs of Australian populations, including those in rural or remote locations.

The Australian Government (Department of Health and Aged Care) has funded Griffith University \$2.7 million (over five years, from 2019) to pilot a tiered, culturally responsive approach to screening, diagnosing and supporting neurodevelopmental delays, including FASD, in primary care. The Project aims to test a less time-intensive and culturally sensitive neurodevelopmental assessment and support process that can be implemented by a range of professionals in community settings, including remote First Nations communities.

Following on from this work, the Department of Health and Aged Care through the MRFF 's Rapid Applied Research Translation Initiative awarded Griffith University \$5 million (over five years from 2024) for a large-scale translational grant which extends its work on support and diagnosis for children and adolescents with neurodevelopmental disorders, including FASD. The project aims to enable rapid uptake of a holistic child health and development monitoring software, 'Tracking Cube', for use in First Nations primary health care and the boarder primary health care sector.

Recommendation 16

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

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

Noted

The Australian Government notes the value in Fetal Alcohol Spectrum Disorder diagnostic training being embedded in training for a range of health professionals.

In 2016, the Australian Government supported the development of an *Australian Guide to the diagnosis of Fetal Alcohol Spectrum Disorder* (the Guide). The Guide was produced to assist Australian health professionals with standardised diagnostic resources on Fetal Alcohol Spectrum Disorder. This resource is available from www.fasdhub.org.au.

In 2020, the Department of Health and Aged Care funded the University of Queensland to undertake a review of the Guide to align it with international and clinical best practice. This project is due to be finalised in late 2024.

In 2017, the Australian Government funded *Patches Paediatrics* to deliver a Fetal Alcohol Spectrum Disorder Diagnostic and Models of Care project. This project included the development of a graduate certificate in the assessment and diagnosis of Fetal Alcohol Spectrum Disorder. This graduate certificate is being delivered through the University of Western Australia.

In addition, the Department of Health and Aged Care provides funding to the FASD Hub Australia (the Hub), which is a central repository for information regarding Fetal Alcohol Spectrum Disorder aimed at clinicians, researchers and policy makers. The Hub includes a series of e-learning modules to support health professionals to understand the risks of maternal alcohol consumption, identify and diagnose Fetal Alcohol Spectrum Disorder, and support families and individuals after a Fetal Alcohol Spectrum Disorder diagnosis. The e-learning modules are available from www.fasdhub.org.au.

The Australian Government notes that while training institutions are autonomous, self-accrediting and responsible for the content and quality of their courses, the Australian Government (Department of Health and Aged Care) regularly seeks opportunities to engage with health professionals to raise awareness of alcohol-related harms and the use of relevant guidelines and diagnostic and screening tools. Further, the Department of Health and Aged Care funds a variety of projects that aim to create useful resources on a range of health-related matters for health professionals.

Recommendation 17

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

Noted

The Australian Government notes the importance of workforce capacity and primary health care involvement in Fetal Alcohol Spectrum Disorder assessments and referrals and is committed to a quality tertiary education sector to assist with this.

The Australian Government notes that universities are autonomous, self-accrediting institutions and therefore responsible for the content and quality of their courses. While the Australian Government does not intervene directly in the day-to-day operations of universities, universities are required to meet the Higher Education Standards Framework (Threshold Standards) 2021. This sets out the minimum standards universities must meet to ensure quality and integrity in the delivery of higher education. Universities must meet criteria for teaching—including course design, staffing, resources and educational support—irrespective of whether courses are delivered online or on campus.

The Tertiary Education Quality and Standards Agency (TEQSA) regulates the higher education sector and it provides self-accrediting authority to higher education providers. This means that universities are responsible for their own course offerings and the content of each unit of study. Unlike schools, universities do not have a consistent curriculum across the sector. The Tertiary Education Quality and Standards Agency ensures the quality of individual offerings in line with the Threshold Standards but it does not have any legislative remit to specify content.

The accrediting body of any one profession is responsible for determining the minimum professional standards or requirements for accreditation. The Australian Government has no authority to mandate the content of higher education courses but will look for opportunities when engaging with accrediting bodies to enquire about their minimum requirements in relation to Fetal Alcohol Spectrum Disorder.

Recommendation 18

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

Supported

The Australian Government supports this recommendation.

The Australian Government is funding the University of Queensland to undertake a review and update of the Australian Fetal Alcohol Spectrum Disorder Diagnostic Tool to ensure it is in line with clinical and international best practice. This project is expected to be finalised by late-2024 and will include broad national dissemination and training activities for the updated *Australian Guide to the Diagnosis of Fetal Alcohol Spectrum Disorder*.

The project will include revision of e-learning modules and provide training to health professionals on the use of the Fetal Alcohol Spectrum Disorder Diagnostic Tool. This will raise awareness among health professionals of the importance of regularly initiating discussions with patients on the risks of alcohol-consumption during pregnancy, while planning a pregnancy and while breastfeeding.

In addition, the health professional stream of the National Awareness Campaign for Pregnancy and Breastfeeding Women highlights available resources such as the *Australian Guide to the Diagnosis of Fetal Alcohol Spectrum Disorder* and includes additional resources, training and tools for use in clinical and professional settings.

Recommendation 19

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.

Supported

Since December 2020, the National Disability Insurance Agency (NDIA) has been progressively resetting the Early Childhood Early Intervention Approach in the NDIS so that it reflects contemporary best practice in early childhood approaches and supports children to participate meaningfully in the key environments in their lives.

The National Disability Insurance Agency's Early Childhood Approach is designed to support each child and their family to build their capacity, and supports greater inclusion in community and everyday settings, with the child's parents, carers, family members and educators playing an important role. This approach applies to all children with disability and those with developmental delay, regardless of the nature of their disability.

The National Disability Insurance Agency early childhood partners have teams of professionals with experience and expertise in working with children with developmental delay or disability and their families. They focus on connecting children to family-centred supports and will assist families to apply for access to the NDIS for their child where this is required.

The National Disability Insurance Agency directly supports children and their families in remote and very remote areas of Australia to access the NDIS.

The NDIA is testing a new remote evidence of developmental delay form to support services in remote and very remote Australia to provide the required evidence to demonstrate that a child may be eligible for the NDIS. This has been developed in partnership with community in recognition of the workforce and remoteness challenges.

The Government is committed to working in partnership with those with lived experience of disability through the Independent Advisory Council and disability representatives, on progressive improvements to the early childhood approach. The NDIA is undertaking comprehensive co-design process with the disability community and, where appropriate, this process will consider and incorporate the new Early Childhood Approach.

Recommendation 20

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.

Supported

The Australian Government recognises that the support needs of children change as they move through different developmental stages and is working towards a future National Disability Insurance Scheme that is more consistent, fair and equitable and improves outcomes for eligible young children and their families and caregivers.

The National Disability Insurance Agency is focussed on enhancing the Early Childhood Approach, differentiated from the general National Disability Insurance Scheme. This enables eligible children to receive the right level and mix of support for the right period of time (including more emphasis on early supports and transitions) through a family-centred approach aligned with best practice. It includes supporting eligible young children through

the Early Childhood Approach for longer, by increasing the age limit from under seven to under nine years of age from mid- 2023.

Under the Early Childhood Approach, children and their families and caregivers receive a range of supports from the National Disability Insurance Agency early childhood partners, including early connections and early supports. Early connections are for children younger than seven with delays in their development or with disability and provides access to supports regardless of whether the child is eligible for the National Disability Insurance Scheme. Early childhood partners may recommend early supports for children younger than six with developmental concerns. Early supports are designed to build capacity for children and families and caregivers to promote everyday learning.

The range of supports and services are different for every child in the Early Childhood Approach because they are based on individual needs, including each child's unique circumstances, and important transitions in a child's or family's life.

Recommendation 21

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

Not Supported

Fetal Alcohol Spectrum Disorder is not currently on the List of Recognised Disabilities (the List). The List and the conditions on it are longstanding and no new conditions have been added since 2006.

The List, under the Disability Care Load Assessment (Child) Determination, is used as a qualification tool for Carer Allowance (child) only. The List does not have broader use. There are two stages in assessing the care receiver for Carer Allowance (child). Firstly, the child is assessed against the List. If a child's condition is included on the List their carer will be granted Carer Allowance (child). This reduces the complexity of the claim process and is a fast-track method for qualification.

Many conditions vary in severity and in the amount of additional care required to support an individual child. For this reason, some conditions, including Fetal Alcohol Spectrum Disorder, are not included on the List. Government policy is for each individual to be assessed based on the care provided to determine their eligibility. This does not mean the carer cannot qualify for Carer Allowance (child), or that the child does not require additional care. Qualification is dependent on an appropriate assessment of the severity of the condition and the level of care provided.

The Australian Government notes that access to Carer Allowance (child) can be met by demonstrating a child has a disability or medical condition and the carer provides a

qualifying level of care.

Recommendation 22

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

Noted

The Australian Government notes that eligibility for the Disability Support Pension is based on a person's level of functional impairment and work capacity; it is not based on medical diagnosis or specific medical conditions alone.

Therefore, the Disability Support Pension eligibility criteria already accounts for a person whose functioning has been impacted due to Fetal Alcohol Spectrum Disorder. People with Fetal Alcohol Spectrum Disorder, who have an intellectual disability where supporting medical evidence clearly indicates an IQ of less than 70, may qualify for a manifest grant of Disability Support Pension, which means they can be granted Disability Support Pension without further assessment. People with Fetal Alcohol Spectrum Disorder who are not considered manifest but have an IQ score of 70 to 85 can be assessed under Table 9 – Intellectual Function or Table 7 – Brain Function or another Table that is relevant to their impairment, under the Social Security (Tables for the assessment of work-related impairment for Disability Support Pension) Determination 2023. The Guide to Social Security Law was amended following a recommendation from the 2015 Inquiry into the harmful use of alcohol in Aboriginal and Torres Strait Islander communities to state people with Fetal Alcohol Spectrum Disorder who do not have a low IQ could be assessed under Table 7.

Recommendation 23

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

Noted

The Australian Government (Department of Education) recognises the need for teachers to have access to high-quality professional learning focused on improving student outcomes and aligned to the Australian Professional Standards for Teachers (the Teacher Standards). The Teacher Standards provide a nationally agreed quality assurance mechanism against which teachers can be assessed to ensure they have the competencies required to be effective educators and which guides their teaching practice. Note the Teacher Standards apply to registered teachers in early childhood education and care settings, though

registration is not consistently required in all early childhood settings in the Australian Capital Territory, Northern Territory, Queensland and Tasmania.

The Teacher Standards are a public statement of what constitutes teacher quality and define what teachers should know and be able to do at different stages across their careers (Graduate, Proficient, Highly Accomplished and Lead). These include several requirements for educators to fully understand and meet the needs of their students. For example, Focus Area 1.6 of the Graduate Standards requires teachers to demonstrate broad knowledge and understanding of legislative requirements and teaching strategies that support participation and learning of students with disability. Focus Area 4.4 specifies that teachers must maintain student safety and be aware of strategies that support students' wellbeing and safety within the school and/or system, curriculum, and legislative requirements. However, the standards do not specify program content.

Responsibility for setting priorities for teacher professional learning sits with state and territory teacher regulatory authorities, government and non-government education departments, schools and their teaching staff.

As a part of the Australian Government's implementation of the recommendations from the 2020 Review of the *Disability Standards for Education 2005*, the Australian Institute for Teaching and School Leadership has completed a project to map the Teacher Standards (as well as other key national teaching and teacher education policies) against the Disability Standards for Education. This project included analysis of the extent to which these frameworks support teachers to develop the skills they need to support school students with disability.

Based on the project, the Australian Institute for Teaching and School Leadership has developed resources to support teachers and school leaders understand and apply the Disability Standards for Education.

The primary role of the Australian Government in the early childhood sector is to provide financial assistance to families, mainly as subsidies through the childcare system. The Australian Government is not an employer in the early childhood sector, and professional development is the responsibility of employers.

The National Quality Framework provides a national approach to regulation, assessment and quality improvement for early childhood education and care services across Australia. As part of the National Quality Framework, early childhood services are required to provide an educational program that enhances each child's learning and development, and to develop respectful relationships with families to support children's inclusion, learning and wellbeing.

All governments collaborated with the sector to co-design a new 10-year National Children's Education and Care Workforce Strategy, released by the Australian Children's Education and Care Quality Authority on 13 October 2021. The Workforce Strategy aims to support the recruitment, retention, sustainability, and quality of the early childhood services workforce.

Implementing the *Workforce Strategy* is a collective responsibility between governments and the sector, as no single stakeholder group can be responsible for all the actions.

An implementation plan to guide collaboration between all stakeholders to achieve the *Workforce Strategy's* aims was released in September 2022. The implementation and evaluation plan commits all governments and the sector to progressing the Strategy's 21 actions as a priority. The plan outlines implementation steps for each action and how progress will be monitored and managed.

One of the actions in the *Workforce Strategy* is to improve access to an increasing range of micro-credentials for educators and teachers in areas of identified need, including educating and caring for children with additional needs. Subject to this action being taken forward in the implementation plan, consideration will be given to the inclusion of other priority subject areas such as Fetal Alcohol Spectrum Disorder and other areas identified by the sector into the range of recognised micro-credentials training.

Furthermore, the Australian Government (Department of Health and Aged Care) funds the FASD Hub Australia, which provides access to online Fetal Alcohol Spectrum Disorder learning packages, face-to-face training, workshops, seminars and conferences conducted by different government and non-government organisations across Australia. The Department of Health and Aged Care is also funding the University of Sydney's Matilda Centre, to develop a suite of teacher and education setting resources. These resources, launched in March 2022, aim to build the capacity of the education workforce (teachers, support staff and mentors) to identify, engage with, and support students with Fetal Alcohol Spectrum Disorder to ensure they have access to equal education opportunities. The suite is a national resource is being promoted to State and Territory education departments.

The Australian Government (Department of Health and Aged Care) also funds the National Organisation for Fetal Alcohol Spectrum Disorder (NOFASD) to develop 'Through Different Eyes', a guide and accompanying resource suite for people working in early childhood education settings. The guide aims to support educators to identify children who potentially have Fetal Alcohol Spectrum Disorder, to build the capacity of educators to assist children with Fetal Alcohol Spectrum Disorder, and to encourage positive outcomes for children and their families.

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

Noted

The Australian Government notes the importance of schools having the capability to support children with Fetal Alcohol Spectrum Disorder.

The Australian Government (Department of Education) notes that the *Disability Standards* for Education 2005 require schools to provide reasonable adjustments for students with disability to enable them to participate in education on the same basis as other students.

The Australian Government's 2020 Review of the *Disability Standards for Education 2005* found a need to strengthen provider and educator capability to support students with disability. To assist educators to better understand their responsibilities under the *Disability Standards for Education 2005*, the Australian Government has developed information products for educators (including teachers and school leaders) which illustrate good practice approaches to support school students with disability.

Information products for students and their caregivers to support increased understanding of their rights under the *Disability Standards for Education 2005* were released in September 2022 and are available at: www.education.gov.au/disability-standards-education-2005. These resources assist students with disability and their caregivers to work with their educators to seek reasonable adjustments that allow them to learn and participate on the same basis as students without disability.

Mechanisms supporting the implementation of the *Disability Standards for Education 2005* in schools include the Nationally Consistent Collection of Data on School Students with Disability - an annual collection of data about Australian school students who are receiving adjustments due to disability - and the Schooling Resource Standard student with disability loading.

The Nationally Consistent Collection of Data on School Students with Disability collects information about school students with disability across Australia in a consistent, reliable and systematic way. All schools and approved authorities for schools in Australia participate in the Nationally Consistent Collection of Data on School Students with Disability. Under the Nationally Consistent Collection of Data on School Students with Disability model, teachers use their professional judgement, supported by evidence, to determine the level of adjustment that students with disability receive over a minimum period of 10 weeks of school education. These adjustments are based on school teams' assessment of the functional impact of the student's disability on their education. Students identified in the Nationally Consistent Collection of Data on School Students with Disability as receiving a

supplementary, substantial, or extensive level of educational adjustment attract funding under the student with disability loading.

The model for the Nationally Consistent Collection of Data on School Students with Disability is based on the existing obligations of all Australian schools under the *Disability Discrimination Act 1992* (DDA) and the *Disability Standards for Education 2005* and draws on the definition of disability in the DDA. The NCCD categories of disability are: physical, cognitive, sensory, and social/emotional. Students with Fetal Alcohol Spectrum Disorder may experience varied challenges depending on their exposure and may present as having a disability in one or more of these categories. Fetal Alcohol Spectrum Disorder may be diagnosed, but the Nationally Consistent Collection of Data on School Students with Disability Guidelines also provide for school teams to 'impute' a disability to a student in the absence of a medical diagnosis, supported by documented evidence that the student is receiving adjustments based on the definition of disability in the DDA. These students would be eligible for inclusion in the Nationally Consistent Collection of Data on School Students with Disability and depending on the level of adjustment they receive may attract the student with disability loading.

The Australian Government provides funding to Education Services Australia to support the Nationally Consistent Collection of Data on School Students with Disability Portal, a free, one-stop-shop for information and resources for teachers, school leaders and parents/carers on the Nationally Consistent Collection of Data on School Students with Disability. Content on the Portal is developed in consultation with State and Territory Government departments of education and the catholic and independent sectors and is updated and added to on an ongoing basis according to need. The Portal contains a podcast to assist teachers to understand Fetal Alcohol Spectrum Disorder and to provide adjustments for students to assist their education.

As part of the 2023-24 Budget, the Australian Government announced funding for the continuation of FASD prevention, diagnosis and support activities. This support includes funding of \$0.761 million over two years (from 2023-24) from the Australian Government Department of Health and Aged Care to the Matilda Centre to develop, maintain and disseminate resources targeting the primary and secondary education sector. The Australian Government will continue to work with the Matilda Centre to explore opportunities for targeted resources to be used in secondary schools.

Recommendation 25

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

Supported-In-Principle

The Australian Government recognises that caring for a child with Fetal Alcohol Spectrum Disorder can impact greatly on families and carers.

The Australian Government (Department of Social Services) has funded family focused alcohol and other drugs support services since 2005, initially under the National Illicit Drug Strategy (NIDS) and then under the Family Support Program. In 2014, alcohol and other drugs services were broad banded into the Children and Parenting Support sub-activity, which is funded under the Family and Children's Activity.

Children and Parenting Support alcohol and other drugs services provide intensive support to vulnerable and disadvantaged families and children affected by substance misuse issues. These services are complimentary to state and territory funded support services. The services aim to minimise harm to children and families through individual and family counselling, home visiting and case management, parenting education and support, and activities to help children maintain positive routines through a focus on school attendance, organised sport and extracurricular activities. Funding of around \$4.5 million will be provided in 2024-25 to nine organisations across Australia to deliver alcohol and other drugs services. Children and Parenting Support funding is fully committed to 2025-26.

The Department of Social Services also funds Carer Gateway to provide supports and services for all carers of any age who provide care to a family member or loved one, including those with disability or a medical condition. Carer Gateway delivers evidence based, early-intervention and preventative supports and services that are tailored to the individual needs and circumstances of a carer.

Furthermore, the Australian Government (Department of Health and Aged Care) funds the National Organisation for Fetal Alcohol Spectrum Disorder (NOFASD) Australia to deliver telephone and online information and support services to individuals, families and carers affected by Fetal Alcohol Spectrum Disorder. Through the 2023-24 Budget, additional funding of \$1.45 million over two years (from 2023-24) is being provided to NOFASD to continue these important services.

Recommendations 26

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

Supported-In-Principle

The Australian Government notes that these systems and the policies in respect to people entering these systems are the responsibility of State and Territory Governments. The Australian Government notes that any such screening policy would be consistent with the *National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018-2028*, which includes an objective to improve capacity for screening, diagnosis and surveillance.

The Australian Government does however provide funding to deliver Fetal Alcohol Spectrum Disorder diagnostic services in locations across Australia, including assessments for youth who have interacted with the youth justice system or are at risk of (further) youth justice engagement and have possible physical, cognitive or behavioural difficulties.

In addition, under the Justice Policy Partnership (JPP) Strategic Framework endorsed by the Joint Council on Closing the Gap in June 2023, the JPP will be strengthening existing and/or new strategic cross-sector partnerships at the national and state/territory levels to consider health and disability support/s for Aboriginal and Torres Strait Islander adults and young people in places of incarceration. The JPP brings together representatives from the Coalition of Peaks, Aboriginal and Torres Strait Islander experts, and Australian, state and territory governments to take a joined-up approach to Aboriginal and Torres Strait Islander justice policy.

Recommendations 27

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

Supported-In-Principle

The Australian Government notes that these systems and the policies in respect to people that access these systems are the responsibility of State and Territory Governments. Any such screening protocols would be consistent with the *National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018-2028*, which includes an objective to improve capacity for screening, diagnosis and surveillance, and identifies an activity to 'develop a Fetal Alcohol Spectrum Disorder screening tool and response system for high-risk groups such as youth entering correctional settings'.

Also see reference to Justice Policy Partnership work and assessment services under Recommendation 26.

Recommendations 28

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

Noted

The Australian Government (Department of Health and Aged Care) funds Small and Up Pty (PATCHES) to undertake a project to increase Fetal Alcohol Spectrum Disorder awareness within the justice and employment workforce. Resources developed through this project see to:

- explain the characteristics of Fetal Alcohol Spectrum Disorder and strategies to improve the outcomes for people with Fetal Alcohol Spectrum Disorder, their families and the community;
- outline the assessment process for someone who is suspected of having Fetal Alcohol Spectrum Disorder; and
- include information on linking people with Fetal Alcohol Spectrum Disorder to employment services.

The resources are available at https://patches.com.au/fasd.

Additional funding is also being provided by the Australian Government of approximately \$2.1 million over three years (from 2021-22) to Small and Up Pty (PATCHES) to deliver Fetal Alcohol Spectrum Disorder diagnostic services within the youth justice system in regional New South Wales. This project includes capacity building for the justice workforce on the effects of prenatal alcohol exposure.

The Australian Government notes that the operation of correctional facilities is the responsibility of State and Territory Governments.

Recommendation 29

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

Noted

The Australian Government notes that the justice system is the responsibility of State and Territory Governments and will look for opportunities to engage on this matter with State and Territory Governments. See reference to Justice Policy Partnership work under Recommendation 26.

Recommendation 30

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

Noted

Funding and support for State and Territory Child Protection authorities is a matter for State and Territory Governments.

The Australian Government more broadly provides support for carers through funding to National Organisation for Fetal Alcohol Spectrum Disorder Australia to deliver telephone

and online counselling services to individuals, families and carers affected by Fetal Alcohol Spectrum Disorder.

Recommendation 31

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.

Supported

The Australian Government recognises the need to improve support for remote communities to understand, apply for and access early interventions and disability support services.

The National Disability Insurance Agency is partnering with Aboriginal Community Controlled Health Organisations (ACCHOs) in several ways to improve access to culturally safe and appropriate services and address services gaps, particularly for First Nations participants living in remote Australia.

In April 2024, the National Disability Insurance Agency appointed a Deputy Chief Executive Officer to lead a First Nations Group that will work on interventions to improve outcomes for First Nations peoples with disability. This dedicated senior executive position will also bring in a First Nations voice into the National Disability Insurance Agency's decisions as a member of the senior executive leadership team. This revised organisational structure will more effectively support prioritisation, coordination of activities and work to improve outcomes for First Nations National Disability Insurance Scheme participants and employees in remote communities.

The National Disability Insurance Agency has established partnerships with First Nations disability individuals and community representatives to undertake a co-design process for the new First Nations Strategy and Implementation Plan. The National Disability Insurance Agency has committed resourcing and funding to deliver the co-design of the First Nations Strategy.

The National Disability Insurance Agency is strengthening its Remote Community Connector model through current reforms with a view of a more consistent, uniform footprint.

The National Disability Insurance Agency is putting in place a range of improvements, including increasing the coverage and capacity of the Remote Community Connectors program to provide localised, community-based support to underserviced remote areas and trialling alternative approaches to commissioning to improve access to services for First Nations and remote communities. These improvements will allow stronger local conversations and understanding the unique needs of each community – where the Agency

is able to tailor services to match the specific requirements and cultural sensitivities of the community.

The National Disability Insurance Agency has committed funding of \$18.1 million in the 2024-25 financial year through the Remote Community Connectors program to mostly Aboriginal Controlled Organisations (primarily Aboriginal Medical Services and Aboriginal Shire Councils) in remote areas to improve support to access the National Disability Insurance Scheme.

In addition, the National Disability Insurance Agency is funding Torres and Cape Hospital and Health Service (TCHHS) \$4 million over two years to deliver an early childhood approach across Cape York and the Torres Strait Islands.

The National Disability Insurance Agency funds the National Aboriginal Community Controlled Health Organisation (NACCHO) \$5.0 million annually to provide dedicated support to First Nations peoples in urban and rural areas to access the National Disability Insurance Scheme and use their plans, in the form of Aboriginal Disability Liaison Officers.

Aboriginal Disability Liaison Officers are expected to reach communities, provide insights and other culturally relevant information in order to complement the work of and connect First Nations peoples with Partners in the Community and National Disability Insurance Agency state and territory Service Delivery teams.

The National Disability Insurance Agency has two trial sites for the Alternative Approaches to Commissioning for Remote and First Nations Communities initiatives. Maningrida in the NT was the first trial site with Katanning in WA recently announced as the second. The program is set to provide a foundation for the future commissioning of services delivered under the National Disability Insurance Scheme and improve access to supports for people in rural, remote, and First Nations communities.

Recommendation 32

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

Supported

The Australian Government is committed to supporting First Nations community-led projects to prevent and manage Fetal Alcohol Spectrum Disorder.

The Australian Government (Department of Health and Aged Care) has funded the National Awareness Campaign for Pregnancy and Breastfeeding Women, which includes a First Nations specific campaign stream under the branding 'Strong Born'. This stream is being led by NACCHO and aims to use tailored community development and health promotion activities to raise awareness of the impacts of alcohol use during pregnancy, while planning

a pregnancy and while breastfeeding. Through the 2023-24 Budget, the Australian Government is providing an additional \$1.4 million over two years (from 2023-24) to support the expansion of the 'Strong Born' campaign, to ensure that all First Nations communities, and the health workers that support them, have access to culturally appropriate knowledge and skills to prevent alcohol exposed pregnancies, yarn sensitively about alcohol use in pregnancy and identify and support children who may have FASD.

On 6 February 2023, the Prime Minister announced a \$250 million landmark package for Central Australia (the Central Australia Plan) to improve community safety, tackle alcohol-related harm and provide more opportunities for young people. As part of this package, the Government committed approximately \$18.4 million over four years (2022-23 to 2025-26) to the Central Australian Aboriginal Congress Aboriginal Corporation (Congress) to expand its existing Child and Youth Assessment and Treatment Services (CYATS) program.

CYATS provides early detection and intervention for neurodevelopmental conditions, such as FASD in six remote communities across Central Australia. Through this expansion Congress will be able to increase the number of assessments they already provided and treatment pathways for Aboriginal children and young people. The expansion will also further extend the reach of services into remote communities in Central Australia, and acting as a regional hub, increase the CYATS teams' capacity to work with schools, other service providers and the youth justice system.

In addition, the Australian Government has funded the MRFF's Indigenous Health Research Fund a total of \$160 million from 2018–19 to 2028–2029. The Indigenous Health Research Fund invests in Indigenous-led research to improve the health of First Nations people.

The Indigenous Health Research Fund's Roadmap and Implementation Plan outline the aims and priority areas for investment for the Indigenous Health Research Fund.

To date, the Indigenous Health Research Fund has invested \$1.24 million in two grants with a focus on research to reduce alcohol use in pregnancy.

In line with the National Agreement on Closing the Gap, the Australian Government (Department of Health and Aged Care) works in partnership with the Aboriginal Community Controlled Health Sector on a range of health priorities for First Nations people.