

FASD Advisory Group

Outcomes of Meeting three, Tuesday 23rd February 2021

Agenda Item 1

- Co-Chair s47F, s47E(c) welcomed members to the teleconference and noted apologies received.
 - s47F, s47E(c) reminded members of the importance of the conflict of interest disclosures and revisited the guidance that was sent out by the secretariat for members to complete.
 - Members only need to complete prior to each meeting if something has changed.
- s47E(c), s47F delivered the Commonwealth update, noting progress of funding announced in September 2020.
 - Members discussed and raised concerns about different funding approaches.
 - Members queried government funding processes and how decisions are made.
 - Secretariat to provide a paper for members outlining government funding processes.
 - Secretariat to send link for grant connect to members.

Actions:

- If individual circumstances have changed, Members to complete a new conflict of interest disclosure prior to future meetings.
- Secretariat to provide a paper for members outlining government funding processes.
- Secretariat to send link for grant connect to members.

Agenda Item 2

- Meeting outcomes from previous meeting accepted with no changes.
 - Members queried the status of the MBS review.
 - Secretariat to seek advice and advise members of the status of the MBS review.
 - The Terms of Reference are now complete.

Actions:

- Secretariat to seek advice and advise members of the status of the MBS review

Agenda Item 3

- The Secretariat presented the stakeholder engagement plan to Members.
 - Members discussed the plan and agreed in principle with some additions to Key Stakeholders at part 2.2.
 - s47F offered to share FARE's stakeholder plan developed through the National Awareness Campaign - Secretariat to obtain from s47F.
 - Members were asked to provide suggestions under part 2.2 to the Secretariat.
 - s47F noted that she can act as a representative for consumers, and can also gather a group of suitable consumers as and when needed.

Actions:

- Secretariat to obtain copy of FARE's stakeholder engagement plan from s47F.

Agenda Item 4

- Members noted the mapping exercise table and data sources table.

- Secretariat asked for member input to tables.
 - Secretariat to send clean template, for both data sources and mapping exercise, to members for input.
- Input still being received from jurisdictions.
- Secretariat to add new column to mapping table for duration of funding.
- Final table will be sent to members for review around May 2021.
- Tables will be used to inform the evaluation undertaken by a consultant.

Actions:

- Secretariat to send clean template, for both data sources and mapping exercise, to members for input.
- Secretariat to add new column to mapping table for duration of funding.

Agenda Item 5

- Members discussed potential topics and structure of advice to be developed for Minister Hunt.
 - Note to frame advice to align with priority areas of the Strategic Action Plan and how to implement some of the actions in the plan.
 - The most immediate piece of advice will concern alcohol during COVID-19, including:
 - online sales,
 - impact on sales and consumption,
 - targeting of messages to women and young people,
 - potential for many babies affected by FASD to be born following this period, leading to high risk obstetrics patients and the potential for increased demand for FASD diagnostic and support services over time.
- Secretariat to begin drafting advice with assistance from Members. Draft advice will be sent to Members for input prior to finalisation with Chairs. Other topics to be considered for future advice include:
 - requesting the Minister write to the alcohol industry and producers for an update on the implementation of warning labels and timeframes for expected rollout
 - suggesting to the Minister to leverage other jurisdictions/agencies investment to get the most out of each service and funding program
 - requesting the Minister to write to The Hon. Stuart Robert MP Minister for National Disability Insurance Scheme to request improved recognition of FASD, and enhanced engagement with the Department of Health in respect to FASD
 - national prevalence study
 - out of home care issues (this will also be discussed further at the next meeting).

Actions:

- Secretariat to begin drafting advice to Minister Hunt with assistance from Members.

Agenda Item 6

- Secretariat noted that the Senate Inquiry into FASD is due to report to the Senate by 17 March 2021.
- The next meeting date will be canvassed out of session.

The Hon Greg Hunt MP
Minister for Health and Aged Care
PO Box 6022
House of Representatives
Parliament House
Canberra ACT 2600

Dear Minister Hunt,

Time for stronger regulation of online alcohol sales and digital marketing

In response to increased sales of alcohol online, the Fetal Alcohol Spectrum Disorder (FASD) Advisory Group (the Advisory Group) seeks ministerial action to tighten the regulation of online alcohol sales and digital marketing, with the aim of reducing alcohol-related harm to young people, families, the unborn child and the community.

The Advisory Group shares the concerns of many public health advocates that increased availability of alcohol through unregulated online home delivery services and heavy, targeted marketing will lead to higher rates of alcohol-related harms, including increased prevalence of FASD, the most common cause of preventable prenatal brain injury.

We request you contact state and territory counterparts to encourage them to follow New South Wales' lead in implementing liquor licensing reforms to regulate online alcohol sales with home delivery.

We also request you contact the Hon Stuart Robert MP to fast track work on standards for online age verification, to help keep children safe from alcohol harm.

Further detail in respect to the need to tighten regulation of online alcohol sales and digital marketing is outlined below.

Online alcohol sales are rising and are unregulated, increasing alcohol-related harms

Retail alcohol sales in Australia increased by \$3.3 billion (26.7 per cent) from 2019 to 2020¹, and online purchases accounted for a greater share of sales than previously – up almost 8 percentage points since 2019.² Although alcohol sales have increased markedly during the COVID-19 pandemic, the rapid growth of online alcohol sales is not simply a consequence of the pandemic, having grown by an average of 14 per cent annually over the last five years.³

Online alcohol sales with the option of home delivery incentivise Australians to drink more through enticements such as rapid (within two hours) delivery, discounts, and bulk-purchase promotions and the use of 'buy now, pay later' options like AfterPay.^{3,4} People who use

rapid alcohol delivery can now drink with less constraint⁴, risking harm to themselves and others. Of concern, the unregulated nature of online sale and delivery allows easier access to alcohol by underage consumers. For example, three-quarters of online retailers advertise a willingness to leave alcohol unattended at an address without verifying the purchaser's age or state of intoxication.³

To guard against online sale of alcohol to children, there must be both online age verification and ID checks upon delivery. NSW has been the first jurisdiction to act on this issue, along with a range of other changes to the liquor license to regulate online sales. Other states and territories need to follow suit to ensure a nationally consistent approach.

The Commonwealth has a key role to play to ensure that technology for online age verification is simple to implement and meets expected standards of privacy and safety. In February 2020, the House of Representatives Standing Committee on Social Policy and Legal Affairs recommended that the Digital Transformation Agency develop standards for online age verification for age-restricted products and services.⁵ The Commonwealth Government supported initial work on this recommendation regarding pornographic material and online wagering, but there remains a pressing need for age verification for online alcohol sales. We request that you fast track the work on standards for online age verification, to help keep children safe from alcohol harm. We also recommend that you write to state and territory counterparts encouraging them to follow New South Wales' lead in implementing liquor licensing reforms to regulate online alcohol sales associated with home delivery.

Digital marketing targets vulnerable and underage consumers, increasing alcohol-related harms

The associated rise in heavy, targeted alcohol marketing through digital platforms also requires attention. The industry's ability to leverage the COVID-19 pandemic as a marketing opportunity points to weaknesses in ability of the Alcohol Beverages Advertising Code's to protect Australians from advertising that promotes harmful drinking behaviour.

During the pandemic nearly three-quarters (71 per cent) of digital alcohol advertisements explicitly or implicitly referenced the pandemic, tapping into Australians' stress, anxiety and isolation with marketing messages known to promote harmful drinking - including drinking to cope, drinking daily, and drinking at home or alone in the home. Harmful drinking is promoted by advertisements for cheap, easily accessible, bulk supplies of alcohol. The volume of digital alcohol advertisements has markedly increased: one personal Facebook and Instagram account attracted one alcohol advertisement every 35 seconds on a Friday night in April 2020.⁶

There are reports that women have been particularly targeted by digital alcohol marketing. Alcohol advertising is often positioned as offering relief and reward to over-burdened or

isolated women. This may in part explain the higher proportion of women (18 per cent) than men (10.8 per cent) who reported increased alcohol consumption early in the pandemic.⁷ Women often carry additional loads of caring work and home schooling while maintaining paid employment. Indeed, mothers report increased alcohol use in lockdown and attribute this to anxiety about COVID-19 and the stress of home schooling and working from home.⁸ The long-term effect of increased consumption on rates of unplanned pregnancy, high-risk pregnancies with associated service needs, FASD prevalence, and the intergenerational effects of prenatal alcohol exposure is unclear. Of concern, rates of both unplanned and planned pregnancies have significantly increased during the pandemic.⁹ During the pandemic there is also anecdotal evidence of increased Reproductive Coercion reported by women and providers of support services for the victims of intimate partner violence.

Underage children are also vulnerable to predatory alcohol advertising online. Advertising technology companies have collected over 72 million data points on a child by the time they are 13 years old.¹⁰ Facebook alone is currently gathering data on almost 2 million children in Australia and New Zealand.

A recent study found that Facebook allows advertisers to target young people (aged 13-17) who Facebook has profiled as interested in alcohol and other age-inappropriate pursuits based on their internet activity. The study found Facebook approved alcohol advertisements targeting 13-17 year olds.¹¹ In response, Facebook and Instagram announced they will no longer allow advertisers to target under 18s based on their profiled interests or online activity.¹² Although this is a positive development, research shows that self-regulation tends to be ineffective.

Australia's current, self-regulatory Alcohol Beverages Advertising Code is ineffective and is failing to prevent alcohol marketing to children and youth.¹³ This problem is amplified by online access to, and digital marketing of, alcohol. This is of concern because of the proven strong association between young people's exposure to alcohol advertising, early use of alcoholic products, and later development of alcohol use disorders.^{14,15}

Call for action to strengthen implementation of national strategies

As Minister for the Health of all Australians we urge you to call for stronger, enforceable regulation of online alcohol sales and digital marketing. You have an opportunity to strengthen and reaffirm the government's commitment to the *FASD Strategic Action Plan 2018-2028* (FASD SAP) and to the prevention of FASD through 'reducing access and consumption of alcohol in the Australian community.' We note that the Plan has strong synergies with the National Alcohol Strategy (the overarching strategy to the FASD SAP), which includes as a key priority 'Reducing opportunities for availability, promotion and pricing contributing to risky alcohol consumption'. We also note the synergies between such

action and the draft National Preventive Health Strategy and National Aboriginal and Torres Strait Islander Health Plan 2013-2023.

Evidence from research shows that implementing bans on advertising and promotion of alcohol, restricting availability and access to alcohol, and pricing and taxation are the most efficient strategies to minimise harms from alcohol throughout society. These strategies are highly cost-effective in reducing alcohol-attributable death and disability at the population level¹⁶ and have been identified by the OECD as critical areas in which Australia can improve its approach to addressing the harmful use of alcohol.¹⁷

We thank you for your ongoing support and look forward to engaging with you further on these critical issues.

Regards,

s47F



Professor Elizabeth Elliott AM FAHMS FRSM

Co-chair, FASD Advisory Group

Professor of Paediatrics & Child Health, University of Sydney

Next Generation Fellow, Medical Research Futures Fund

Consultant Paediatrician, Sydney Children's Hospitals Network (Westmead)

Director, Australian Paediatric Surveillance Unit

The **FASD Advisory Group** was established to monitor and report on implementation of the *National FASD Strategic Action Plan 2018-2028* and advise Government on emerging issues, trends, opportunities and gaps that may exist across the domains of the Plan. It consists of representatives from clinical, research, policy and parent/carer sectors.

Membership:

s47F, s47E(c)

Co-chair

s47F



s47F



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- ¹ Foundation for Alcohol Research and Education, '[Retail During COVID-19](#)', February 2021, accessed 14 May 2021.
- ² Roy Morgan, '[Online alcohol sales soar in 2020, but will this market continue to grow in a post-COVID environment?](#)', 23 March 2021, accessed 14 May 2021.
- ³ S Colbert, L Thornton and R Richmond, 'Content analysis of websites selling alcohol online in Australia', *Drug and Alcohol Review*, 2020, 39(2): 162-169.
- ⁴ La Trobe University, '[Rapid alcohol delivery service risks](#)', 17 November 2019, accessed 14 May 2021.
- ⁵ Commonwealth of Australia, '[Protecting the age of innocence, report by the House of Representatives Standing Committee on Social Policy and Legal Affairs](#)', February 2020, accessed 19 July 2021.
- ⁶ Foundation for Alcohol Research and Education, '[An alcohol ad every 35 seconds](#)', May 2020, accessed 14 May 2021.
- ⁷ Australian Bureau of Statistics, '[Household Impacts of COVID-19 Survey 29 April to 4 May 2020](#)', 18 May 2020, accessed 14 May 2021.
- ⁸ Alcohol and Drug Foundation, '[Why we need to talk about parents drinking during lockdown](#)', 22 May 2020, accessed 14 July 2021.
- ⁹ SPHERE, '[Women's Sexual and Reproductive Health COVID-19 Coalition: A Consensus Statement on Reproductive Coercion](#)', 13 July 2021, accessed 14 July 2021.
- ¹⁰ D Collins, '[How much data do adtech companies collect on kids before they turn 13?](#)', December 2017, accessed 19 July 2021.
- ¹¹ Reset Australia, '[Profiling Children for Advertising: Facebook's Monetisation of Young People's Personal Data](#)', April 2020, accessed 14 May 2021.
- ¹² C Duffy, '[Facebook and Instagram ban inappropriate ads for young people, after data harvesting revealed by ABC](#)', ABC News, 28 July 2021, accessed 28 July 2021.
- ¹³ S Pettigrew et al. '[Alcohol advertisement characteristics that increase the likelihood of code breaches](#)', *International Journal of Drug Policy*. 2020, 81: 102776.
- ¹⁴ A Roche et al, '[Young people and alcohol: the role of cultural influences](#)', *National Centre for Education and Training on Addiction*, 2008, accessed 14 May 2021.
- ¹⁵ NHMRC, '[Australian Guidelines to Reduce Health Risks from Drinking Alcohol](#)', 2020, accessed 14 July 2021.
- ¹⁶ World Health Organization, '[Global strategy to reduce the harmful use of alcohol](#)', 2010, accessed 14 May 2021.
- ¹⁷ Organisation for Economic Co-operation and Development (OECD), '[Preventing Harmful Alcohol Use](#)', May 2021, accessed 2 June 2021.

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by the Department of Health, Disability and Ageing



**The Hon Greg Hunt MP
Minister for Health and Aged Care**

Ref No: MC21-025146
20 AUG 2021

Professor Elizabeth Elliott AM FAHMS FRMS
Co-chair
Fetal Alcohol Spectrum Disorder Advisory Group
s47F [redacted]@gmail.com

Dear Professor

Elisabeth

I refer to your correspondence of 4 August 2021 concerning the regulation of online alcohol sales and digital marketing on behalf of the Fetal Alcohol Spectrum Disorder (FASD) Advisory Group.

I acknowledge the FASD Advisory Group's concerns about the harms associated with unregulated digital marketing, online sales and home delivery of alcohol products, and I would like to assure you that the Australian Government is committed to preventing and reducing the impact of alcohol-related harms on individuals, families, and communities.

I have asked the Secretary of my Department, Dr Brendan Murphy, to raise this matter with his state and territory counterparts at a future meeting of Health Chief Executive Officers. Furthermore, my office will bring this matter to the attention of the office of the Minister for Employment, Workforce, Skills, Small and Family Business, the Hon Stuart Robert MP and emphasise the importance of the fast-tracking of standards for online age verification to help keep children safe from alcohol-related harm.

I will ensure that my Department provides an update on these items at a future FASD Advisory Group meeting.

I would like to take this opportunity to thank you and the FASD Advisory Group for their commitment to improving the prevention, diagnosis, support and management of FASD in Australia through monitoring the implementation of the FASD Strategic Action Plan and developing advice for Government.

Thank you for writing on this matter.

Yours sincerely

Greg Hunt

24 September 2021

The Hon Greg Hunt MP
 Minister for Health and Aged Care
 PO Box 6022
 House of Representatives
 Parliament House
 Canberra ACT 2600

Dear Minister Hunt,

Re: Recognition of contemporary diagnostic criteria and terminology for Fetal Alcohol Spectrum Disorder (FASD) by the National Disability Insurance Scheme (NDIS) and facilitation of timely access to NDIS services for people living with FASD

The National FASD Advisory Group (the Advisory Group) urges you to seek ministerial engagement with the National Disability Insurance Agency (NDIA) to suggest that it:

1. Updates NDIS definitions to be consistent with the Australian Guide to the Diagnosis of FASD; and
2. In the NDIS List D, amend diagnosis from Fetal Alcohol Syndrome (FAS) under 7 years to Fetal Alcohol Spectrum Disorder (FASD) without age qualification.

The Advisory Group, responsible for monitoring implementation of the National FASD Strategic Action Plan 2018-2028 (the Plan) ¹ comprises clinicians, researchers, policy experts and representatives from the parent/carer sector. One of the objectives of the Plan is to improve management, support and care models for people living with FASD. The actions we request above are critically important to further this objective.

As outlined in the 'Australian Guide to the Diagnosis of FASD', FASD is a lifelong disability underpinned by a brain injury caused by prenatal alcohol exposure and is characterised by a range of severe neurodevelopmental impairments. ² Although the prevalence of FASD is not known in the general Australian population, over 60% of Australian women use alcohol in pregnancy. ^{3,4} Based on international estimates, 2% or more of all Australian babies may be affected by FASD. ⁵ However, certain groups are at higher risk of FASD ⁶ and this is reflected in prevalence data from remote Australian indigenous community (19%) ⁷ and juvenile justice (36%) ⁸ settings.

FASD results in a broad range of financial costs to people living with the condition, their families, carers and the community. These costs include health care and accommodation, education, employment support services, income support, community, and justice services. ¹

Many people living with FASD and their families and carers have trouble accessing any support services through the NDIS. This was confirmed by the recent Senate Community Affairs References Committee Inquiry into Effective approaches to prevention, diagnosis, and support for Fetal Alcohol Spectrum Disorder (the Senate Inquiry) ⁹ and the Joint Standing Committee on the National Disability Insurance Scheme into the Independent Assessments. ^{10,11}

The need for contemporary diagnostic terms

One barrier to obtaining NDIS support is the use of outdated terminology. Currently, the NDIA lists 'Fetal Alcohol Syndrome' (FAS) in children under the age of 7 years as a condition potentially eligible for NDIS-funded services. FAS describes people with all three characteristic facial features of FASD, neurodevelopmental impairment and growth deficit. FAS has not been used as a diagnostic term since publication in 2016 of the 'Australian Guide to the Diagnosis of FASD'.² The Guide recommends use of the term 'Fetal Alcohol Spectrum Disorder' (FASD) to include children and adults with severe neurodevelopmental impairment - attributed to prenatal alcohol exposure and in at least three domains of function - but who may or may not exhibit facial features and other birth defects. The diagnostic criteria for FASD used in Australia align with criteria used in Canada, New Zealand and the United Kingdom. The FASD Advisory Group strongly recommends that, in line with the recent Senate Inquiry, the NDIA amend use of the term 'FAS' and its application to children aged less than 7 years to the contemporary diagnostic term of 'FASD' without the age qualification.

The need to improve access to NDIS services for people living with FASD

Another barrier to timely access to much needed NDIS services and supports for individuals and families with FASD is the prospect of additional, often duplicative assessments that must be performed by an NDIA independent assessor to determine the child's level of functional impairment and thus eligibility for services. This process can generate considerable stress and delay appropriate treatment.

The process is also unnecessary in some cases because children with a FASD diagnosis have already undergone a complex, time consuming and often expensive assessment. Diagnosis requires input from a multi-disciplinary team of health professionals, either in a specialised FASD diagnostic service or child development service, or through developmental and community paediatricians. Specialised services are few, demand is high and wait times for multi-disciplinary assessments are long.

The 'Australian Guide to the Diagnosis of FASD' requires assessing clinicians to document the impact of FASD on a range of neurodevelopmental functions including executive function; adaptive behaviour, social skills, and social communication; cognition; memory; attention; academic achievement; and motor skills. This tool enables clinicians to rate the level of impairment for each domain from 'none' to 'severe' based on direct assessment using validated tools (e.g., the WISC-V for IQ) and/or indirect assessment based on parent/teacher report (e.g., the Vineland-3 for adaptive function).

A management plan is developed based on the assessment and communicated to families, schools and relevant health professionals and agencies. Thus, people with a FASD diagnosis have undergone an authoritative assessment of their functional impairments and support needs *before* applying to access the NDIS. To avoid repeat assessments by an independent assessor, it would be appropriate that NDIA instead accept a report containing detailed results of recent diagnostic assessments.

Feedback from individuals and carers confirms that accessing the NDIS is time-consuming and difficult and that the outcome is unpredictable, sometimes resulting in no support being granted. It is thus important that whoever conducts assessment of functional capacity is adequately qualified e.g. a clinical psychologist or neuropsychologist must assess brain-based disabilities, rather than another allied health professional.

As of 30 September 2020, 988 people with FASD as their primary disability had an approved NDIS plan. If we consider a potential national prevalence of FASD of ~2 per cent, this number should be much higher. Access is particularly difficult for people with English as a second language or poor literacy and for Aboriginal families. For example, in the remote Fitzroy Valley of Western Australia, only a handful of people diagnosed with FASD have NDIS plans, despite a known FASD prevalence of 19%.^{11,12}

The lack of access to NDIS supports is partly due to a lack of diagnostic services, meaning many people are undiagnosed and therefore unsupported. However, this is not the only explanation. Of the 21 young people diagnosed with FASD in the first Australian prevalence study (Lililwan project) none have received NDIS funding.^{11,12} The most common reasons for this are that there is a lack of support for families to apply for NDIS support and a lack of professionals to provide up-to-date assessments of functional capacity. Even people with NDIS funding find it difficult to access disability services in remote settings and may be unable to spend the available funding.

The lack of access to NDIS-funded services for children with FASD is particularly concerning given early access to disability services is one of the strongest protective factors against secondary disabilities in adolescents, such as mental health problems, and contact with the justice system.

Recommendations

We encourage you to engage with the Minister for the NDIS, Senator the Hon Linda Reynolds CSC, to implement contemporary diagnostic terms for FASD, remove the age limitation, and understand how the NDIS experience for people living with, or impacted by, FASD, can be improved and service accessibility streamlined. To this end, we would also welcome opportunities to engage directly with the NDIA and be involved in ongoing consultations relating to NDIS reform.

Thank you for your ongoing support. We look forward to engaging further with you and the NDIA on these important issues.

Regards,

s47F



Professor Elizabeth Elliott AM FAHMS FRSN

Co-chair, FASD Advisory Group

Professor of Paediatrics & Child Health, University of Sydney

Consultant Paediatrician, Sydney Children's Hospitals Network (Westmead)

Director, Australian Paediatric Surveillance Unit

Next Generation Fellow, Medical Research Futures Fund

cc: Senator the Hon Linda Reynolds CSC

The **FASD Advisory Group** was established to monitor and report on implementation of the *National FASD Strategic Action Plan 2018-2028* and advise Government on emerging issues, trends, opportunities and gaps that may exist across the domains of the Plan. It consists of representatives from clinical, research, policy and parent/carer sectors.

Membership:

s47F, s47E(c) , Co-chair

s47F

s47F

¹ Department of Health, '[National Fetal Alcohol Spectrum Disorder \(FASD\) Strategic Action Plan 2018-2028](#)', 2018, accessed 4 June 2021.

² Bower C, Elliott EJ 2016, on behalf of the Steering Group. Report to the Australian Government Department of Health: Australian Guide to the diagnosis of FASD. ISBN: 978-0-6481297-4-5

³ McCormack C, Hutchinson, D, Burns, L, Wilson, J, Elliott, E, Allsop, S, Najman, J. et al. Prenatal Alcohol Consumption Between Conception and Recognition of Pregnancy. *Alcohol Clin Exp Res*, 2017; 41(2):369-378.

⁴ Muggli E, O'Leary C, Donath S, Orsini F, Forster D, Anderson PJ, Lewis S, Nagle C, Craig JM, Elliott E, Halliday J. Did you ever drink more?" A detailed description of pregnant women's drinking patterns. *BMC Public Health* (2016) 16:683

⁵ Lange S, et al. Global Prevalence of Fetal Alcohol Spectrum Disorder Among Children and Youth: A Systematic Review and Meta-analysis. *JAMA Pediatr*. 2017. Doi:10.1001/jamapediatrics.2017.1919

⁶ Popova et al. Prevalence of fetal alcohol spectrum disorder among special subpopulations: a systematic review and meta-analysis. *Addiction* 2019. doi:10.1111/add.14598

⁷ Fitzpatrick J et al. Prevalence and profile of Neurodevelopment and Fetal Alcohol Spectrum Disorder (FASD) amongst Australian Aboriginal children living in remote communities. *Res Dev Disabil*. 2017;65:114-126.

⁸ Bower C, et al. Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia. *BMJ Open* 2018;8:e019605. doi:10.1136/bmjopen-2017-019605

⁹ Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder. March 2021. Commonwealth of Australia 2021. ISBN: 978-1-76093-197-1.

¹⁰ Joint Standing Committee on the National Disability Insurance Scheme (NDIS) inquiry into independent assessments under the NDIS. [Terms of Reference – Parliament of Australia \(aph.gov.au\)](#)

¹¹ Carter, E., Rice, L., Elliott, E., Thomas, S., (2021). Marninwarntikura Women's resource Centre and The University of Sydney's submission to the Joint Standing Committee on the National Disability Insurance Scheme inquiry into Independent Assessments.

¹² Carter, E., Rice, L., Elliott, E., Thomas, S., Einfeld, S., Bower, C. (2021). Marninwarntikura Women's resource Centre and The University of Sydney's additional information requested from the Joint Standing Committee on the National Disability Insurance Scheme inquiry into Independent Assessments.

From: s47E(c), s47F
To: s47F
Cc: @health.nsw.gov.au; s47E(c), s47F
Subject: Notes from 5 October 2021 meeting with Minister Reynolds [SEC=OFFICIAL]
Date: Thursday, 21 October 2021 9:04:00 AM
Attachments: image001.png

Hi s47F,

Please see below broad notes from the 5 October meeting with Senator the Hon Linda Reynolds. We are following up with her diary manager on potential future meetings.

Context

- Minister recently returned from Kimberly trip, including visit to the Fitzroy Valley.
- Minister noted there are approximately 1600 people with FASD receiving NDIS support.
- Advisory Group Chair and representatives shared issues raised by parents/carers in their experience of the NDIS:
 - NDIS assessors don't understand FASD well
 - FASD doesn't neatly fit into NDIS criteria
 - Parents feel they need to be considered experts on FASD and disability services
 - NDIS funding is inflexible
 - Rural and remote families are disadvantaged (travel time to services; lack of assessors; difficulty spending funds etc)
 - Feel deadline on submissions regarding NDIS legislation changes was too short.

FASD nomenclature and categorisation by NDIS

- Minister was open to considering FASD nomenclature and categorisation on NDIS lists.
- Discussion re: including FASD on the NDIS List A as well as List D, due to comparability to List A conditions.
- s47B(b)

Models of care

- Minister was particularly interested in models of care for rural/remote and indigenous communities, while acknowledging that FASD is not an indigenous-specific issue. Appropriate workforce and access to early intervention are key.
- Professor Elliott outlined the holistic Fitzroy Valley model of care which includes legal services, early childhood clinic, domestic violence shelter, positive parenting program, art studio etc.
- Discussion on potential pilot to provide screening and assessment for a range of conditions, and referral to NDIS and other supports.

Kind regards,

s47E(c), s47F

A/g Assistant Director

Drug and Alcohol Policy Section

Alcohol, Tobacco and Other Drugs Branch

Australian Government Department of Health

Ph: 02 s47E(c), s47F @health.gov.au

I acknowledge the traditional custodians of the lands and waters where we live and work, and pay my respects to elders past, present and future.

This document has been released under
the Freedom of Information Act 1982
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NATIONAL FASD ADVISORY GROUP MEETING NO.4
Monday 18 October 2021
14:00 to 16:00 (AEDT) (held via video conference)

Meeting Outcomes

ATTENDEES

Members

Professor Elizabeth Elliott, Co-Chair

s47F

Apologies

s47E(c), s47F, Co-Chair

s47F

Ms Belinda Roberts (Department of Health)

Presenters

s47F, Deakin University (Item 4)

s47F, Deakin University (Item 4)

s47F, Deakin University (Item 4)

s47F, New Zealand Ministry of Health (Item 5)

Department of Health

Ms Angela Wallbank

s47E(c), s47F, Co-Chair (in s47E(c), absence)

Observers

s47F, National Indigenous Australians Agency
 National Indigenous Australians Agency

Secretariat (Department of Health)

s47E(c), s47F

NOTE: Meeting was Co-Chaired by Professor Elizabeth Elliott and s47E(c), s47F

1. Welcome members, acknowledgement of country, recording of apologies, confirmation of agenda, conflict of interest, introductions, update on Commonwealth activities – Professor Elliott and [redacted]

[redacted] opened the meeting with acknowledgement of country, welcomed members and introduced the Alcohol, Tobacco and Other Drugs Branch's newly appointed Assistant Secretaries: Ms Angela Wallbank who was in attendance and Ms Belinda Roberts who was an apology.

[redacted] delivered the update on Commonwealth activities which included:

- **Currently funded FASD Diagnostic Services** (Monash Health, Patches, Griffith University Enterprises, and Griffith University Health): These services have had their funding extended for a further four years (to 2023-24) through a non-competitive process.
- **Expansion of FASD Diagnostic Services:** An open competitive grant round for the expansion of FASD Diagnostic Services in NSW, southern and central QLD, and regional VIC opened on 6 July 2021 and closed on 24 August 2021. Assessments are currently being finalised.
- **Evaluation of the National FASD Strategic Action Plan (the Plan) 2018-2028:** Deakin University was successful in securing the contract for the first three-year review of the Plan. The recently completed mapping exercise on FASD activities will be provided to Deakin to aid the evaluation.
- **National Awareness Campaign for Pregnancy and Breastfeeding Women:** Campaign messaging will target specific priority groups and the general population. Information, education and messaging will be 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 Indigenous populations.

The mainstream campaign will be advertised on TV stations and other social platforms across Australia and is expected to launch in late 2021 or early 2022.
- **Commonwealth update on the MBS:** The MBS Review Taskforce's recommendations are currently being considered by Government.

Members had no conflict of interest to disclose.

2. Previous meeting outcomes and action items – Professor Elliott

No outstanding meeting outcomes or action items.

3. Stakeholder Engagement and Communication Plan – [redacted]

[redacted] presented the Stakeholder Engagement and Communication Plan to Members for endorsement.

- Members discussed the possibility of including additional key stakeholders.
- [redacted] suggested the following representatives be included as key stakeholders: [redacted] from the Western Australian FASD Aboriginal Services; a representative from the Australian National Advisory Council on Alcohol

and Other Drugs; and a Director from the Department of Health funded Research Centres.

- s47F noted a representative from Neurodevelopmental and Behavioural Paediatric Society of Australasia (NBPSA) would be beneficial.

ACTION: Secretariat to approach s47F, ANACAD, Research Centres and the NBPSA to discuss their inclusion as a key stakeholder in the Stakeholder Engagement and Communication Plan.

ACTION: Stakeholder Engagement and Communication Plan to be amended and recirculated to Members out-of-session for final endorsement.

4. Evaluation of the National FASD Strategic Action Plan (2018-2028) - Presentation by Deakin University

Professor Elliott welcomed s47F from Deakin University who will be the project leads in undertaking the evaluation of the National FASD Strategic Action Plan 2018-2028.

- Members noted the presentation by Deakin University titled: Three-year formal review of the implementation of the National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018-2028.
- Members noted the mapping exercise on FASD activities will be provided to Deakin to aid the evaluation.
- Members noted that absence of direct consumer engagement is a limitation of the research methodology. s47E(c), s47E noted that the Department would seek opportunities to engage consumers through later evaluations.

ACTION: Secretariat to circulate the presentation to Members.

5. New Zealand Ministry of Health - Presentation by s47F

s47E(c), s47E welcomed s47F, Program Manager - Family and Community Health, Ministry of Health, New Zealand.

- Members noted the presentation by s47F titled: Update from New Zealand Ministry of Health on 2016-19 *Taking Action on FASD Action Plan*, including lessons learnt and future steps.
- s47F noted that NZ Ministry of Health are interested in creating a FASD Advisory Group and has requested a copy of the Group's Terms of Reference and further information on how Australia's FASD Advisory Group links in policy makers and government.
- Members were particularly interested in treatment of FASD in the NZ justice system. Possibility for a further presentation on this.

ACTION: Secretariat to circulate the presentation to Members.

ACTION: Secretariat to email s47F the FASD Advisory Group Terms of Reference, and any further information which can assist NZ in forming their own Advisory Group.

ACTION: Members to email the Secretariat any information which can assist NZ in forming its own Advisory Group, for sharing with s47F.

ACTION: Secretariat to invite the NZ Ministry of Health, through s47F, to present at the next Advisory Group meeting on treatment of FASD in the NZ justice system.

6. Discussion of potential advice for Ministers – Professor Elliott

Members discussed the following items:

- **Australian FASD prevalence study:** Members broadly supported the need for a study, with careful consideration of design. Members noted the importance of engaging with FASD diagnostics clinics. Professor Elliott noted she is happy to share the data set for the FASD Register.
- **Issues in out of home care:** Professor Elliott noted about 75% of children in her FASD diagnostic clinic are in out of home care. Members noted that child protection services can be reluctant to facilitate FASD diagnoses due to perceived stigma; and the need for foster carers to have access to early advice around FASD, and access to appropriate assessments.
- **Lack of diagnostic services for adults:** s47F to present on this topic at next meeting.

ACTION: Members, with assistance of Secretariat, to prepare a briefing for Minister Hunt regarding the need for FASD prevalence study, and design considerations of a study.

ACTION: s47F, with assistance of Secretariat, to prepare a letter briefing Minister Hunt on issues around FASD diagnosis for children in out of home care.

ACTION: s47F to present at the next meeting on lack of FASD diagnostic services for adults, including Australian suicide rates in students with FASD.

- **Issues accessing support through the National Disability Insurance Scheme (NDIS):**
 - FASD Advisory Group wrote to Minister Hunt on 24 September 2021, cc'ing Minister Reynolds, raising several issues around access to NDIS services for individuals with FASD and their families.
 - On 5 October members of the National FASD Advisory Group (Professor Elliott, s47F) and the Department of Health (Ms Wallbank and s47E(c), s47E) had a virtual meeting with Minister Reynolds to discuss these issues further.
 - Members noted Minister Reynolds was engaged in the meeting, and interested in further meetings with the National FASD Advisory Group and consumer groups.
 - Members agreed that s47F would lead the identification of consumer representatives for this meeting.

ACTION: Secretariat to continue to liaise with Minister Reynold's Office regarding availability for meetings with the National FASD Advisory Group and consumer groups.

ACTION: s47F, with assistance of Secretariat, to lead preparation of a brief for Minister Reynolds on key issues to progress in respect to FASD and the NDIS (eg. nomenclature, List A & D).

- **Alcohol online sales and digital marketing:** Correspondence on the rise of online alcohol sales and digital marketing was provided from the FASD Advisory Group to Minister Hunt on 4 August 2021. Minister Hunt replied on 20 August 2021.

ACTION: Secretariat to continue to progress actions arising from this letter, including raising the issue with states and territories through the Health Chief Executive Forum, and raising the issue of online age verification with the Hon Stuart Robert MP, who is responsible for the Digital Transformation Agency.

7. Other Business and Next Meeting – Professor Elliott and s47F

- s47F noted there is a push in Canada for a national FASD strategy and the US is hoping to pass a FASD Respect Act in Congress.
- Members noted the need for discussion at the next meeting around raising the criminal age of intent, as a number of jurisdictions are currently reviewing this.
- Potential agenda items and next meeting date to be canvassed out of session.

ACTION: Secretariat to canvass a suitable meeting date out-of-session.

This document has been released under
the Freedom of Information Act 1992
by the Department of Health, Disability and Ageing



**The Hon Greg Hunt MP
Minister for Health and Aged Care**

Ref No: MC21-034512

Professor Elizabeth Elliott AM
Co-chair
National Fetal Alcohol Spectrum Disorder Advisory Group
s47F [REDACTED]@gmail.com

11 NOV 2021

Dear Professor 

I refer to your correspondence on behalf of the National Fetal Alcohol Spectrum Disorder (FASD) Advisory Group (Advisory Group) concerning access to National Disability Insurance Scheme (NDIS) services for people living with FASD, and the use of contemporary diagnostic criteria and terminology for FASD by the NDIS. I regret the delay in responding.

The Australian Government is committed to reducing the prevalence of FASD and the impact it has on individuals, families, carers and communities. I thank the Advisory Group for its ongoing efforts in support of this objective, particularly monitoring the implementation of the *National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018–2028*.

The Government is working towards a future NDIS that is more consistent, fair and equitable and improves outcomes for eligible people and their families/carers as part of the National Disability Insurance Agency's long-term commitment to service improvement.

I understand that you and other members of the Advisory Group recently met with the Minister for the National Disability Insurance Scheme and Minister for Government Services, Senator the Hon Linda Reynolds CSC, to discuss in more detail the issues raised in your letter. I am advised that this was a productive discussion and I have asked my Department to continue to engage with the National Disability Insurance Agency and the Department of Social Services in respect to these issues.

I understand that Minister Reynolds is keen to further engage with the Advisory Group on these important issues. My Department will support the Advisory Group in arranging the next meeting, and I understand work is underway to facilitate this.

I appreciate you bringing these matters to my attention and I look forward to further updates on how this work is progressing. I have also copied this correspondence to Minister Reynolds.

Thank you for writing on this matter.

Yours sincerely


Greg Hunt

cc: Senator the Hon Linda Reynolds CSC, Minister for the National Disability Insurance Scheme, Minister for Government Services

Record of meeting

Minister Reynolds and National Fetal Alcohol Spectrum Disorder (FASD) Advisory Group

Purpose: To discuss the NDIS experience for people living with FASD and their families.

Date: 9 December 2021

Attendees:

Senator the Hon Linda Reynolds CSC

s47F (NDIS Senior Adviser to the Minister)

Professor Elizabeth Elliott (Co-chair, National FASD Advisory Group)

s47F (National FASD Advisory Group)

s47F (National FASD Advisory Group)

s47F (National FASD Advisory Group)

s47F (National FASD Advisory Group)

s47F (National FASD Advisory Group)

s47F (National FASD Advisory Group)

s47F (National FASD Advisory Group)

s47F (National FASD Advisory Group)

s47F (National FASD Advisory Group)

s47F (National FASD Advisory Group)

s47F (National Indigenous Australians Agency)

s47F (National Disability Insurance Agency)

Mr Edward Huddy (A/g Assistant Secretary, Alcohol, Tobacco and Other Drugs Branch, Department of Health)

s47E(c), s47F (Alcohol, Tobacco and Other Drugs Branch, Department of Health)

Outcomes:

Agenda Item 1 - NDIS nomenclature

- The FASD Advisory Group proposed that the NDIA update its terminology from Fetal Alcohol Syndrome to the contemporary term Fetal Alcohol Spectrum Disorder (FASD), consistent with diagnostic guidelines.
- s47F, NDIA, acknowledged the out of date terminology and advised the update would be made to operational guidelines by first quarter 2022.

Agenda Item 2 - NDIS List A conditions

- The FASD Advisory Group proposed that the NDIA include FASD on List A (*Conditions which are likely to meet the disability requirements in section 24 of the NDIS Act*) in recognition of its comparability to other List A conditions.
- The FASD Advisory Group shared the FASD diagnostic standards and guidelines and the rigor that is applied to the process of diagnosis in Australia, emphasising that FASD is by definition a severe impairment.
- The group shared that inclusion on List A would appropriately recognise FASD as a severe and complex neurodevelopmental disorder requiring lifelong support and streamline access to the NDIS for individuals with the condition.
- s47F reflected that NDIS eligibility is largely based on functional impairment rather than diagnosis and, as applicable to all other neurodevelopmental conditions,

cautioned against relying on a FASD diagnosis alone to determine eligibility for support as opposed to considering the degree of functional impairment in each individual child.

- Minister Reynolds accepted the rationale of including FASD on List A but echoed s47F comments. The Minister also encouraged a focus on system development between the NDIS and Health at the local /regional level with stronger collaboration, support and information for FASD families and the broader community. (This discussion linked into Agenda items 3 and 4)
- NDIA to consider the proposal further, and work with the National FASD Advisory Group.

Agenda Item 3 - Improving NDIS access in remote communities

- Minister Reynolds spoke about the need to identify areas of the NDIS where improvements can be made and to define “what ‘good’ looks like” and acknowledged the report prepared on NDIS access in very remote settings by Maminwarntikura Women’s Resource Centre in Fitzroy Crossing.¹ With regard to FASD, the Minister spoke about a focus on early identification, intervention and support to improve future outcomes.
- Minister Reynolds asked the National FASD Advisory Group for their input in developing a streamlined screening, assessment and support model to trial in a few sites.
- The group suggested inclusion of an urban trial site in addition to the proposed Kimberly/Cape York sites in recognition that FASD is a national issue that cuts across socio-economic cohorts.
- s47F to facilitate further engagement between the National FASD Advisory Group and the Department of Social Services / National Disability Insurance Agency on trial design. s47F suggested a targeted list of questions would help focus the Advisory Group’s input.
- Minister Reynolds also welcomed input from the National Indigenous Australians Agency and the Department of Health.
- The Minister suggested a further meeting with the National FASD Advisory Group in February 2022.

Agenda Item 4 - Improving the NDIS experience for parent/carers of children with FASD

- The FASD Advisory Group proposed that Minister Reynolds meet with parents and carers of people with FASD to hear first-hand their experiences of the NDIS.
- The group articulated that families of people with FASD are likely to be vulnerable and have difficulty applying for NDIS support. While some families are satisfied with NDIS support, others feel ‘frustrated, confused and distressed.’
- Minister Reynolds agreed to a meeting with parents/carers, with s47F to liaise with s47F, CEO, NOFASD, to arrange this.

Agenda Item 5 - The need for Australian FASD prevalence data

- The group briefly touched on the need for reliable Australian FASD prevalence data to quantify the social and economic cost of the condition and inform effective policy development.

¹ ‘People Don’t Know What Good Looks Like’, Creating equity for people with disability in the Fitzroy Valley. September 2021. Maminwarntikura Women’s Resource Centre.

NATIONAL FASD ADVISORY GROUP MEETING NO.6
Wednesday 23 March 2022
13:00 to 15:30 (AEDT) (held via video conference)

Meeting Outcomes

ATTENDEES

Members

Professor Elizabeth Elliott, Co-Chair

s47F, s47E(c) [redacted], Co-Chair

s47F [redacted]

Apologies

s47F [redacted]

aternity leave)

Ms Belinda Roberts (Department of Health)

Presenters

s47F [redacted], Deakin University (Item 3)

s47F [redacted], Deakin University (Item 3)

s47F [redacted], New Zealand Ministry for Children (Item 5)

Department of Health

s47E(c), s47F [redacted]

Observers

s47F [redacted], National Indigenous Australians Agency

s47F [redacted], National Indigenous Australians Agency

Secretariat (Department of Health)

s47E(c), s47F [redacted]

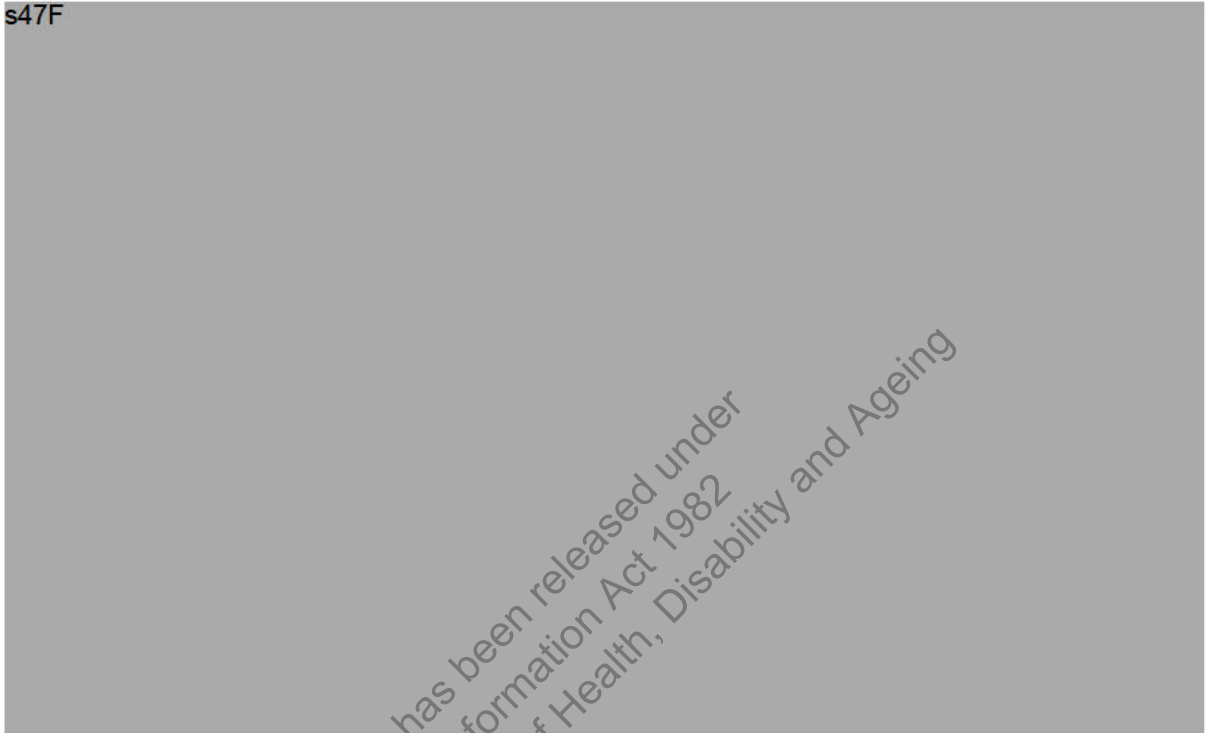
- Welcome members, recording of apologies, acknowledgement of country, confirmation of agenda, conflict of interest and introductions, update on Commonwealth activities – Professor Elliott, s47F, s47E(c) [redacted]**

Professor Elliott welcomed members and recorded apologies from s47F, followed by an acknowledgement of country.

s47F, s47E(c) advised members that the conflict-of-interest declaration forms completed in 2021 are now expired and must be renewed by all members on an annual basis. The forms should also be updated at any time as required. The Secretariat has circulated the declaration form out-of-session to members for completion and return to the Secretariat.

s47F, s47E(c) sought verbal confirmation of any conflicts of interest by members:

s47F



s47F, s47E(c) introduced s47F, Acting CEO of the Foundation for Alcohol Research and Education (FARE) and s47E(c), s47F from the Department of Health Secretariat and sought confirmation of the agenda.

Professor Elliott requested that members respond to the Secretariat with any updates to the Advisory Group membership list (circulated by the Secretariat on 22 March 2022) which outlines members' qualifications, affiliations and contact details. The updated membership list will be provided to members out-of-session for their reference.

s47E(c), s47F delivered the update on Commonwealth activities which included:

- **National Preventive Health Strategy 2021-2030:** launched in December 2021 and outlines the Government's continued commitment to reducing alcohol and other drug harms. The Strategy includes the following targets:
 - at least a 10 per cent reduction in harmful alcohol consumption by Australians (aged 14 years and over) by 2025, and at least a 15 per cent reduction by 2030;
 - less than 10 per cent of young people (14–17 year-olds) are consuming alcohol by 2030; and

- less than 10 per cent of pregnant women aged 14–49 years are consuming alcohol whilst pregnant, by 2030.
- **‘Every Moment Matters’, the mainstream component of the National Awareness Campaign for Pregnancy and Breastfeeding Women:** launched on 30 November 2021 across TV, radio, billboards, and social media. To date the campaign has been well received and during the first three months over 12 million completed video views were delivered across digital platforms, as well as good coverage across free-to-air TV. Later this year there will be streams for Indigenous groups and health professionals.
- **Evaluation of the National FASD Strategic Action Plan 2018-2028:** Deakin University are undertaking the formal three-year review. Members of Deakin’s project team will address the group later in the meeting on the progress of the evaluation.

Professor Elliott congratulated s47F on the FARE campaign and invited FARE to provide a presentation on the feedback from the campaign at the next meeting.

Professor Elliott welcomed any opportunity by the Department for the Advisory Group to have input into the implementation of the National Preventive Health Strategy.

ACTION: Members to review/update the Advisory Group membership list and return to the Secretariat for distribution to members out-of-session.

ACTION: Members to complete the annual conflict-of-interest declarations and return to the Secretariat.

ACTION: FARE to provide a presentation at the next meeting on the feedback from the evaluation of the ‘Every Moment Matters’, the mainstream component of the National Awareness Campaign for Pregnancy and Breastfeeding Women.

ACTION: Secretariat to investigate opportunities for the Advisory Group to provide input to the implementation of the National Preventive Health Strategy, and to engage with Advisory Group in respect to these opportunities.

2. Previous meeting outcomes and outstanding action items – s47F, s47F(c)

s47F, s47F(c) noted the following:

Agenda Item 2 – Meeting outcomes 18 October 2021. Endorsed by all members.

Agenda Item 2.1 – Rolling action item status report. Update provided.

- s47F resignation and replacement: s47F

Members discussed the importance of having lived experience representation on the group and ensuring they are appropriately supported. s47F expressed a preference for a birth parent if possible. s47F, s47F(c) noted it would be beneficial to have another First Nations representative to support s47F

s47F will email the Secretariat out-of-session with suggestions for potential candidates.

- s47F retirement: s47F. The Secretariat is currently considering options for a member with a policy/state or territory government background.

ACTION: s47F to email suggestions for s47F replacement to the Secretariat. This item will be actioned out-of-session.

ACTION: Secretariat to liaise with s47F regarding s47F membership. Chairs to consider options for a member with a policy/state or territory government background.

3. Evaluation of the National FASD Strategic Action Plan (2018-2028) - Presentation by Deakin University

Professor Elliott welcomed s47F from Deakin University to provide an update on the evaluation and its progress.

- Members noted the presentation by Deakin University titled: Three-year formal review of the implementation of the National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018-202 – update on the evaluation and its progress. Presentation to be circulated to members.
- Members discussed the evaluation's small sample size and queried whether opportunities exist for additional data collection. Deakin advised additional data collection would require a contract and funding extension. Deakin will discuss with the Secretariat offline.
- As outlined in Deakin's contract, they will present the Evaluation Report to the Advisory Group at the next meeting.

ACTION: Secretariat to circulate Deakin University's presentation to members.

ACTION: Deakin University to present the Evaluation Report at the next meeting.

ACTION: Secretariat to circulate the Evaluation Report when finalised to members (expected late May 2022).

ACTION: Secretariat to discuss data collection with Deakin University and share findings with members and discuss as needed.

4. Update from meeting with Minister Reynolds

s47F updated the members on the meeting with Minister Reynolds on 9 December 2021 around issues accessing support through the National Disability Insurance Scheme (NDIS).

s47E(c), s47E updated the members on items 1 and 2:

- Item 1 (NDIS nomenclature), the National Disability Insurance Agency (NDIA) has started the process of updating all documentation and operational guidance to

reflect use of the contemporary term 'FASD' rather than 'FAS', as requested by the AG. This should be completed by 30 June 2022.

- Item 2 (NDIS List A conditions), List A was developed during a time of rapid transition to the NDIS from the previous State and Territory disability systems to assist in the inclusion of large numbers of applicants for NDIS support in a short period of time.
- A person's diagnosis does not need to be on the List A to gain entry to the NDIS. Nevertheless, listing of a condition does facilitate timely access to support.
- To recognise that FASD can be diagnosed at any age, Fetal Alcohol Syndrome is included on List B (permanent condition), and List D (permanent impairment for children under 7) under 'Congenital conditions'. This will be amended to read FASD.
- The NDIA will work with the Advisory Group to arrive at a shared understanding of use of Lists in the future, as this work is progressed and undertaken in 2022.
- Noted that Secretariat will continue to liaise with Minister Reynolds Office regarding availability for meetings with the National FASD Advisory Group and consumer groups.

ACTION: Secretariat to continue to liaise with Minister Reynold's Office regarding availability for meetings with the Advisory Group and consumer groups.

ACTION: The Advisory Group will work with the NDIA in relation to a shared understanding of List A conditions.

5. New Zealand Ministry for Children – Presentation by s47F

s47F, s47F(c) welcomed s47F, Regional Disability Advisor, New Zealand Ministry for Children to provide an update to members on the NZ FASD approach and Youth Justice.

- Members noted the presentation by s47F titled: FASD and Youth Justice. The presentation will be circulated to members.
- Members welcomed the opportunity to continue and further develop linkages between NZ and the Advisory Group, and a conference was suggested to facilitate this.
- s47F raised the discrepancies in legislation amongst different parts of the world and also within Australia.

ACTION: Secretariat to circulate the presentation by s47F to Members.

ACTION: Secretariat to continue to liaise with NZ further developing linkages between NZ and the Advisory Group. A conference was suggested to facilitate this. Members to forward other suggestions to the Secretariat.

6. Discussion of potential advice for Ministers

Members discussed the following items:

Australian FASD prevalence study: s47E(c), advised that the Department is investigating potential funding options and will seek advice on an appropriate study design. Secretariat will provide a further update including a background paper at the next meeting.

Issues in out of home care (OOHC): Members discussed the draft letter to the Minister for Health and Aged Care, Minister for Families and Social Services and Assistant Minister for Children and Families.

Members discussed the prevalence of children in the OOHC system with FASD. It is not well understood, which limits appropriate service design for this cohort. While Australian FASD Registry data indicate that the prevalence of children in OOHC with FASD is high, this must be confirmed through a formal, robust prevalence study.

Members agreed to add a recommendation to the OOHC letter in relation to the need for a prevalence study of children with FASD in the OOHC system.

s47F noted there are many undiagnosed Indigenous men, women and children in her community. Diagnosis is resource intensive and requires a paediatrician to sign off, and additional resources and better systems need to be in place. A specific FASD health check not only in OOHC but also in juvenile detention is required.

The Advisory Group agreed to consider ways to incorporate screening for pre-natal alcohol exposure into the indigenous health check MBS item. Proxy measures such as growth and head circumference may indicate the need for screening. This will be discussed offline with s47F in the first instance.

Prof Elliott and s47F, agreed to update the letter according to the discussion and to forward it to Minister Hunt.

Lack of diagnostic services for adults: s47F to present on this topic at next meeting.

s47F queried whether paediatricians working in private practice can undertake and bill for FASD assessments for adults. The AG agreed that this was a matter of professional practice rather than a matter of clarification of Medicare remuneration. The Secretariat will seek clarification from the Royal Australasian College of Physician (RACP).

Raising the age of criminal responsibility: s47F, noted the Secretariat has provided a summary from each jurisdiction around raising the age of criminal responsibility.

Members discussed Australia's effort to date to raise the age of criminal responsibility from 10 to 14 years and the barriers around the lack of alternatives and diversion programs. Members noted this is a critical area and an advocacy issue which requires each jurisdiction's support.

Members agreed that this issue was relevant to FASD. They agreed to write to the Minister for Health and Aged Care asking that he raise this issue with Attorneys General from each jurisdiction. The letter from the Health and Aged Care Minister will specifically seek to raise awareness of the over-representation of children with FASD in the criminal justice system, many with diminished cognitive capacity and other disabilities, and lend support to the UN

recommendation to raise the age of criminal responsibility in accordance with UN recommendations. Members also discussed the importance of the letter reflecting the need to focus on developmental rather than chronological age and functional capacity.w

It was agreed that an item about adults with FASD in the justice system would be added to next meeting's agenda.

ACTION: Secretariat to provide advice at the next Advisory Group meeting in respect of a FASD prevalence study.

ACTION: Secretariat to add the following additional recommendation to the OOHC letter and recirculate to members out of session for endorsement: *Determine the prevalence of children with FASD in the OOHC system through a formal, robust prevalence study.*

ACTION: Secretariat to discuss the indigenous health check MBS item with s47F, particularly re: inclusion of screening for pre-natal alcohol exposure.

ACTION: Secretariat to seek guidance from the RACP about the validity of specialist paediatricians conducting FASD assessments for adults, and report back by the next meeting.

ACTION: s47F to present at the next meeting on lack of FASD diagnostic services for adults, including Australian suicide rates in youth with FASD.

ACTION: Secretariat with the assistance of s47F, to prepare a letter for Minister for Health and Aged Care to the overall Attorney General group regarding awareness raising and raising the functional development age from 10 to 14 years.

7. Other Business and next meeting – Professor Elliott

- s47F noted the Commonwealth has provided a sponsorship contribution to NOFASD Australia who are hosting the inaugural FASD@50 Conference. The virtual conference will take place on Friday 13 May and Saturday 14 May 2022.
- Potential agenda items for next meeting.
Next meeting date to be canvassed out of session.

ACTION: Secretariat to canvass a suitable meeting date out-of-session.

Meeting closed at 15:24.

7 April 2022

The Hon Greg Hunt MP
Minister for Health and Aged Care
PO Box 6022
House of Representatives
Parliament House
Canberra ACT 2600

Dear Minister Hunt,

Re: Better support for children with Fetal Alcohol Spectrum Disorder (FASD) in the out-of-home care system and their carers

The National FASD Advisory Group (the Advisory Group) seeks your assistance to facilitate diagnosis and support for children with FASD who live in out-of-home care (OOHC). Specifically, there is a need to reduce stigma, facilitate timely access to assessment, diagnosis and treatment, and to better support foster carers in order to improve long term outcomes for their children.

FASD is a diagnostic term used to describe the collective impacts of prenatal alcohol exposure on the brain and body. FASD is associated with permanent disability and characterised by severe neurodevelopmental impairment. FASD may include a range of physical, cognitive, behavioural, and learning impairments which can have lifelong implications.

Children and adolescents with FASD are overrepresented in the OOHC population. Australian FASD Registry data show that of 616 children diagnosed with FASD between 2015 and 2019, 74% had been involved with child protection and 79% lived in OOHC. Once in the OOHC system, children with FASD experience more frequent placement transitions and are at higher risk of poor long-term outcomes.¹ These children also have a greater risk of youth justice involvement, mental ill-health, suicide and early mortality.²

Early diagnosis of FASD and tailored interventions significantly improve life outcomes for individuals affected by FASD and benefit their families and carers.² In addition, improving targeted supports for carers of children with FASD increases the likelihood that children will remain long term within that household. Currently however, screening for FASD is inadequate and access to diagnostic services and supports is limited for children in OOHC and their carers throughout Australia.

The following issues require priority action to better support children with FASD and carers in the OOHC system:

Routine screening for prenatal alcohol exposure (PAE)

Diagnosis of FASD is often delayed or missed in children in OOHC because information about alcohol use in pregnancy has not been requested or recorded. Children with PAE enter care at four times the rate of their peers³. Therefore, targeting this group of children for assessment of risk from PAE is appropriate.

Recommendations:

- Integrate routine investigation for PAE (from biological mothers, families and maternal medical records), and document PAE in the child's health records at the time of their first contact with child protection services.
- Encourage use of a standardised tool e.g. AUDIT-C to record maternal alcohol intake in pregnancy to facilitate consistent documentation for all children entering OOHC.

Improving OOHC providers' understanding of children with FASD

As outlined above, early diagnosis and tailored interventions significantly improve the life outcomes for individuals affected by FASD, their families and carers. Despite this, there is currently inadequate recognition of FASD, referral for assessment and support for children and carers in the OOHC system.

Recommendations:

- Provide training for child protection and OOHC staff regarding FASD, including the development of resources to improve the recognition, support, and management of children with FASD in OOHC.
- Develop a national FASD specialist practice guide for OOHC staff.

Targeting timely assessment for young people in OOHC

As children and adolescents with FASD are overrepresented in the OOHC population, assessment services targeting this group are needed. However, current waitlists for services, where they are available, often extend beyond 18 months. As highlighted above, a lack of documentation of alcohol use in pregnancy further compounds delays in referral for assessment.

Recommendation:

- Implement a policy which prioritises timely assessment for FASD for all children in OOHC who were exposed to alcohol prenatally.

Supporting guardians and carers

Many children with FASD have challenging behaviours and experience frequent placement disruptions due to carer stress and burnout. Consequently, children with FASD often move between OOHC and child protection services. This can increase the risk of poor long-term outcomes, including disengagement from school, youth justice involvement, mental ill-health, suicide, and early mortality.^{4,5}

Recommendations:

- Invest in training and support for foster carers in the management and care of children with FASD, to reduce carer burnout and enable placements to continue.
- Increase access to follow-up support for children and their carers, including for management of developmental needs, family support, parent coaching and advocacy for children and families.
- Provide support to assist carers to gain timely access to the National Disability Insurance Scheme when required.

- Ensure carers are informed of a child's likely developmental and behavioural needs at the time of placement in OOHC, to enable informed decision-making regarding the family's care capacity and the child's health and educational needs.

Understanding prevalence

The prevalence of FASD in children in the OOHC system in Australia is not known. This limits appropriate service design for this cohort. Although Australian FASD Registry data indicate that the majority of children diagnosed with FASD have been in OOHC, the prevalence in this high-risk population must be confirmed through a formal, robust prevalence study. This will provide reliable data to inform effective and efficient policy design and ensure that appropriate supports are provided for children, carers and OOHC providers.

Recommendation:

- Determine the prevalence of children with FASD in the OOHC system through a formal, robust prevalence study.

Call for Action

The Advisory Group asks that you raise the issues outlined in this letter with the Hon Anne Ruston, Minister for Families and Social Services, and the Hon Michelle Landry MP, Assistant Minister for Children and Families (copied into this letter) for their consideration and action.

The Advisory Group is available to meet with relevant Ministers to discuss the issues and recommendations outlined in this letter.

We believe that by addressing these recommendations the government has an opportunity to strengthen and reaffirm its commitment to the National FASD Strategic Action Plan 2018-2028 and National Alcohol Strategy 2019-2028 and to improve outcomes for children with FASD and their families and carers and specifically for children in OOHC.

We thank you for your support of the Advisory Group during your time as Minister for Health and Aged Care and wish you well with your future endeavours.

Regards,

s47F

Professor Elizabeth Elliott AM FAHMS FRSN

Co-chair, National FASD Advisory Group

Professor of Paediatrics & Child Health, University of Sydney

Next Generation Fellow, Medical Research Futures Fund

Consultant Paediatrician, Sydney Children's Hospitals Network (Westmead)

Director, Australian Paediatric Surveillance Unit

cc. Senator the Hon Anne Ruston

cc. The Hon Michelle Landry MP

The **Advisory Group** was established to monitor and report on the implementation of the *National FASD Strategic Action Plan 2018-2028* and advise government on emerging issues, trends, opportunities and gaps that may exist across the domains of the plan. It consists of representatives from clinical, research, policy and parent/carer sectors.

Membership:

s47F, s47E(c) , Co-chair

s47F

s47F

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

² National Fetal Alcohol Spectrum Disorder Strategic Action Plan 2018-2028. (Page 24). Retrieved from <https://www.health.gov.au/sites/default/files/national-fasd-strategic-action-plan-2018-2028.pdf>

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

⁴ Richards, Bertrand, J., Newburg-Rinn, S., McCann, H., Morehouse, E., & Ingoldsby, E. (2022). Children prenatally exposed to alcohol and other drugs: what the literature tells us about child welfare information sources, policies, and practices to identify and care for children. *Journal of Public Child Welfare*, 16(1), 71–94.

⁵ Walker, P. (2019). Submission to the Senate Inquiry into effective approaches to prevention and diagnosis of Fetal Alcohol Spectrum Disorder (FASD), Submission no 47

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NATIONAL FASD ADVISORY GROUP MEETING NO.7
Wednesday 17 August 2022
13:00 to 15:30 (AEDT) (held via video conference)

Meeting Outcomes

ATTENDEES

Members

Professor Elizabeth Elliott, Co-Chair

s47F, s47E(c) [redacted], Co-Chair

s47F [redacted]

Apologies

s47F [redacted]

Ms Belinda Roberts (Department of Health and Aged Care)

Presenters

s47F [redacted] (Item 4)

s47F [redacted] (Item 5)

s47F [redacted], Foundation of Alcohol, Research and Education (Item 5)

Department of Health and Aged Care

s47E(c), s47F [redacted]

Observers

s47F [redacted], National Indigenous Australians Agency

s47F [redacted], National Indigenous Australians Agency

Secretariat (Department of Health and Aged Care)

s47E(c), s47F [redacted]

1. Acknowledgement of country, welcome members and introductions including newly appointed members, recording of apologies, confirmation of agenda, conflict-of-interest – Professor Elliott, s47F, s47E(c)

s47F, s47E(c) sought members' permission for the Secretariat to record the meeting; all members agreed.

Professor Elliott opened the meeting with acknowledgement of country, welcomed members and newly appointed members:

- s47F, s47E(c), La Trobe Rural Health School, La Trobe University;
- s47F, s47E(c), Community Partnership Co-ordinator/Teacher Fitzroy Valley District high school and carer to young adults with FASD; and
- s47E(c), s47F, s47E(c), Director, Drug and Alcohol Policy section within the department.

Recorded apologies from:

- s47F, s47E(c);
- s47F, s47E(c);
- s47F, s47E(c); and
- Ms Roberts.

s47F, s47E(c) confirmed the agenda and sought declaration of any conflicts-of-interest from members; nothing to report from members in addition to existing declarations on record.

s47F, s47E(c) advised that good process is that a conflict-of-interest declaration form is completed by all members on an annual basis, and this can be updated at any time as required. There are currently 14 conflicts of interest declarations on file dated August 2022 and two are outstanding. s47F, s47E(c) requested that members who had yet to complete their forms, please do so and return to the Secretariat.

ACTION 1: Members who are yet to complete the annual conflict-of-interest declarations to do so please and return to the Secretariat.

2. Commonwealth update – s47F, s47E(c)

s47F, s47E(c) delivered the update on Commonwealth activities which included:

- **Alcohol online sales and digital marketing:** The department has engaged with jurisdictions and received updates regarding the letter from the FASD Advisory Group to the former Minister for Health on online sales and digital marketing. The department is in the process of seeking the jurisdictions' approval to share their responses with the Advisory Group.
- **Evaluation of the National FASD Strategic Action Plan 2018-2028:** Deakin University has undertaken the formal three-year review. The department is working with Deakin on some final edits and will then circulate the Evaluation Report to members for information once finalised. The department's preference is to publish the report.

- **Australian Government response to FASD senate inquiry report:** The Australian Government is currently finalising its response to the Senate Inquiry report.
- **National Preventive Health Strategy (NPHS) 2021-2030:** The Preventive Health team provided an update on the early implementation of the NPHS. Paper was circulated to members out-of-session.
- **Issues accessing support through the National Disability Insurance Scheme (NDIS) Group and consumer groups:** In May 2022, the National Disability Insurance Agency (NDIA) updated their terminology in Lists B & D and other NDIS guidance material to the contemporary term FASD in response to a letter from and meeting between the Minister for the NDIS, Minister Reynolds and the FASD Advisory Group.
- **Update on the Medical Benefits Scheme (MBS) items:** The MBS Review Taskforce (the Taskforce) has recently completed its review of all MBS items and has made extensive recommendations to Government on possible changes to ensure that the MBS remains contemporary. Under the auspice of this Taskforce, three clinical committees (specialist and consultant physicians, psychiatry, and allied health) considered the issue of appropriate access to MBS items for children with FASD and other complex neurodevelopmental disorders, through amendments to existing MBS items. The final Taskforce reports can be found at www.health.gov.au by searching clinical committee reports. The Taskforce's recommendations are being progressively considered.

Changes to items 135, 137, 139 and 289 to include FASD will be implemented from 1 March 2023.

ACTION 2: Secretariat to circulate the Deakin University Evaluation Report when finalised to members.

ACTION 2.1: Secretariat to recirculate the early implementation of the NPHS paper update to members.

ACTION 2.2: Secretariat to provide a written update to members regarding relevant MBS items. Refer to update above.

3. **Previous meeting outcomes and outstanding action items** – s47F, s47F(c)

Agenda Item 3 – Meeting outcomes 23 March 2022. Endorsed by all members.

Agenda Item 3.1 – Rolling action item status report. Update provided.

- **3.1 (a)** - s47F retirement: s47F and has been sent a letter of thanks for his contribution to the Advisory Group. The Secretariat through the Alcohol Tobacco and Other Drugs Policy Officers Group (ATOD POG) has sought nominations for a replacement state government member. Members will be advised on the outcome of this process.
- **3.1 (b)** - **Issues accessing support through the NDIS:** Members agreed to continue to pursue these issues with the incoming Minister for the NDIS, via the Minister for

Health and Aged Care. Members noted that the Secretariat will liaise with Minister Butler's office regarding availability for meetings with the Advisory Group and FASD consumer groups, and this might include other interested MPs such as Minister for the NDIS, the Hon Bill Shorten; Minister for Indigenous Australian, the Hon Linda Burney; Assistant Minister for Indigenous Australians and Indigenous Health, Senator the Hon Malarndirri McCarthy; and Attorney General the Hon Mark Dreyfus.

- **3.1 (c) - Key issues to progress in respect to FASD and the NDIS:** No further updates from NDIA colleagues on the status/ongoing function of List A. The Secretariat will provide updates to the Advisory Group when they become available. (For noting, the issue regarding NDIS access for children and adults with FASD in remote locations warrants further advocacy and attention).
- **Australian FASD prevalence study:** Addressed at item 7.
- **3.1 (d) - Indigenous health check MBS item:** In response to recommendations from the MBS Review Taskforce the department is reviewing the health assessment items in the MBS, including item 715 for health assessment services for First Nations peoples. Secretariat will keep members updated on the review's progress, including opportunities to contribute to consultation processes. Members agreed to pursue adding screening for prenatal alcohol exposure to the item (add to item descriptor/explanatory notes), ensuring language is culturally appropriate.
- **3.1 (e) - Guidance from the Royal Australasian College of Physicians (RACP) around FASD assessments:** Secretariat has reached out to the RACP on several occasions to seek guidance about the validity of specialist paediatricians conducting FASD assessments for adults for reporting back to members. s47F will pursue this item with her contacts at the College. Note the Secretariat will provide updates to the Advisory Group when they become available.
- **Issues in out-of-home care:** This will be addressed at item 8.
- **Raising the age of criminal responsibility:** This will be addressed at item 8.

ACTION 3.1 (a): Department of Health and Aged Care to continue the process for a new state/territory government member to take s47F position.

ACTION 3.1 (b): Secretariat to engage with Minister's office regarding future opportunities for meeting with the Advisory Group and FASD consumer groups and prepare correspondence on NDIS access and support to the Minister for Health and Aged Care, with a cc to the Minister for the NDIS on behalf of the Advisory Group.

ACTION 3.1 (c): Secretariat will pursue with the NDIA and provide updates to the Advisory Group regarding List A when they become available.

ACTION 3.1 (d): Secretariat will keep members updated on the review of MBS Item 715 (Indigenous health check), including opportunities to contribute through the consultation process to any amendments to this item to include prenatal alcohol exposure.

ACTION 3.1 (e): s47F to pursue RACP item with her contacts at the College. The Secretariat will provide updates to the Advisory Group when they become available.

4. FASD diagnostic services for adults – Presentation by s47F

Professor Elliott asked s47F to present on the lack of FASD diagnostic services for adults and the implications, including Australian suicide rates in youth with FASD.

- Members noted the presentation by s47F titled: *Characterising Suicidality in Young People living with FASD in WA: Implications for Adults*. The presentation and assessment tool will be circulated to members.
- Members noted the paper/assessment tool (when published) should be rolled out to people who work in the services to better support them. Members discussed how to take this matter forward. It was agreed the issue, and paper (once accepted), would be raised with Minister for Health and Aged Care through a letter prepared by the Secretariat on the Advisory Group's behalf and in collaboration with Associate Professor Pestell.

ACTION 4 (a): Secretariat to circulate the presentation and assessment tool by s47F to members.

ACTION 4 (b): Secretariat with the assistance of s47F, to prepare a letter for Minister for Health and Aged Care on behalf of the Advisory Group on this issue, attaching the paper once accepted.

5. Update from FARE 'Every Moment Matters' – Presentation by s47F and s47F

s47F, welcomed s47F to present on the evaluation of 'Every Moment Matters', the mainstream component of the National Awareness Campaign for Pregnancy and Breastfeeding Women.

- Members discussed if there was a way of monitoring the influx of Campaign-related calls to the various FASD hotlines (eg. NOFASD and FASD Hub). s47F noted she will liaise with her evaluation team and collate a list of organisations who are experiencing increased Campaign-related enquiries to gather data and report back to the Department.
- Members noted the presentation by s47F titled: *Every Moment Matters. A National awareness campaign for pregnancy and breastfeeding women*. The presentation will be circulated to members.

ACTION 5 (a): FARE to liaise with their evaluation team and collate a list of organisations who are experiencing increased Campaign-related enquires to gather data and report back to the Department.

ACTION 5 (b): Secretariat to circulate the presentation by s47F to members, noting this contains unpublished data and is not for broader circulation.

6. New Zealand and Advisory Group linkages – s47F, s47F(c)

s47F, s47F(c) updated the members following a ‘without prejudice’ discussion with NZ around developing linkages between NZ and the Advisory Group and opportunities for further engagement with NZ on common areas of interest relating to FASD. A conference was suggested to facilitate this in March/April 2023. A paper outlining the meeting discussion was circulated to members out-of-session.

- s47F, s47F(c) noted there was an appetite for greater collaboration between the Advisory Group and NZ in the FASD space. To facilitate this collaboration a virtual 1 to 1.5 day conference was suggested, inviting government and the broader FASD community to network and build understanding, followed by a strategic discussion on joint actions to take forward.
- Members noted the paper which was circulated by the Secretariat and supported the virtual conference in March/April 2023 and noted it would build collaboration, momentum, and global awareness on FASD.

ACTION 6: Secretariat to work with NZ colleagues to develop a proposal and circulate to members for review/input prior to seeking authority from senior executives and Minister to proceed.

7. FASD prevalence study design parameters - Professor Elliott, s47F, s47F(c)

Professor Elliott introduced this item and thanked members for their input to the background paper on a potential Australian FASD prevalence study.

- Members raised the need for better Australian FASD prevalence data. s47F, s47F(c) noted a prevalence study was identified as an action in the FASD Strategic Action Plan. She queried whether we could estimate prevalence now from the various available datasets/resources and that prevalence will continue to be an estimate whilst diagnostic access/attainment and reporting nationally is incomplete, uncertain. There was acknowledgement that prevalence could be estimated with existing resources.
- Members agreed to form a Prevalence Study Working Group to workshop this issue further. s47F elected to join the Working Group.
- s47F noted if we are going to undertake a prevalence study it needs to help us explore some of the complexities of diagnosis and the latest evidence and techniques. s47F noted the following study would be relevant for members: [Population-based prevalence of fetal alcohol spectrum disorder in Canada.](#)

- He also suggested inviting s47F, the University of Queensland who currently leads the 'Review and Dissemination of the Australian FASD Diagnostic Tool' to participate in the Prevalence Study Working Group. It was noted that additional members with epidemiological/methodological expertise might also be invited to contribute.
- s47F suggested we look at the Canadian research methods and revisit the background paper with the Working Group to reframe it into a more explicit study design/method approach.

ACTION 7: Secretariat to facilitate a Prevalence Study Working Group with s47F to develop a prevalence study design/method.

8. Discussion of potential advice for Ministers - Professor Elliott, s47F, s47F(c)

Members discussed the following items:

- **Issues in out-of-home care:** A letter was progressed to the former Minister for Health on 7 April 2022 asking the Minister to raise several issues with the then Minister for Families and Social Services and Assistant Minister for Children and Families. Members agreed the letter to be revised, to reflect the current Government's preferences, and sent to the current Minister for Health and Aged Care for his consideration.

Members also agreed to raise other topics with the incoming Minister for Health and Aged Care that were the subject of previous correspondence:

- Online alcohol sales and digital marketing (addressed at item 2)
- Access to NDIS supports (addressed at item 3.1)
- **Raising the age of criminal responsibility:** Action item from previous meeting. A letter has been prepared on behalf of the Advisory Group to the Minister for Health and Aged Care regarding raising the age of criminal responsibility from 10 to 14 years. The letter was circulated to members out-of-session for consideration.
 - s47F, National Indigenous Australians Agency (NIAA) provided an update on recent action in this space, and noted the issue is on the agenda of Attorneys General nationally. s47F agreed to review and provide input to the draft letter. The Secretariat will liaise with the NIAA on this matter.

ACTION 8: Secretariat to revise the out-of-home care and other previous correspondence and resend to the current Minister for Health and Aged Care on behalf of the Advisory Group.

ACTION 8.1: Secretariat to provide the letter on raising the age of criminal responsibility to the NIAA for review and input, prior to sending to the Minister for Health and Aged Care.

9. Other Business and Next Meeting - Professor Elliott, s47F, s47F(c)

- **Discuss Terms of Reference and Membership:** s47F, s47E(c) noted the National FASD Advisory Group Terms of Reference (ToR) require reviewing and updating in parts ie: membership, rotating external Co-Chair, conflict-of-interest etc. Members are appointed for a period of up to three years, meaning some memberships expire in November 2022. Members may be further appointed at the discretion of the Co-Chairs. s47F, s47E(c) noted the Secretariat will mark up the ToR document in track changes and circulate to members for their review and approval out-of-session. Membership including Co-Chair rotation will also be addressed out-of-session.
- **Potential topics for the next meeting:** Secretariat to seek potential topics, presenters, and presentations for next meeting out-of-session.
 - s47F, s47E(c) raised the need to regroup letters sent to the former Minister for Health and current drafted letters for the Minister of Health and Aged Care to make a consolidated representation. Note Secretariat discuss internally and address with members out-of-session.
- **Next meeting date:** Professor Elliott noted next meeting date will be canvassed out-of-session with the possibility of extending the meeting for an extra 30 minutes including a 10-minute break in between and the potential of an additional Advisory Group meeting – totalling three per calendar year.

Meeting closed at 15:30.

ACTION 9: Secretariat to mark up current ToR document in track changes and circulate to members for review and approval out-of-session.

ACTION 9.1: Secretariat to review Advisory Group membership expiry (November 2022) and address Co-Chair rotation out-of-session.

ACTION 9.2: Secretariat to seek potential topics, presenters and presentations from members for the next meeting out-of-session.

ACTION 9.3: Secretariat to consider the best approach for progressing multiple letters to the Minister for Health and Aged Care and liaise with members out-of-session to confirm preferred option.

ACTION 9.4: Secretariat to circulate the Advisory Group membership list to members for review and updating, if necessary.

ACTION 9.5: Secretariat to canvass a suitable meeting date out-of-session and consider (if departmental resourcing allows) for an additional Advisory Group meeting - totalling three per calendar year.

NATIONAL FASD ADVISORY GROUP MEETING NO.8
Wednesday 22 February 2023
12:30 to 15:00 (AEDT) (held via video conference)

Meeting Outcomes

ATTENDEES

Members

Professor Elizabeth Elliott, Co-Chair

s47F, s47E(c) [redacted], Co-Chair

s47F [redacted]

Apologies

s47F [redacted]

s47E(c), s47F [redacted] (Department of Health and Aged Care)

Presenters

s47F [redacted] (Item 5)

Department of Health and Aged Care

Ms Carolyn Paterson

s47E(c), s47F [redacted]

Observers

s47F [redacted] National Indigenous Australians Agency
ational Indigenous Australians Agency

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1. Acknowledgement of country, welcome members, recording of apologies, confirmation of agenda, conflict-of-interest – Professor Elliott, s47F, s47E(c)

Professor Elliott opened the meeting with acknowledgement of country and welcomed members.

s47F, s47E(c) recorded apologies from:

- s47F
- s47E(c), s47F, Director, Drug and Alcohol Policy section within the department.

s47F, s47E(c) welcomed Ms Carolyn Paterson the newly appointed Assistant Secretary of the Alcohol and Other Drugs Branch.

s47F

s47F, s47E(c) confirmed the agenda and sought declaration of any conflicts-of-interest from members; no conflicts were declared. There are currently 14 conflicts of interest declarations on file as of February 2023 and one outstanding. A number of declarations are due for renewal in the coming months; the Secretariat will email members out-of-session requesting an update.

ACTION 1: Secretariat will contact members where conflict-of-interest declarations require renewal.

2. Commonwealth update – s47E(c), s47E

s47E(c), s47E delivered the update on Commonwealth activities which included:

- **A Better, Safer, Future for Central Australia media release** - On 6 February 2023, the Australian and Northern Territory Governments announced it will invest \$250 million in a plan for *A Better, Safer, Future for Central Australia*. The package will improve community safety, tackle alcohol-related harm including FASD, and provide more opportunities for young people.
- **Minimum Age of Criminal Responsibility (MACR)** - On 12 August 2022, the Meeting of Attorneys-General (now referred to as the Standing Council of Attorneys-General (SCAG)) reconvened the Age of Criminal Responsibility Working Group (Working Group) to continue to develop a proposal to increase the minimum age of criminal responsibility (MACR), paying “particular attention to eliminating the overrepresentation of First Nations children in the criminal justice system”. The Working Group is co-chaired by the Commonwealth and Western Australia. The focus of the Working Group will be options to support raising the age of criminal responsibility, including how jurisdictions can:
 - support children exhibiting offending behaviours.
 - divert children away from the criminal justice system.

- pay particular attention to eliminating the overrepresentation of First Nations children in the criminal justice system.
- **National Information and Awareness Campaign for Pregnant and Breastfeeding** - To date, the mainstream campaign Every Moment Matters has generated 28 million completed ad views. The First Nations specific campaign, Strong Born, was launched on 22 February 2023. A consultation process with community stakeholders was undertaken to inform resource development and culturally appropriate messaging.
- **Australian Government response to FASD senate inquiry report** - On 17 March 2021 the Senate Inquiry report on '*Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder (FASD)*' was released. The department advised that the Australian Government response to the FASD senate inquiry was slowed due to the need to seek input from new Ministers following the change of government. Once finalised the report will be tabled in Parliament and made publicly available and included on an upcoming Advisory Group meeting agenda.
- **Initial Three-Year Review of the National FASD Strategic Action Plan** - The department is seeking approval from Minister Butler to publish the review report on our website. In response to the review report's recommendation for increased information sharing across jurisdictions, the department plans to convene a FASD policy officers forum in 2023 with relevant State and Territory government departments to discuss implementation of the *National FASD Strategic Action Plan 2018-2028*. The forum will initially be one-off, although further meetings may be held subject to interest.
- **Alcohol Beverages Advertising Code Scheme** - The department continues to represent the Government on the Alcohol Beverages Advertising Code Scheme Management Committee. The last meeting occurred on 1 March 2023.

ACTION 2: Following the tabling of the FASD Senate Inquiry report at Parliament, item to be added to the agenda for the next meeting

3. **Previous meeting outcomes and outstanding action items** – s47F, s47E(c)

s47F, s47E(c) sought members' permission for the Secretariat to record the meeting; all members agreed.

Agenda Item 3 – Meeting outcomes 17 August 2022. Endorsed by all members.

Agenda Item 3.1 – Rolling action item status report. Update provided.

- **6.5 - Alcohol online sales and digital marketing (action from 18 October 2021 meeting):** s47F, s47E(c) provided an update on Commonwealth engagement with States and Territories in early 2022 concerning the under-regulation of online alcohol sales with home delivery and resultant health harms.

As of February 2022:

- Three jurisdictions (New South Wales, Victoria, and Western Australia) had passed legislation containing new provisions directed at minimising the risk of harm associated with the online sale and delivery of alcohol.

s47B(b)

s47F, s47E(c) advised as this information is now out of date, we have the opportunity to recapture this item in the omnibus letter.

s47F provided some supplementary information, particularly that jurisdictions have broadly implemented restrictions that prevent under-18s from accessing home delivery, and some jurisdictions are considering restricting late-night home delivery to prevent supply to intoxicated individuals. s47F also noted time delays (eg. 2 hours) between sale and delivery would reduce risky drinking, but to date no jurisdictions have taken this up.

s47F also highlighted a couple of relevant data releases:

- i) University of Queensland/Monash University/ VicHealth released data on 21 February 2023 that Facebook and Instagram are bombarding young people aged 16 to 25 with targeted ads for alcohol, gambling and unhealthy food; and
- ii) Australian Bureau of Statistics (ABS) data on retail sales on alcohol has been released, showing an increase for retail sales of alcohol by \$1 million from 2022.

s47F will share these publications with the Secretariat for broader circulation to members.

- **3.1 (a) - s47F retirement and appointment of new State and Territory Government representative to Advisory Group (action from 17 August 2022 meeting):** Secretariat to pursue options for new representative through State and Territory FASD policy officer's forum later this year – work is in progress. In the interim the Co-Chairs are considering a direct approach for representation. If members have suggestions for an interim state or territory government representative, they can forward these to the Secretariat for consideration. Members will be advised on the outcome of this process.
- **3.1 (b) - Indigenous health check MBS item 715 (action from 17 August 2022 meeting):** MBS team confirmed they are currently finalising a systematic review of evidence for Health Assessment items, being conducted by Bond University. Information from this review, and MBS data insights on how the items are being used, will help guide the next steps in the review, including how the sector can be best engaged. The Secretariat will continue to update members on the review of the MBS Item 715 including opportunities to contribute through the consultation process.

- **Issues accessing support through the National Disability Insurance Scheme (NDIS) Group and consumer groups (action from 17 August 2022 meeting):** Addressed in omnibus letter to Minister Butler at Item 7.
- **FASD diagnostic services for adults:** Addressed in omnibus letter to Minister Butler. Members agreed to add this as an agenda item at the next meeting for the opportunity to brainstorm around adolescent adult services including training of health professionals.
- **New Zealand and Advisory Group linkages:** On hold until mid-23 due to competing priorities. Next steps include fleshing out a proposal with NZ colleagues and seeking authority from senior executives and Minister to proceed.
- **FASD prevalence study design and parameters:** Prevalence Study Working Group first meeting was held on Tuesday 21 February 2023. Addressed at Item 6.
- **Issues in out of home care:** Addressed in omnibus letter to Minister Butler at Item 7.
- **Raising the age of criminal responsibility:** Addressed in omnibus letter to Minister Butler at Item 7.
- **Terms of Reference:** The Secretariat are currently reviewing the Terms of Reference and will circulate an amended version with suggested (minor) updates out-of-session for member review. Addressed at Item 7.
- **Regroup letters (Omnibus letter) to the Minister for Health and Aged Care:** Members agreed to this action at the Advisory Group meeting in August 2022. An omnibus letter was prepared by the Secretariat on behalf of members and has two purposes: i) to introduce the Advisory Group to Minister Butler; and ii) to bring a number of issues around FASD prevention, diagnosis, and support to the Minister's attention. Addressed at Item 7.

ACTION 6.5 (action from 18 October 2021 meeting): Alcohol online sales and digital marketing - s47F to share i) the data from University of Queensland/ Monash University/VicHealth study around unhealthy social media advertising targeting young people; and ii) ABS data around retail sales.

ACTION 3.1 (a) (action from 17 August 2022 meeting): s47F retirement and appointment of new State and Territory Government representative to Advisory Group - If members have suggestions for an interim state or territory government representative, please forward to the Secretariat for consideration.

ACTION 3.1 (b) (action from 17 August 2022 meeting): Indigenous health check MBS item 715 - Secretariat will keep members updated on the review of MBS Item 715 (Indigenous health check), including opportunities to contribute through the consultation process to any amendments to this item to include prenatal alcohol exposure.

ACTION 3.1 (c): FASD diagnostic services for adults: Add this as an agenda item at the next meeting.

4. National Disability Insurance Scheme Review - All

The Minister for the National Disability Insurance Scheme (NDIS), the Hon Bill Shorten MP, announced a review of the NDIS on Tuesday 18 October 2022 and released Terms of Reference which are available on the Review website.

The NDIS Review have a dedicated 'have your say' page. The page includes information on the National Disability Insurance Agency approach to the independent review and provides a list of guidance/prompting questions for submissions. (Note per advice on the Review website, submissions can be made at any time).

Members agreed it would be a valuable opportunity for the Advisory Group to provide a written, audio or video submission. The Secretariat will forward the NDIS Terms of Reference and guidance/prompting questions to members to review and provide individual input. The Secretariat will collate members input and facilitate next steps with members out-of-session.

Discussion around evidence previously provided to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability – Secretariat to forward transcript from Alice Springs hearing to members (if publicly available).

ACTION 4 (a): Secretariat will forward the NDIS Terms of Reference and guidance/prompting questions to members to review and provide individual input. The Secretariat will collate members' input and facilitate next steps with members out-of-session.

ACTION 4 (b): Secretariat to forward transcript from Alice Springs hearing of Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability to members (if publicly available).

5. FASD Edinburgh update – Presentation by s47F

s47F, s47E(c) welcomed s47F to present the work he has been undertaking with the Fetal Alcohol Advisory, Support, and Training Team at the University of Edinburgh.

- Members noted the presentation by s47F titled: *Fetal Alcohol Advisory, Support and Training (FAAST) Team. University of Edinburgh*. The presentation will be circulated to members.

ACTION 5: Secretariat to circulate the presentation by s47F to members.

6. FASD Prevalence Study – s47F, s47E(c)

s47F, s47E(c) provided an update following the Prevalence Study Working Group meeting on Tuesday 21 February 2023. Consensus from the meeting was that estimating Australian prevalence would be a worthwhile exercise from an awareness raising, policy development and service planning perspective. The group agreed in the first instance to investigate whether existing data sets can be leveraged to determine prevalence, focusing on whole-of-population prevalence. If there were to be an active case ascertainment study in future the consensus was that this should be through via school settings and be inclusive of broader neurodevelopmental disorders such as autism and ADHD.

s47G

ACTION 6: Secretariat to forward the Prevalence Study Working Group outcomes to members once finalised.

7. Other Business and Next Meeting - s47F, s47F(c), Professor Elliott

- **Omnibus letter to Minister Butler:** Letter circulated to members on 21 February 2023 for review and endorsement out-of-session. It was agreed by members to add another dot point in the letter noting we are exploring the potential for a FASD Prevalence Study.
- s47F provided an update on:
 - Australian ADHD Clinical Practice Guideline (ADHD Guidelines): s47F raised concern that the recently released ADHD Guidelines do not mention the link between ADHD and FASD. Members agreed a letter would be drafted by the Secretariat to the editors/owners to request an amendment in future iteration.
 - NordAN Copenhagen Conference: s47F attended the Conference in Copenhagen in late 2022 and was concerned at the lack of knowledge and awareness of FASD among conference attendees. s47F flagged the upcoming 7th Global Alcohol Policy Conference (GAPC 2023) in Cape Town on 24-26 October 2023 and that Australia should have a presence. Members agreed an Australian presence, ideally a government representative, would be beneficial. The Secretariat will enquire internally about appetite for this. s47F will send further information on the conference, including abstract lodgement instructions, to the Secretariat for distribution to members.
- **Discuss Terms of Reference:** The Secretariat are currently reviewing the Terms of Reference and will circulate an amended version with suggested (minor) updates out-of-session for member review.
- **Potential topics for the next meeting:** Secretariat to seek potential topics, presenters, and presentations for next meeting out-of-session. Potential agenda items to date include:
 - Northern Territory alcohol-initiated restrictions - s47F suggested invited s47F who has recently completed her PHD into self-determination for First Nations people and based her work around the Alice Springs.

- s47F, Curtin University WA to present on recent research she has undertaken in relation to FASD in Australia with focus on First Nations communities.
 - FASD diagnostic services for adults: Brainstorm around adolescent adult services including training of health professionals.
 - Discussion about treatment services for pregnant females with alcohol use disorder.
- **Transparency of Advisory Group business:** The group discussed the transparency of its business, including the dissemination of outcomes in the public domain. This is not part of the current Terms of Reference; however, members were in favour of a public Communique after each meeting. The Secretariat will explore this possibility with departmental colleagues and advise members of outcome.
 - **Next meeting date:** Professor Elliott noted next meeting date will be canvassed out-of-session.

Meeting closed at 15:25.

ACTION 7 (a): Secretariat to add another dot point in the Omnibus letter noting we are exploring the potential for a FASD Prevalence Study and send to members for out-of-session endorsement.

ACTION 7 (b): Secretariat to draft a letter to the editor/owner of the ADHD Guidelines to request an amendment to reference FASD.

ACTION 7 (c): s47F to send abstracts and instructions around the GAPC 2023 – Cape Town to Secretariat for further distribution to members.

ACTION 7 (d): Secretariat to canvass the idea of an Australian government presence at GAPC 2023 – Cape Town.

ACTION 7 (e): Secretariat to mark-up current Terms of Reference document in track changes and circulate to members for review and approval out-of-session.

ACTION 7 (f): Secretariat to seek potential topics, presenters, and presentations from members for the next meeting out-of-session.

ACTION 7 (g): Secretariat to further explore the option of a National FASD Advisory Group Communique.

ACTION 7 (h): Secretariat to canvass a suitable meeting date out-of-session.

9 March 2023

The Hon Mark Butler MP
 Minister for Health and Aged Care
 Deputy Leader of the House
 PO Box 6022
 House of Representatives
 Parliament House
 Canberra ACT 2600

Dear Minister,

Re: Fetal Alcohol Spectrum Disorder key areas of focus

On behalf of the National Fetal Alcohol Spectrum Disorder Advisory Group (the Advisory Group) I congratulate you on your appointment as Minister for Health and Aged Care and welcome you back into the health portfolio.

The Advisory Group was established by the Department of Health and Aged Care in November 2019 to monitor and report on the implementation of the *National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018-2028*¹ and to advise the Australian Government, via the Minister for Health and Aged Care, on emerging issues, trends, opportunities, and gaps that may exist in the plan. The Advisory Group consists of representatives from the clinical, research and policy sectors as well as parents/carers with lived experience and advocates.

As you will know, FASD is the leading preventable developmental disability in Australia and describes the impacts on the brain and body of individuals prenatally exposed to alcohol. FASD is a lifelong disability and impacted individuals may need healthcare support with motor skills, physical health, learning, memory, attention, communication, higher-level reasoning, emotional regulation and social skills. FASD is costly – to families and society. Many individuals require special education, National Disability Insurance Scheme (NDIS) support, out-of-home care and have contact with the justice system.

FASD is currently prominent in the national and international news, in the context of the challenges facing Alice Springs and the issue of community-led alcohol restrictions in Aboriginal communities in the Northern Territory.

Currently, key areas of focus for the Advisory Group include:

1. Estimating Australian FASD prevalence

Australia currently uses international estimates from Canada to estimate FASD prevalence in the general population (roughly 2% or 1 in 50 people). However, FASD prevalence is higher in some

¹ <https://www.health.gov.au/sites/default/files/national-fasd-strategic-action-plan-2018-2028.pdf>

vulnerable populations such as First Nations communities and justice settings, as shown by local West Australian studies in Fitzroy Valley (19 per cent prevalence for children born between 2002 and 2003)² and Banksia Hill detention centre (36 per cent of 10-18 year olds).³ Australian FASD prevalence is difficult to determine for several reasons, including a lack of routine assessment and screening for maternal alcohol use and FASD, a lack of national diagnostic criteria until 2016, a lack of nationally consistent data collection and reporting until 2016, and a lack of awareness of and diagnostic capacity for the full spectrum of disorders in FASD.

The Advisory Group is working with the department and other relevant agencies including the AIHW to understand how Australian FASD prevalence in the general population might be reliably estimated using existing health datasets, with the view to better informing policy development and service planning.

2. Ensuring individuals with FASD, and their caregivers, are supported to navigate and access services through the National Disability Insurance Scheme

Many people living with FASD and their families and carers have trouble accessing support services through the NDIS in part because FASD has not always been clearly recognised as an eligible disability under the NDIS. The Advisory Group recently engaged with the National Disability Insurance Agency and was successful in advocating for a change in the use of diagnostic terminology in NDIS materials, including in lists of eligible disabilities, to reflect contemporary use of terminology consistent with Australian Guide to the Diagnosis of FASD.⁴

Access to NDIS support is particularly difficult for children and adults living in remote, including Aboriginal and Torres Strait communities, due to lack of availability of specialist assessments, assistance in applying to the NDIS, and relevant local services.⁵

Continued cross-portfolio engagement is recommended to understand how the NDIS experience for people living, or caring for someone, with FASD can be improved and service accessibility streamlined, particularly in rural and remote communities. The Advisory Group also welcomes any opportunities to advise on NDIS reform.

3. Improving outcomes for children with FASD in the out-of-home care system through better access to screening, diagnosis and support

Children and adolescents with FASD are overrepresented in the out-of-home-care system and have poorer outcomes compared with other fostered children, including more frequent placement changes. There is a need to facilitate timely access for health professionals to maternal, obstetric, child protection and medical records and to screening, diagnostic and

² Fitzpatrick JP et al, Elliott EJ. Prevalence and profile of Neurodevelopment and Fetal Alcohol Spectrum Disorder (FASD) amongst Australian Aboriginal children living in remote communities. *Res Dev Disabil.* 2017, 126. doi: 10.1016/j.ridd.2017.04.001.

³ Bower, C et al, Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia. *BMJ Open* 2018;8:e019605. doi: 10.1136/bmjopen-2017-019605

⁴ https://www.fasdhub.org.au/contentassets/32961d4a5cf94de48ebcf985c34d5456/australian-guide-to-the-diagnosis-of-fasd_all-appendices_feb2020_isbn.docx.pdf

⁵ "People don't know what good looks like" Creating equity for people with disability in the Fitzroy Valley. <https://mwrc.com.au/pages/research-and-reports>

treatment services. Reducing stigma and providing better support for foster carers is also essential in order to improve long term outcomes for these children.

4. Improving outcomes for individuals with FASD in the criminal justice system through a higher minimum age of criminal responsibility and better access to screening, diagnosis, supports, and non-custodial therapeutic pathways

People with FASD including children and adolescents are overrepresented in the criminal justice system. This is often despite a lack of criminal intent, because of the way that FASD can impact cognition, cause-and-effect reasoning, impulsivity, memory, language and adaptive function. These factors also impact individuals within the justice system. In a 2018 study over one third of all young people in Western Australia's youth detention centre (Banksia Hill) had FASD. Being unable to negotiate a system that is not set up to support them, people with FASD often enter a cycle of reoffending and reincarceration.

It is encouraging to see recent traction in Australia regarding the urgent need to raise the minimum aged of criminal responsibility from 10 to 12 years, though this falls short of the age of 14 years recommended by the United Nations. The Advisory Group is eager that this momentum continues, in conjunction with system change to embed early assessment and therapy for neurodevelopmental disorders and non-custodial, therapeutic diversionary programs and services as an alternative to incarceration.

5. Improving diagnostic pathways and supports for adolescents and adults with FASD to improve mental health outcomes

Children, adolescents and adults with FASD represent a vulnerable group in our society due to their neurodevelopmental impairments. Not only is this group at greater risk of involvement with the justice system, but they are also susceptible to challenges including severe mental ill-health and substance use. Of particular concern is the consistent global finding that individuals living with FASD are at a much higher increased risk of suicidality throughout their lives.

Recent research at the University of Western Australia⁶ is in keeping with this overseas trend. In a sample of 195 individuals with FASD aged 5 to 21 years, 21 per cent reported having suicidal ideation or a past suicide attempt. This rate is much higher than the 9 per cent reported in the general population. In addition, the Western Australian study found that the average age for suicidality was 14 years, with the youngest being five years old. Additionally, the risk of suicide increased with age, likely because the challenges (for example, substance use, incarceration, insecure housing, unstable employment) experienced by individuals with FASD increase in adolescence and adulthood.

The mental health and other adult outcomes for individuals with FASD can be improved through early diagnosis and early appropriate supports, particularly at key transition points, such as leaving high school.

⁶ Tan, G. K. Y., Quinn, S., Connor, S.G., Fitzpatrick, J.P., Adams, I., & Pestell, C.F. (2022)

6. Stronger regulation of digital marketing and online alcohol sales with home delivery, to protect youth and other vulnerable groups from harmful alcohol use

Along with many public health stakeholders, the Advisory Group is concerned that increased availability of alcohol through under-regulated online home delivery services and heavy, targeted marketing will lead to higher rates of alcohol-related harms, including increased prevalence of FASD.

Online alcohol sales with home delivery options account for a growing share of the alcohol market in Australia, having increased by an average annual rate of 19.1 per cent since 2016, bringing the revenue to an expected \$1.8 billion in 2021.⁷

The associated rise in online advertising also requires attention. Sophisticated algorithms, heavy, targeted marketing, and a blurring of lines between advertiser and consumer (in the case of social media influencers), combined with a lack of transparency by digital platforms, make it difficult for regulators to monitor digital marketing content and prevent harms. In 2021, 73 per cent of complaints referred to the Alcohol Beverages Advertising Code panel related to digital advertising; however, this industry-led scheme is not effective at preventing advertising that promotes harmful drinking behaviour. This is in the context of documented increases in alcohol sales during the Covid-19 pandemic.

Children under the age of 18 should not be exposed to alcohol promotions - evidence indicates exposure is associated with positive expectations about alcohol and drinking, increased intention to drink and increased drinking. The community supports such controls. The exceptions to this simple and sensible public health measure, such as promotions occurring during sporting events and broadcasts, result in widespread exposure of children to alcohol advertising and promotion. Our message is simple- children under the age of 18 should not be exposed to alcohol promotions.

The Advisory Group would welcome the opportunity to meet with you and other interested members of your government, given the cross-portfolio nature of topics raised in this letter, to further discuss these issues.

We look forward to working with you in your role as the Minister for Health and Aged Care.

Regards,

s47F

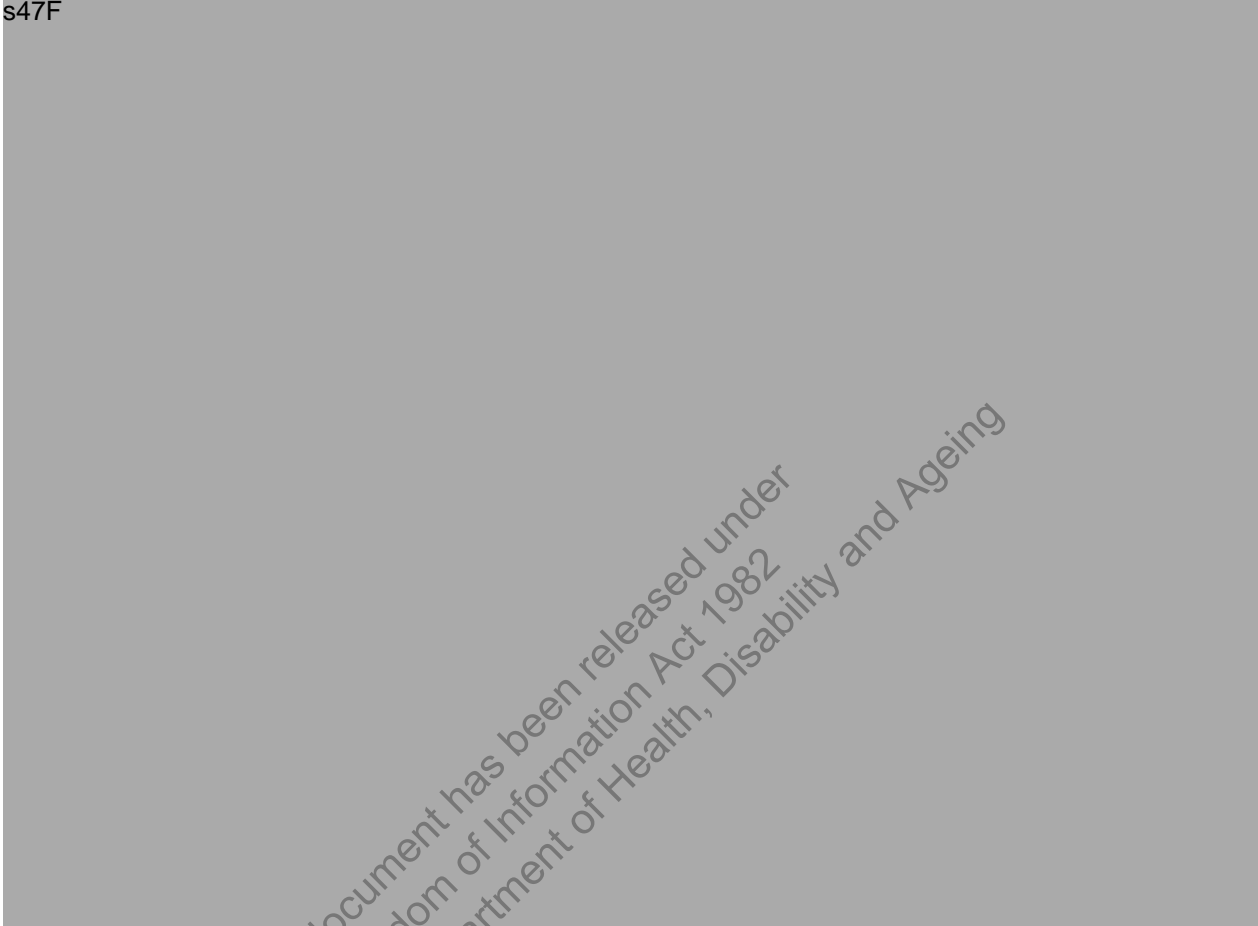
Professor Elizabeth Elliott AM FAHMS FRSN
 Co-chair, National Fetal Alcohol Spectrum Disorder Advisory Group
 Distinguished Professor of Paediatrics & Child Health, University of Sydney
 Next Generation Fellow, Medical Research Futures Fund
 Consultant Paediatrician, Sydney Children's Hospitals Network (Westmead)
 Director, Australian Paediatric Surveillance Unit

⁷ IBISWorld, Australia Specialized Industry report OD4087, Online Beer, Wine and Liquor Sales in Australia, Industry at a Glance, April 2021 (updated 23 February 22)

National Fetal Alcohol Spectrum Disorder Advisory Group Membership:

s47F, s47E(c) , Co-chair (Principal Medical Advisor, Population Health Division,
Department of Health and Aged Care)

s47F



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by the Department of Health, Disability and Ageing



**The Hon Mark Butler MP
Minister for Health and Aged Care**

Ref No: MC23-006667

Professor Elizabeth Elliott AM
Co-Chair
National Fetal Alcohol Spectrum Disorder Advisory Group
s47E(c), s47F [REDACTED]@gmail.com

Dear Professor

Thank you for your correspondence of 9 March 2023 outlining the key areas of focus for the National Fetal Alcohol Spectrum Disorder (FASD) Advisory Group (Advisory Group) and for your kind congratulations on my appointment as Minister for Health and Aged Care. It is an honour to be appointed Minister for Health and Aged Care in the Albanese Government.

As you have noted in your letter, FASD is a lifelong disability which can significantly impact individuals, their families and carers, and the broader community. I would like to assure you that the Australian Government remains committed to reducing the prevalence and impact of FASD in partnership with state and territory governments, non-government organisations, and communities.

I would also like to acknowledge the Advisory Group's collective expertise on this issue and thank you for your ongoing support with monitoring the implementation of initiatives under the National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018-2028 (Strategic Action Plan).

I am pleased to be able to advise you that I have recently approved the public release of the three-year formal review of the Strategic Action Plan, which was undertaken by Deakin University. Whilst I am aware that there were a number of challenges in undertaking this work, it was pleasing to see that some progress has been made against each of the priority areas under the Strategic Action Plan in this time frame.

As you have also noted in your letter, the impacts of FASD are not specific to health alone but cut across a number of portfolios, including for example the disability sector, education, out-of-home care and the criminal justice system. Addressing these issues therefore requires a collaborative approach across sectors and across all levels of government.

To this end, the Department of Health and Aged Care is actively seeking to strengthen engagement with our state and territory counterparts to develop a better understanding of the service gaps and key priorities across each of the jurisdictions. I have also been heartened to learn of the Advisory Group's ongoing role in advocating for change across a number of these portfolios and am hopeful that the exploratory work underway to estimate the prevalence of FASD in Australia's general population will also be of assistance in this regard.

For your information, the Assistant Minister for Indigenous Health, Senator the Hon Malarndirri McCarthy, has also advised that she would welcome a meeting with the Advisory Group to hear more about these issues. Senator McCarthy's office can be contacted directly via email at Senator.McCarthy@aph.gov.au to arrange a suitable time.

Thank you again for writing on this matter and look forward to working with you on this important issue into the future.

Yours sincerely



Mark Butler

19/04 / 2023

cc: Senator the Hon Malarndirri McCarthy, Assistant Minister for Indigenous Health and Assistant Minister for Indigenous Australians

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NATIONAL FASD ADVISORY GROUP MEETING NO.9
Wednesday 13 September 2023
13:00 to 15:30 (AEDT) (held via video conference)

Meeting Outcomes

ATTENDEES

Members

Professor Elizabeth Elliott, Co-Chair

s47F, s47E(c) [redacted], Co-Chair

s47F



Apologies

s47E(c), s47F [redacted] (Department of Health and Aged Care)

s47F



Presenters

s47F [redacted], Co-Chair (Item 5)

s47F [redacted], FASD Hub (Item 5)

Department of Health and Aged Care

Ms Carolyn Paterson

s47E(c), s47F [redacted]

s47E(c), s47F [redacted]

Observers

s47F [redacted], National Indigenous Australians Agency

s47F [redacted], National Indigenous Australians Agency

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1. Acknowledgement of country, welcome members, recording of apologies, confirmation of agenda, conflict-of-interest – Professor Elliott, s47F, s47E(c)

s47F, s47E(c) sought members' permission for the Secretariat to record the meeting; all members agreed.

Professor Elliott opened the meeting with acknowledgement of country and welcomed members.

s47F, s47E(c) recorded apologies from:

- s47F
- s47F
- s47F

s47F, s47E(c) welcomed s47F Western Australian Mental Health Commission.

s47F, s47E(c) confirmed the February meeting outcomes, agenda and sought declaration of any conflicts-of-interest from members; no conflicts were declared. There is currently one outstanding conflicts of interest declaration on file; the Secretariat will email the member out-of-session requesting an update.

ACTION 1: Secretariat will contact members where conflict-of-interest declarations require renewal.

2. Commonwealth update – Ms Paterson

Ms Paterson delivered the update on Commonwealth activities which included:

- **2023-24 Budget announcements** – Through the 2023-24 Budget the Australian Government has committed:
 - \$1.4 million over two years to expand the national reach of the 'Strong Born' FASD awareness campaign being rolled out by the National Aboriginal Community Controlled Health Organisation (NACCHO). The measure will increase the funding available to Aboriginal Community Controlled Health Organisations, including in urban and regional locations, to deliver tailored campaign initiatives in their communities. It is expected that the new contract will be in place by Q4 2023.
 - \$4.9 million to extend a number of FASD prevention, diagnosis and support activities to 30 June 2025. It is expected that new contracts will be in place in Q4 2023.
 - \$18.4 million to support the Central Australian Aboriginal Congress to expand their existing Child and Youth Assessment and Treatment Services program which provides early detection and intervention services for neurodevelopmental conditions, such as FASD, for Aboriginal children and young people in Central Australia. This funding is part of the \$250 million *A Better, Safer Future for Central Australia* package.
- **Other Australian Government funded projects** - Griffith University will receive \$1.5m through a National Health and Medical Research Council (Partnership Project grant to test the Tracking Cube model in a number of other First Nations health services across

Australia. The Tracking Cube is a culturally sensitive tool to screen and support children with neurodevelopmental delays in primary care, including FASD.

- **State and Territory FASD information sharing forum** - In June, policy officers from Australian health departments held a networking and information-sharing session on FASD. The session was a chance to discuss cross-jurisdictional FASD issues in the absence of formal governance arrangements. Improving cross-jurisdictional sharing of information was a key recommendation from Deakin University's three-year progress review of implementation of the National FASD Strategic Action Plan 2018-2028. It was interesting to hear from the jurisdictions about the different issues and priorities they are facing – common themes included:
 - Universal early childhood screening and intervention
 - Universal approach to data collection
 - FASD awareness and education for high school students
 - FASD support in out-of-home care, including better linking of child and maternal health records.
- **FASD Awareness Month** - September is International FASD Awareness Month. Foundation for Alcohol Research and Education (FARE), National Organisation for Fetal Alcohol Spectrum Disorder (NOFASD) and NACCHO have collaborated on an impressive program of events and awareness raising activities. This included lighting up over 50 landmarks and monuments across the country and hosting an event at Parliament House attended by many parliamentarians.
- **Every Moment Matters campaign** - s47F provided some preliminary data based on wave polls to date. Positive shifts in awareness and attitudes, including:
 - 24% increase in people in the target audience who said that 0 drinks were safe in pregnancy;
 - 10% increase in people who are aware of FASD;
 - 10% increase in partners willing to go alcohol-free during pregnancy.

Members then further discussed a couple of issues raised by jurisdictions during the June state and territory FASD information sharing forum, including:

- **FASD awareness and education for high school students** - Professor Elliott reiterated the importance of this topic and suggested the Advisory Group write a letter to Minister Butler on raising awareness of alcohol harms for adolescents and options for inclusion in high school curriculums. Members were supportive of this approach and made a number of further suggestions including:
 - Exploring what existing evidence-based approaches could be added into school curriculums (noting curriculums are set by and differ per jurisdiction);
 - The need to reach those less connected to the school system as these children are often a higher risk group in relation to alcohol consumption and FASD (for example, integrating screening and education into out-of-home-care settings);
 - Including FASD content on the national 'Positive Choices' website (run by University of Sydney Matilda Centre) in addition to approaching it from a curriculum perspective; and
 - Reaching teens via social media platforms.

Professor Elliott offered to reach out to s47F, Director of the Matilda Centre to canvass the idea of s47F presenting at the next meeting around the Positive Choices website and her work in this field. Following this discussion, a working group may potentially be formed to draft a letter to the Minister on these issues.

- **Universal early childhood screening and intervention** – s47F discussed the lack of clarity across jurisdictions around FASD screening protocols in early childhood development services, child protection and youth justice settings, and whether these are FASD-informed.

s47F raised the Healthy Kids check as one potential ‘universal’ health check where FASD screening could occur.

s47F clarified that FASD screening has two aspects – an alcohol exposure history; and/or a screen for developmental difficulties. And these can be approached differently in different settings. s47F concurred and noted it was a complex ethical area as many pregnancies in Australia will be alcohol-exposed and many children seeing paediatricians will have developmental delays. So many children will screen positive, and what are we doing with that information? Should screening focus on high risks groups? (out-of-home-care, youth justice, children with siblings with FASD and/or with mothers who have alcohol dependence).

Members agreed on the merits of undertaking an environmental scan to map existing child development health services (in the first instance) and if they are appropriately screening for FASD. Members agreed a sub-working group may need to be formed to further unpack this issue.

ACTION 2: Professor Elliott to reach out to s47F from the Matilda Centre for Research in Mental Health and Substance Use to discuss including FASD content on the Positive Choices website.

ACTION 2.1: Secretariat to invite s47F to present on the Matilda Centre’s work at the next Advisory Group meeting.

ACTION 2.2: Secretariat to canvass potential sub-working groups to work through next steps for the two issues discussed i. FASD awareness and education for high school students; and ii. Universal early childhood screening and intervention.

3. Co-Chair’s update – Professor Elliott, s47F, s47E(c)

- **FASD prevalence work** - Professor Elliott and s47F, s47E(c) provided an update on the prevalence work staff from the FASD Australia Registry are undertaking with Drug and Alcohol Policy Section, s47F, s47E(c) and colleagues from the Department’s Health Economics and Research Division (HERD). Professor Elliott noted that while a population-level prevalence study has not been discounted as a way to ascertain prevalence, current efforts are focused on looking at what can be done with existing data.

The FASD Registry team is exploring replicating a recent New Zealand study by Romeo et al¹ 2023 where the prevalence of FASD in New Zealand was estimated using WHO methods and known rates of prenatal alcohol exposure and the risk of having a child with FASD, which has been estimated in international studies.

The team is also exploring whether FASD incidence data from the FASD Registry can be used with other data to estimate prevalence, and the appropriate methods for this. s47F, s47F(1) noted that verbal advice from HERD is that under-ascertainment of FASD cases in the Registry suggests that using this method may be less accurate.

The team will progress this work, including development of a paper estimating prevalence which is underway through the Working Group and will be shared with the FASD AG for feedback when available.

- **Meeting with Assistant Minister McCarthy's Office** – s47F, s47F(1) provided an update on the Co-Chairs' meeting with Assistant Minister McCarthy's Office on 1 August 2023. Unfortunately, Assistant Minister McCarthy had to give her apologies as she was called into the Senate just as the meeting was commencing, but the Co-Chairs had a good meeting with her Chief of Staff, s47F.

A summary of the meeting was emailed to members on 22 August.

s47F suggested the FASD Advisory Group meet with other Ministers such as the Hon Amanda Rishworth MP, Minister Social Services, and has flagged with Minister Rishworth's office that the Advisory Group Co-Chairs will reach out to request a meeting.

The Co-Chairs also floated the idea of a Parliamentary Friends group around FASD, or alternatively, incorporating FASD under the existing Parliamentary Friends of Children and Adolescents group. s47F was receptive to this and is raising with Assistant Minister McCarthy. Professor Elliott also noted she will speak with s47F about showcasing FASD through the Parliamentary Friends of Children and Adolescents and report back to the broader group.

ACTION 3: Secretariat to provide updates to members on the ongoing prevalence work including a draft of the paper currently being prepared, when available.

ACTION 3.1: Secretariat to canvass date for a Co-Chair meeting with Minister Rishworth's office.

ACTION 3.2: Secretariat to follow up with s47F around incorporating FASD under the existing Parliamentary Friends of Children and Adolescents group. Members to lead this work thereafter.

ACTION 3.3: Professor Elliott to speak with s47F about showcasing FASD through the Parliamentary Friends of Children and Adolescents group.

¹ [Foetal alcohol spectrum disorder in Aotearoa, New Zealand: Estimates of prevalence and indications of inequity - Romeo - 2023 - Drug and Alcohol Review - Wiley Online Library](#)

4. Previous meeting outcomes and action items - s47F, s47E(c)

Agenda Item 4 – Meeting outcomes 22 February 2023. Endorsed by all members.

Agenda Item 4.1 – Rolling action item status report was provided to members ahead of the meeting. s11C touched on a few key items, including:

- **4.1 (a) - Indigenous health check MBS item 715 (action from 17 August 2022 meeting):** MBS team confirmed they are currently finalising a systematic review of evidence for Health Assessment items, being conducted by Bond University. Information from this review, and MBS data insights on how the items are being used, will help guide the next steps in the review, including how the sector can be best engaged. The Secretariat will continue to update members on the review of the MBS Item 715 including opportunities to contribute through the consultation process.
- **4.1 (b) - New Zealand and Advisory Group linkages (action from 17 August 2022 meeting):** On hold due to competing priorities.
- **4.1 (c) - New Zealand and Advisory Group linkages (action from 17 August 2022 meeting):** Professor Elliott suggested there may be an opportunity for representatives from the Advisory Group to report back to NZ colleagues on the Advisory Group's activities.
- **4.1 (e) - Australian Government response to FASD senate inquiry report (action from 22 February 2023 meeting):** Following the tabling of the FASD Senate Inquiry report at Parliament, item to be added to the agenda for the next meeting.
- **7 (d) - 7th Global Alcohol Policy Conference (GAPC 2023) (action from 22 February 2023 meeting):** The department had to withdraw its abstract for the GAPC 2023 as travel funding could not be secured, and no virtual option is available.

Discussion continued around upcoming conferences, which include:

- Professor Elliott flagged the 3rd World Congress of the International Society for Biomedical Research on Alcoholism (ISBRA) and the Asia Pacific Society for Alcohol and Addiction Research (APSAAR) which will be held in Melbourne from 23 to 26 September 2024. Professor Elliott has been asked to present on the first 1000 days. Professor Elliott suggested FARE present on the Every Moment Matters campaign and noted there will be an opportunity for the Advisory Group and others to submit abstracts. Secretariat to circulate conference details to members.
- Professor Elliot noted the 9th International Research Conference on Adolescents and Adults with FASD which will be held in Seattle, USA from 1 to 14 April 2024. s47F suggested a collective approach to present at the conference on behalf of the Advisory Group. s47F will draft a concept on what this may look like and share it with the Secretariat for circulation to the broader group. Secretariat to circulate conference details to members.
- s47F noted CanFASD is hosting its inaugural Canadian national conference on FASD which will be held in Saskatchewan in November 2023. s47F noted that VicFAS has a neuropsychologist presenting at the conference.

- s47F noted the Kettil Bruun Society for Social and Epidemiological Research on Alcohol Conference is being held in Fremantle, WA in May 2024 which is another opportunity to showcase work on FASD. s47F to share conference details with Secretariat for broader circulation to members.
- Professor Elliott posed the question would Government support the Advisory Group submitting a paper on its role and activities to upcoming domestic and international conferences. The Secretariat will follow up out of session and report back to members.

ACTION 4.1 (a): Indigenous health check MBS item 715 (action from 17 August 2022 meeting): Secretariat will keep members updated on the review of MBS Item 715 (Indigenous health check), including opportunities to contribute through the consultation process to any amendments to this item to include prenatal alcohol exposure.

ACTION 4.1 (b): New Zealand and Advisory Group linkages (action from 17 August 2022 meeting): On hold due to competing priorities.

ACTION 4.1 (c): New Zealand and Advisory Group linkages (action from 17 August 2022 meeting): Secretariat to reach out to our NZ colleagues to determine if there is an opportunity for representatives from the Advisory Group to report back to NZ on Advisory Group activities.

ACTION 4.1 (e): Australian Government response to FASD senate inquiry report (action from 22 February 2023 meeting): Secretariat to add item to agenda following the tabling of the FASD Senate Inquiry report at Parliament.

ACTION 4.1: Upcoming conferences (action 13 September 2023 meeting): Secretariat to circulate ISBRA conference details to members.

ACTION 4.1 (a): Upcoming conferences (action 13 September 2023 meeting): s47F to draft a concept for the 9th International Research Conference on Adolescents and Adults with FASD for circulation to the broader group.

ACTION 4.1 (b): Upcoming conferences (action 13 September 2023 meeting): Secretariat to circulate details on the 9th International Research Conference on Adolescents and Adults with FASD to members.

ACTION 4.1 (c): Upcoming conferences (action 13 September 2023 meeting): s47F to share the Kettil Bruun Society for Social and Epidemiological Research on Alcohol Conference details with the Secretariat for circulation to the broader group.

ACTION 4.1 (d) Upcoming conferences (action 13 September 2023 meeting): Secretariat to seek approval from the department for members wishing to submit papers on the Advisory Group's role/activities to upcoming domestic and international conferences.

5. FASD diagnostic services for adults - All

s47F, s47F(c) introduced item 5 and provided a brief overview of the agenda paper that was circulated to members prior to the meeting. s47F, s47F(c) noted the meeting was an opportunity to brainstorm around barriers to diagnosing adults and how these might be

overcome. s47F, s47E(a) noted there is no data on how many adults have a diagnosis of FASD nor how many seek diagnosis.

s47F noted she is currently undertaking a scoping review to identify common indicators of FASD that may be specific to adults. Ethics approval has been obtained for a qualitative research project that seeks to understand how adult diagnostic assessments occur. Current identified barriers include professional knowledge; concerns from professionals about the usefulness of the diagnosis; and how we better include adults in the diagnostic guidelines.

Members to provide any other information/data which may assist with the scoping review directly to s47F.

Other points raised by members include:

- One current barrier is the cost of testing and difficulty in obtaining a referral.
- Who is best equipped to make the diagnosis? (ie: what is the role of GPs, psychiatrist, psychologists); how do they get upskilled?; how do we facilitate referrals depending on where clients are located? (often it's within the justice system). Starting point could be an educative piece of work through the Colleges etc to raise FASD awareness.
- There could be scope for paediatricians to assist in the developmental aspects of an adult assessment, noting that an adult physician would still be required to be involved in adult patients' care.
- s47F suggested looking at the adult autism assessment model which is moving towards emphasising the functional assessment and de-emphasising the medical evaluation components. s47F countered that the medical component is still important for FASD especially given complexity in diagnosis for adults as they get older with co-occurring mental health and substance issues. Important that medical practitioners exclude differential diagnoses.
- The diagnostic guide should have more explicit content around adult diagnosis as the diagnostic pathways are varied.
 - Working parties are currently developing the revised diagnostic guidelines which is due to be released July 2024. There will be a consultation phase and training opportunities for clinicians to learn the revised guidelines.
 - Reach out to s47F from the University of Queensland to propose including an independent section in the revised guidelines on FASD diagnosis for adults, and associated training opportunities as part of dissemination of the updated guide.
- Members noted transition pathways to adult medical and allied health care need to be in place for children and adolescents currently being diagnosed with FASD. Professor Elliott to look at the FASD Registry data to see how many children fall into the 12–15-year bracket and will shortly transition to adult care.
- First Nations perspective – NIAA highlighted the racism element in relation to screening and diagnosis. These services need to be culturally safe because of the institutional issues at play.

ACTION 5: Members to provide information/data directly to s47F which may assist with the scoping review.

ACTION 5.1: Secretariat to reach out to s47F to propose including an independent section in the revised guidelines on FASD diagnosis for adults.

ACTION 5.2: Professor Elliott to look at the FASD Registry data to see how many children are in the 12-15 year bracket, for the Secretariat to share with the broader group.

ACTION 5.3: Members may consider convening their own working group to look at an approach to adolescents with FASD once the scoping review is complete.

6. FASD Hub – Presentation by Professor Elliott and s47F

Professor Elliott welcome s47F, project manager from the FASD Hub. s47F provided an overview of the FASD Hub's development, its current use, website rebuild and future considerations.

Members noted the presentation titled: FASD Hub Update. The presentation will be circulated to members – please note this is not for further distribution.

ACTION 6: Secretariat to circulate the FASD Hub presentation to members.

7. Other Business and Next Meeting - s47F, s47F(c), Professor Elliott

- **Potential topics for the next meeting:** Secretariat to seek potential topics, presenters, and presentations for next meeting out-of-session. Potential agenda items to date include:
 - Commonwealth update to include 2021 diagnostic funding. How the clinics are tracking etc.
 - Advocacy around minimising population-level access to alcohol.
 - Progress on implementation of the *National FASD Strategic Action Plan 2018-2028*.
 - Northern Territory alcohol-initiated restrictions - s47F suggested inviting s47F who has recently completed her PHD into self-determination for First Nations people and based her work around Alice Springs. s47F was unable to attend the September 2023 meeting, however, has expressed interest in attending the next meeting.
- **Next meeting date:** Next meeting date will be canvassed out-of-session.

Meeting closed at 15:30.

ACTION 7: Secretariat to seek potential topics, presenters, and presentations from members for the next meeting out-of-session.

ACTION 7.1: Secretariat to canvass a suitable meeting date out-of-session.



Australian Government
Department of Health and Aged Care

NATIONAL FASD ADVISORY GROUP
Wednesday 21 February 2024
13:00 to 15:30 (AEST)
Video Conference Meeting

Attendees:

Members

Professor Elizabeth Elliott, Co-Chair

s47F, s47E(c) [redacted], Co-Chair

s47F [redacted]

Apologies

s47F [redacted]

Presenters

s47F [redacted]

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by the Department of Health, Disability and Ageing

Department of Health and Aged Care

Ms Carolyn Paterson

s47E(c), s47F [redacted]

Observers

s47F [redacted], National Indigenous Australians Agency

s47F [redacted], National Indigenous Australians Agency

s47F [redacted], National Indigenous Australians Agency



Item 1 – Welcome/introductions

Professor Elliot opened the meeting with an acknowledgement of country and welcomed members. Apologies were recorded for:

s47F

s47F, confirmed the agenda, previous meeting outcomes and sought **any** conflicts of interest from members.

- s47F

This was noted and assessed as low risk by Co-Chairs.

s47F, noted that updated conflict of interest declarations are now due for most members of the Advisory Group.

- The Secretariat will reach out to members to provide updated conflict-of-interest forms after the meeting.

ACTION 1	Secretariat will provide updated conflict-of-interest forms to members.
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Item 2 – Commonwealth update

s47F, invited Carolyn Paterson, (Assistant Secretary, Alcohol and Other Drugs Branch) to provide the update on behalf of the Department of Health and Aged Care.

Ongoing progress against FASD related budget commitments

- The FASD specific commitments made by the Australian Government through the 2023-24 Budget are progressing well. These include
 - \$4.9 million measure to extend a number of FASD prevention, diagnosis and support activities to 30 June 2025.
 - \$1.4 million over two years to expand the national reach of the ‘Strong Born’ FASD awareness campaign being rolled out by NACCHO.
 - The measure builds on the work developed under Stream 4 of the national Every Moment Matters Campaign and will increase the funding available to ACCHOs, including in urban and regional locations, to deliver tailored campaign initiatives in their communities.

FARE Every Moment Matters Campaign

- Ongoing evaluation data show the FARE Every Moment Matters campaign continues to have a positive impact. Survey results between January 2022 and November 2023 show:
 - an increase in the proportion of women who would abstain from alcohol during pregnancy if they were to become pregnant (from 82.6 per cent to 90.9 per cent)
 - a decrease in the proportion of women who would consume at least some alcohol (from 15 per cent to 9.7 per cent); and an



- increase in awareness that it is best to abstain from alcohol completely during pregnancy to protect the health of the baby (from 53.5 per cent to 58.1 per cent)

Ms Paterson asked s47F to provide any additional commentary relevant to the campaign.

- s47F noted that:
 - there have been statistically significant increases in awareness across the population,
 - 5 wave polls have been completed,
 - 52 million views have been completed for the campaign video.
- Updated data provided by FARE will be circulated to members with meeting minutes.

National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018-2028 (FASD SAP)

- The department is currently considering options for progressing the next iteration of the National Drug Strategy 2017-2026
- Any reviews of the broader suite of national Alcohol and other Drug (AOD) sub-strategies, including the FASD SAP, will be considered within this context. No timeframes are currently available for progressing this work with final decisions to be a matter for government.

Other Commonwealth initiatives

First Nations Health Division Update

- The Department is providing funding to the Central Australian Congress Aboriginal Corporation (Congress) to expand its Child and Youth Assessment and Treatment Services (CYATS). This is part of the Government's \$250 million Central Australia Plan to improve community safety, tackle alcohol-related harm and provide more opportunities for young people.
- The specialist service provides formal diagnostic assessment, speech pathology and occupational therapy interventions for children and young people in Central Australia suspected of having a neurodevelopmental delay or disorder including fetal alcohol spectrum disorder, autism spectrum disorder and attention deficit hyperactivity disorder.

Updates to Alcohol chapter of Clinical Practice Guidelines: Pregnancy Care (Pregnancy Care Guidelines) and Postnatal Care Guidelines addressing alcohol and breastfeeding

- The Commonwealth has engaged Monash University to update the [Pregnancy Care Guidelines](#) and develop new Postnatal Care Guidelines.
- Priorities for action for the Guidelines are being determined by the Living Evidence for Australian Pregnancy and Postnatal care (LEAPP) Steering Committee.
 - s47F (FARE) advised that FARE have been involved in providing some input into the text.
- A website has been created for stakeholders to be kept informed of the project. If interested, Advisory Group members can also subscribe to receive updates on the Guideline review process.
- Initial priorities include aligning the alcohol chapter of the Pregnancy Care Guidelines with the [Australian guidelines to reduce health risks from drinking alcohol](#) in line with Recommendation 7 of the Senate Inquiry into [Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder](#).
- Most recently, an alcohol related recommendation for breastfeeding has been developed for the Postnatal Care Guidelines. The recommendation and supporting information was released for public consultation on 14 February 2024.



Drug Strategy Household Survey

- The 2022-23 National Drug Strategy Household Survey (NDSHS) is being finalised by the Australian Institute of Health and Welfare (AIHW) for release on 29 February 2024.
- The option for the AIHW to attend a future Advisory Group meeting was discussed with the AIHW providing an overview of relevant Household Survey information. Members were supportive of this idea.
- s47F noted that expertise is brought into successive Household surveys and it would be beneficial if they had consulted with members of this group to discuss FASD.
- Ms Paterson noted that these points can be explored by the department in upcoming meetings with the AIHW.

ACTION 2.1	Secretariat to seek AG member views on points of interest for a future AIHW presentation.
ACTION 2.2	The department will explore with AIHW potential for consultation with co-chairs or FASD AG member representative in developing the next NDSHS survey.

Item 3 - Previous meeting outcomes and outstanding action items

s47F, sought member acceptance of previous minutes and actions circulated to members prior to the meeting.

- Member acceptance recorded.

s47F, delivered updates on outstanding action items:

- **Indigenous health check MBS item 715 (action from meeting of 17 August 2022):** The department is continuing its review of all health assessment services under the MBS to help inform their effectiveness and any future improvements. This includes annual health assessments available to Australia's First Nations peoples. The department intends to engage with stakeholders on the outcomes of the systematic review and on additional MBS data insights on the use of health assessment services in 2024.
 - s47F, noted this MBS item is a potentially important vehicle for discussing FASD with patients. The department is following up on updates.
- **New Zealand and Advisory Group linkages (action from meeting of 17 August 2022):** On hold due to competing priorities. Next steps include the Secretariat confirming a date for the Advisory Group (Co-Chairs) to attend the NZ AG in the coming months to discuss common issues. s47E(C), noted the Secretariat is due to confirm dates.
- **Australian Government response to FASD senate inquiry report (action from meeting of 17 August 2022):** The response to the FASD senate inquiry report is well progressed and in the process of being finalised. Timing for tabling of the response will be a matter for Government. Members will be updated when possible.
- **Potential working groups raised at last meeting (action from meeting of 13 September 2023):**



1. Call for member volunteers to participate in a working group to *'progress issues discussed on the topic of FASD awareness and education for high school students with a view to writing to the Minister on this topic'*
 - Note: since the last meeting funding has been awarded to the consortium led by the Matilda Centre to develop resources for secondary school members. AG members may instead wish to participate in a brainstorming session to identify key issues which could be offered to the Matilda Centre.
 - Interest in brainstorming and an ongoing conversation on the topic noted from members s47F likely interest in participating was noted in her absence.
 2. Call for member volunteers to participate in a working group to *progress discussion on the topic of universal early childhood screening and intervention with a view to mapping existing child developmental health services'*.
 - Members agreed to go ahead with this working group with interest indicated by s47F.
- **Meeting with Minister Rishworth (action from meeting of 13 September 2023):** Secretariat canvassing potential dates for co-chairs to meet.
 - **Showcasing FASD through the Parliamentary Friends of Children and Adolescents group (action from meeting of 13 September 2023):** Professor Elliot provided an update, noting s47F raised that members of the FASD AG could potentially present to the Friends group in the future.
 - s47F **to draft a concept for the 9th International Research Conference on Adolescents and Adults with FASD for circulation to the broader group (action from meeting of 13 September 2023):** s47F, s47F thanked s47F for updating the Secretariat, noting that: *The FASD Conference 2024 - FASD United program has been finalised in terms of presenters.*
 - Action to be closed
 - **Secretariat to seek approval from the department for members wishing to submit papers on the Advisory Group's role/activities to upcoming domestic and international conferences (action from meeting of 13 September 2023):** Ms Paterson provided an update, noting that papers could not be provided on behalf of the FASD AG. However, a communique may be able to be developed.
 - **Professor Elliott to look at the FASD Registry data to see how many children are in the 12-15 year bracket, for the Secretariat to share with the broader group (action from meeting of 13 September 2023):** Professor Elliot provided an update:
 - 19% of children with FASD recorded on the Registry are 12-15 year olds. 228 children.
 - 1 in 5 children on the FASD Registry are within that age group at diagnosis
 - **Members may consider convening their own working group to look at an approach to adolescents with FASD once [s47F] scoping review is complete (action from meeting of 13 September 2023):** Members were asked whether there is interest in this working group noting the working groups already raised earlier. Members may wish to discuss as part of Agenda Item 4.



Item 4 –

Advisory Group Work Plan for 2024

- Members were invited to raise issues they think should be addressed as priorities in 2024.
- s47F requested the below topics be raised in her absence:
 - Support for adults with FASD and teenagers in the transition to adulthood.
 - Whilst Adult FASD diagnosis has been limited, many children diagnosed with FASD through the specialist clinics established within the last 15 years will be approaching adulthood.
 - Given the high frequency of adverse psychosocial outcomes for adults who are not adequately supported, this is going to be a significant issue in the future that will not be solely addressed through NDIS.
 - Pathways to adult diagnosis.
 - Screening and professional development regarding FASD in Child Protection and Out of Home Care. Both in terms of children within the child protection system or at risk, and parents who may have FASD.
- Key points discussed in relation to the **work plan**:
 - Explore if further information on overall government funding of FASD activities can be provided.
 - A targeted study into research on facial features (to be captured as part of future prevalence discussions).
 - Look at consistent messaging relating to unplanned pregnancy.
 - A need for scoping on sustainable services and whether they are likely to continue in each jurisdiction.
 - s47F, noted this discussion point could be included as part of the open Action item **Potential working groups raised at last meeting (action from meeting of 13 September 2023)**:
 - Call for member volunteers to participate in a working group to *progress discussion on the topic of universal early childhood screening and intervention with a view to mapping existing child developmental health services*.
 - The Advisory Group to review status of actions and outcomes under the Strategic Action Plan.
 - It was noted that the ability to implement programs in schools is particularly difficult.
 - The ability to conduct a successful intervention is impacted by resource and time limitations of educators.
 - The work conducted by organisations like The Matilda Centre provides a good example where interventions are successful as they do not heavily impact on educator time and fit well with the curricula (leveraging years of relationship building).
 - Future opportunities need to ensure there is a focus on how a program will be delivered, not only what it is delivering.

ACTION 3	Secretariat to summarise feedback and provide Advisory Group with a proposed 2024 workplan.
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Item 5 – FASD prevalence update and presentation

Professor Elliot welcomed s47F, s47E(c) from the department's Health Economics and Research Division to present on their work on FASD prevalence methods.

Post presentation the group noted the benefit of updated estimates. s47F, s47E(c) thanked all involved noting the lengthy time period over which the prevalence study project was under development. s47F, s47E(c) noted that the prevalence information was confidential, and that further discussion needed to occur within the department and including with Minister Butler.

ACTION 4	Secretariat to provide Departmental presentation slides and information with meeting minutes (Actioned).
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Item 6 – Presentation from Curtin University

s47F, s47E(c) welcomed s47F, Research Fellow with the National Drug Research Institute.

- Presentation of PhD work on the Northern Territory alcohol-initiated restrictions and self-determination for First Nations people. Noting:
 - The importance of conserving how can we embed First Nations right to self-determination into Alcohol Policy.
 - Self-determination is not just consultation.
- s47F was thanked for the presentation.

ACTION 5	Secretariat to provide Curtin University presentation slides with meeting minutes (Actioned).
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Item 7 – Presentation from The University of Sydney

s47F, s47E(c) welcomed s47F from *The Matilda Centre for Research in Mental Health and Substance Use*.

- Presentation on *Positive Choices and Learning with FASD* work being undertaken by the Matilda Centre
- s47F, s47E(c) also welcomed s47F who joined the meeting for the presentation.
- Presenters noted that they have seen evidence of behaviour change through the *Learning with FASD* portal. There were also future opportunities in areas related to:
 - The gap in access to training
 - Professional development for educators, and
 - Raising awareness and reducing stigma.
- The group queried how the program has been put into schools and whether it is volunteer driven?
 - Presenters noted that there had been years of relationship building to ensure uptake.



- Presenters invited member thoughts and feedback on resources for *Positive Choices* and *Learning with FASD*.

ACTION 6	Secretariat to provide Matilda Centre presentation slides and information with meeting minutes (Actioned).
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Item 8 – Other business and next meeting

Other business and potential topics for the next meeting:

- Members discussed time constraints in the meeting.
- It was suggested that presentations be limited to a maximum of two going forward to ensure there is less time pressure on the meeting.

Next meeting date:

- The next meeting is proposed for 18 September 2024, subject to member availability.
- The Secretariat will write to members to confirm availability or alternative dates.

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NATIONAL FASD ADVISORY GROUP

Tuesday 19 November 2024 - 13:00 to 15:30 (AEST)
Video Conference Meeting

MEETING OUTCOMES

ATTENDEES

Members

Professor Elizabeth Elliott (Chair)

s47F

Proxies

s47F, FARE, attending on behalf of s47F.

s47F, Mental Health Commission WA, attending on behalf of s47F.

s47F, Health and Wellbeing Branch, NIAA, attending on behalf of s47F.

Department of Health and Aged Care (Health)

Ben Mudaliar, Assistant Secretary, Alcohol and Other Drugs Branch

s47E(c), s47F, Director, Alcohol and Other Drugs Branch

Secretariat, Alcohol and Other Drugs Branch

Apologies

s47E(c), s47F

s47F



1. Welcome

The Chair opened the meeting with an Acknowledgment of Country. She welcomed all members and noted all apologies.

The Chair welcomed new members:

- s47F, interim CEO for NOFASD, replacing s47F
- Ben Mudaliar, Assistant Secretary for the Department of Health and Aged Care's Alcohol and Other Drugs Branch, replacing Carolyn Paterson.

The Chair noted s47F will be joining after 2pm.

The Chair provided an opportunity for members to raise any conflicts of interest (COIs). No new COIs were declared.

ACTION 1.1: The Secretariat will circulate a COI form to new attendees.

2. Commonwealth Update

s47E(c), s47F, Director, Department of Health and Aged Care, provided an update on progress against FASD-related Budget commitments.

- As part of the 2024-25 Budget, the Australian Government announced a \$5 million extension to the Every Moment Matters campaign to support Australians to go alcohol free through all stages of pregnancy right from the moment they start trying to get pregnant.
- An additional \$0.9 million was also announced for the Tracking Cube project to support the provision of diagnostic services in Queensland, as well as in rural Queensland, specifically focusing on First Nations communities.
- Commitments that have been made by the Australian Government to extend FASD diagnosis, prevention and support activities continue to progress.
- s47E(c), s47F noted activities that are scheduled to cease between 30th of June 2025 and 30th of June 2026 are currently pending budget decisions by government.

ACTION 2.1: FARE to circulate impact report from International FASD Awareness Month.

ACTION 2.2: FARE to share Social Return on Investment Report once finalised.

ACTION 2.3: Department to present outcomes of FASD diagnostic funding over past three years to Advisory Group.



Update from the Foundation for Alcohol Research and Education (FARE)

s47F, FARE, provided an update on the National Awareness Campaign for Pregnancy and Breastfeeding Women work, including:

- the success of the Red Shoes Rock campaign as part of International FASD Awareness Month.
- the final report on the evaluation of the Every Moment Matters campaign, delivered by the University of Adelaide.
 - Over the three years of the campaign, there have been over 1 million visits to the website, 65 million completed video views, over 9.8 million people reached via social media, 9.8 million reached via audio listens through radio and podcasts, and 5800 PDF downloads from the website.
 - The campaign saw strong, statistically significant results and movement around campaign awareness, knowledge of risks around alcohol use during pregnancy as well as intention to abstain and an increase in the likelihood of partners intending to abstain, to support their partner's pregnancy.
 - FARE also received their social return on investment report, following the evaluation of the campaign findings. With every dollar invested in the campaign, it generated a \$9 social return on investment. FARE noted that this was a conservative estimate.

Members noted challenges in obtaining training for health practitioners, and suggested expanding the criteria for registration on the public health system, especially for First Nations psychologists.

Members queried the distribution of FASD services across jurisdictions and the need for further communication on the outcomes of these funded services. NOFASD noted that through representing parents, carers and individuals on a national basis, parity is an emerging and consistent issue. Opportunities for states and territories to contribute to ongoing, enduring, and sustainable funding of services was also raised by s47F.

The Department of Health and Aged Care will be reaching out to jurisdictional counterparts to map FASD-related funding and activities that are planned or underway to gain a better understanding of current initiatives, with the aim of reducing duplication of services and identifying gaps. The Department will look to convene a meeting with jurisdictions next year to discuss priority areas and responsibilities.

Members suggested convening a face-to-face Advisory Group meeting in Canberra to discuss future opportunities, current issues and plan strategically for the future.

3. Previous meeting outcomes and outstanding action items

s47E(c), Department of Health and Aged Care, provided an update on previous outcomes and outstanding action items in s47F, s47E(c) absence:

Outstanding Action Item	Next Steps
Indigenous Health Check MBS 715	Advisory Group Members are encouraged to provide any additional feedback around the importance or use case of including prenatal alcohol exposure within the health check, to the Secretariat by 25 November which will be collated and provided to the Taskforce ahead of finalisation to add to their existing findings.



	Once the review and findings are completed, the Secretariat will recirculate any final findings back to the group at the next meeting or beyond.
New Zealand and Advisory Group linkages	On hold due to competing priorities. The New Zealand Public Health Agency has confirmed that FASD is a top priority for their Minister with a refresh of the NZ FASD Action Plan ongoing. NZ have agreed to meet with Co-Chairs of the Advisory group to discuss topics of interest.
Australian Government response to FASD senate inquiry report	Members suggested that a matching exercise with the recommendations in both the Senate Inquiry report and the SAP may be useful to see what has not been addressed.
Potential working groups raised at last meeting (AI 2.2)	<i>FASD awareness and education for high school students</i> Key issues were offered to the Matilda Centre given their current funding to develop resources for secondary school members. The Secretariat will email members to arrange a short time to formally hold this session and capture key points to pass on to the Matilda Centre. This action item will be closed and replaced by a new action focused on holding such a session. <i>Universal early childhood screening and intervention with a view to map existing child developmental health services</i> Secretariat can reach out to relevant members to convene a first meeting of the working group to align progress with the work plan. Members suggested an audit of assessment services to understand how they are funded and their capacity.
Meeting with Minister Rishworth	No available date has been able to be identified. The Secretariat will continue to canvas potential dates.
Showcasing FASD through the Parliamentary Friends of Children and Adolescents group (AI 3.2 and 3.3)	The group, including doctors Monique Ryan and s47F, would be interested in meeting with the Co-chairs of the FASD Advisory Group, and they will advise of a suitable date in due course.
Secretariat to reach out to s47F to propose including an independent section in the revised guidelines on FASD diagnosis for adults (AI 5.1)	Closure of this item with a new action item created to invite s47F to present on the FASD Guidelines including on how the Guidelines address diagnosis in adults.
Members may consider convening their own working group to look at an approach to adolescents with FASD once [s47F] scoping review is complete (AI 5.3)	Marked as complete and transferred to the work plan to track and discuss in the future.



ACTION 3.1: Secretariat to invite the Matilda Centre to provide a brief presentation on their work, methods, and proposed evaluation at a future meeting.

ACTION 3.2: The Department will update the group once there has been new information around the submission of the guidelines and approval by NHMRC.

ACTION 3.3: The Department will update the group once there has been new information around the submission of the guidelines and approval by NHMRC.

ACTION 3.4: Secretariat to follow up with s47F on the scope of the review, the current stage of the publication process, and next steps.

ACTION 3.5: Secretariat to invite s47F to present s4 work at a future Advisory Group meeting.

4. 2024 Advisory Group Work Plan

Members discussed the draft FASD Advisory Work Plan and raised issues to be addressed as priorities in 2025. Members advocated for a mid-point review of the National FASD Strategic Action Plan, and noted that understanding the impact of the Action Plan could inform forward planning in its next iteration.

ACTION 4.1: The Secretariat will record any agreed priorities or issues to update and re-circulate the work plan after the meeting along with proposed next steps (as relevant).

ACTION 4.2: Members to provide feedback on what is needed for a mid-term review that the Department can provide as a recommendation to government, noting current scoping underway for the National Drug Strategy and its flow on effects to the SAP.

5. Presentation from s47F

The Chair welcomed s47F from Curtin University, who presented on the Development of the Solid Families Program.

- The aim is to support healthy pregnancies and reduce pregnancies that are exposed to alcohol and other drugs.
- The project provides a plan for providing culturally safe long term case management supports for eligible young First Nations women. The Solid Families program is modelled on an evidence-based model and has been widely replicated in Canada and the US.



- The project acknowledges the over representation of First Nations children and low engagement with mainstream services, which requires resources that are co-designed with community, to ensure it is culturally safe and focus on social and emotional wellbeing.

6. Presentation from s47F

The Chair welcomed s47F from Griffith University, who presented on Griffith's work with young children (3-7 years) with pre-natal alcohol exposure.

- s47F showed the progress of their Child Development Clinics, facilities fully funded by Griffith University, in diversifying clinical pathways and unifying clinical practice and research.
- The program of work has provided benefits through:
 - FASD awareness training to family support practitioners, child safety and others
 - upskilling our allied health work force to undertake diagnostic assessment - 2018-current
 - embedding research expertise in FASD
 - supporting the training of family practitioners in Adaption for FASD

7. Other business and next meeting

Members discussed screening and integrating alcohol history into existing systems and its possible inclusion as a mandatory field into government required documents.

- Members noted integrating the Audit-C and the options referral into the electronic maternity records, which was implemented throughout NSW. This collects the information at the time when it is most current.
- Members expressed that data on facial features would be useful across different ethnicities.

Members noted that 50% of pregnancies are still unplanned, so there needs to be different messaging around unplanned pregnancies and contraception.

- In Western Australia, the public education health promotion team are developing a new campaign, and the target group is unplanned and planning pregnancy, which is still in early development stages. Members noted that this could be adopted nationally to reduce duplication of investment.

Members emphasised that overriding legislation will be the biggest driver of behaviour change.

The next meeting date is proposed to be in March 2025, subject to member availability.

The Chair closed the meeting.

ACTION 7.1: Secretariat to circulate proposed dates for a March 2025 meeting.

ACTION 7.4: s47F to provide an update on the unplanned and planning pregnancy campaign in WA to the next Advisory Group.