

Parliament of Australia

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

Senate Community Affairs References Committee

**A submission from *FASD Research Australia*,
the NHMRC Centre of Research Excellence**



THE UNIVERSITY OF
SYDNEY



This submission is made by the Co-Directors of *FASD Research Australia*, the NHMRC Centre of Research Excellence, on behalf of its Chief Investigators and supporting partners.

FASD Research Australia, funded by the National Health and Medical Research Council (NHMRC), aims to contribute to the sustainable empowerment of communities, organisations and professionals to address Fetal Alcohol Spectrum Disorder (FASD) and reduce its compounding impact on affected children, their families and the wider community. It harnesses the extensive skills and experience of a multidisciplinary research and clinical team and their networks to support high-quality and high-impact research to address three key areas related to FASD: prevention, screening and diagnosis and management.

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FASD Research Australia appreciates the opportunity to provide a submission to this Inquiry. In this submission we focus on research and translation of evidence that addresses the terms of reference.

Terms of Reference

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

In a national Australian survey of 1103 women in 2006, 61.5% had heard about the effects of alcohol on the fetus and 55.3% had heard of Fetal Alcohol Syndrome. Although 92.7% agreed that alcohol can affect the unborn child, 16.2% did not know that the resulting disabilities could be lifelong. Of the women surveyed, approximately one third had drunk alcohol during a previous pregnancy and one third intended to drink during a future pregnancy (Peadon 2010). We do not know of any other more recent national data on community awareness.

Importantly, research shows that awareness of harms alone does not necessarily result in behaviour change and is less likely to influence drinking behaviour in pregnancy than a tolerant attitude to alcohol use in pregnancy, providing a challenge for public health awareness campaigns (Peadon 2010, Chambers 2005, LaChausse 2008). Despite efforts to spread a message that prenatal alcohol exposure may harm the unborn child there is evidence of ongoing and unacceptably high rates of alcohol use in pregnancy, at between 50-60%, Australian [National Household Survey 2016](#), Kingsland 2018, Muggli 2016, McCormack 2017).

A qualitative interview study with pregnant women in Australia found that blanket abstinence messages are often ineffective because the decision-making around alcohol use by pregnant women is influenced by their individual understanding and conceptualising of its potential harms. In addition, women's wider social and cultural environment impacts on their ability to abstain. Health advice should be tailored to women's individual and community contexts (Gibson 2019).

To determine community awareness in high risk populations, a community Knowledge, Attitudes and Practice (KAP) survey was administered in the Fitzroy Valley and Pilbara (Western Australia) communities. While a true pre-post prevention intervention evaluation of KAP was difficult to achieve because of multiple FASD related activities occurring over time, the trend is encouraging. In the Fitzroy Valley where the KAP survey was administered with 403 adult participants (~20% of the adult population) across the period 2015-2016, preliminary data indicate that more than nine in ten respondents were aware that drinking in pregnancy can harm the baby and held an attitude that women should not drink in pregnancy. Around half of participants had heard of FASD, however detailed knowledge about the effects of FASD across the life course was low (and inconsistent across the whole population). Most (8 of 10) respondents planned not to drink during their own or their partner's pregnancy, and 7 out of 10 indicated they would actively support a woman not to drink in pregnancy (Fitzpatrick J, personal communication). In the Pilbara, the KAP survey has been administered to 1,300 participants since 2016 and preliminary results indicate high rates of knowledge that alcohol in pregnancy is harmful, though lower levels of specific knowledge about FASD and its effects (Fitzpatrick J, personal communication).

The Pregnant Pause campaign is an initiative of the Foundation for Alcohol Research and Education (FARE) which encourages women to stop drinking during pregnancy and asks their partners, friends and families to pledge to go alcohol free in support. The intent of the campaign is both to support women

who choose not to drink during pregnancy and to raise awareness of the harms of alcohol use in pregnancy in the community. FASD Australia researchers have championed this campaign, which is run via a website and social media and has received funding from the Australian Government.

Recommendation:

We strongly support national, evidence-based, community campaigns to raise awareness of the risks of alcohol consumption during pregnancy and promote behaviour change. This could be stand-alone or embedded in a campaign to promote healthy pregnancy and should be government funded and evaluated.

The identification of population subgroups based on factors such as behaviour, risk, and attitudes towards alcohol is necessary. This will allow program developers and researchers to understand what awareness or health promotion campaigns should look like, and what they should set out to achieve. Without this first step, a campaign is unlikely to change attitudes or behaviour. Robust formative work and evaluation is crucial.

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

Antenatal clinical guidelines recommend that during initial and subsequent antenatal visits all pregnant women are assessed for alcohol consumption, advised of the potential risks of consumption, advised that the safest option is to avoid alcohol during pregnancy, and treated or referred if necessary. In a survey of 1363 pregnant women in the Hunter New England Region of NSW (July 2017 – February 2018) less than two thirds (64.3%) of pregnant women reported that they were asked about their alcohol consumption at the first clinic visit and just over one third (34.9%) received advice and referral appropriate to their self-reported level of alcohol consumption. (Doherty 2019a). Fewer than 10% of women received recommended care in subsequent clinic visits. Women who were less educated, of lower socioeconomic status and in their first pregnancy were more likely to receive evidence-based care at the first clinic visit. At subsequent visits younger women and Aboriginal women were most likely to receive appropriate care. Most (88.3–99.4%) women found all elements of recommended care highly acceptable. These findings suggest that the women who are most likely to continue drinking during pregnancy are older and of higher socio-economic status, and they are the least likely to receive appropriate advice. (National Household Survey 2016, Muggli 2016). It confirms that women want to be asked and advised about alcohol use in pregnancy and provided appropriate support. This NHMRC project is led by researchers from the University of Newcastle in collaboration with the University of Sydney and *FASD Research Australia*.

Our research shows that many health professionals are reluctant to ask about alcohol use in pregnancy, don't know what to advise or where to refer and are uncertain about how to treat (Payne 2011a and Payne 2011b). As a result, numerous evidence-based Australian resources have been developed to train and educate health professionals in how to ask and advise women about the harms of alcohol during pregnancy and breastfeeding, however their uptake by health professionals has been limited and few programs have been adequately evaluated.

Research is currently underway, through *FASD Research Australia*, that aims to identify the psychosocial determinants of alcohol use in pregnancy and which behaviour change techniques are best suited for prevention in Australia.

FASD prevention and health promotion resources

Menzies School of Health Research, in partnership with the National Aboriginal Community Controlled Health Organisation and researchers from *FASD Research Australia* and Telethon Kids Institute, developed and implemented a flexible, modular package of FASD Prevention and Health Promotion Resources (FPHPR) for health professionals. The FPHPR Package aims to prevent and reduce the impact of FASD in Aboriginal and Torres Strait Islander women presenting to maternity services and their children. Health professionals are provided access to culturally appropriate resources to enhance their capacity to provide accurate, consistent information on the risks associated with alcohol consumption during pregnancy. The resources are intended to be delivered via face to face training. This work was funded by the Australian Government Department of Health. [Further information and access the training modules.](#)

Women Want to Know

This project was initiated by the Foundation for Alcohol Research and Education (FARE) with input from researchers from Telethon Kids Institute and the University of Sydney, and aims to give health professionals the skills they need to discuss alcohol and pregnancy with women and provide sound advice. Resources include training, brochures, alcohol charts and videos. There are three free online e-Learning courses with Continuing Professional Development accreditation available for health professionals through the:

- Royal Australian College of General Practitioners
- Royal Australian and New Zealand College of Obstetricians and Gynaecologists
- Australian College of Midwives

This work was funded by the Australian Government Department of Health. [Access the learning modules](#)

FASD Hub Australia

The [FASD Hub website](#) provides a one-stop shop for Australian information about FASD for health and other professionals (including justice, education, child protection and disability services), researchers, policy makers and parents and carers. The FASD Hub, established in 2017, includes information for health professionals on alcohol use and pregnancy, asking questions about alcohol use, working with women with alcohol and substance use problems and FASD assessment and diagnosis. The FASD Hub is widely used and over 80% of evaluation survey respondents commented that it was extremely easy to use, was trustworthy and evidence based, and were likely to recommend the website. The videos produced by the FASD Hub have been viewed approximately 8500 times. The development and maintenance of the FASD Hub has been auspiced by *FASD Research Australia* and the University of Sydney. The work has been funded by the Australian Government Department of Health.

GPaskthequestion

General Practitioners are usually the first health professional to see a woman who thinks or knows she is pregnant. The '***GPaskthequestion***' project provides videos and resources to highlight the importance of asking all pregnant women about their alcohol use irrespective of age, socioeconomic status or ethnicity. This project was led by researchers from *FASD Research Australia* and Telethon Kids Institute and funded by the WA Primary Health Alliance. [Access the GPaskthequestion page and resources.](#)

WA Mental Health Commission Strong Spirits Strong Future

The Strong Spirit Strong Future campaign was an initiative of the Drug and Alcohol Office (now Mental Health Commission) to improve awareness among Aboriginal people, families and communities in metropolitan, regional and remote Western Australia of the harms associated with alcohol use in pregnancy to prevent the occurrence of FASD. In a partnership between the Drug and Alcohol Office and the Telethon Kids Institute free online modules were developed for human service providers. The modules provide an overview of alcohol use and why women drink, the impact of alcohol on the developing fetus, FASD diagnosis and prevention. [Access the package](#)

WA Health AUDIT-C Learning Guide

The Midwives and Women AUDIT-C Intervention Project was conducted by the Alcohol and Pregnancy & FASD Research Team at Telethon Kids Institute, in conjunction with *FASD Research Australia* and under contract from the WA Department of Health. The Learning Guide draws on a range of high quality education and informational resources developed nationally and internationally by those concerned with raising awareness of alcohol, pregnancy & FASD. The self-directed learning guide was initially developed for Australian midwives. The language has been amended to refer to health professionals more generally. [Access the Learning Guide](#)

eLearning modules to accompany the Australian Guide to the diagnosis of FASD

These modules, developed by clinicians from the University of Sydney and *FASD Research Australia*, are designed to provide clinicians with a range of information and include a module on 'an understanding of the risks and effects of alcohol use in pregnancy and how to assess alcohol use in pregnancy'. The modules were developed with funding from the Australian Government Department of Health to accompany the Australian Guide to the Diagnosis of FASD and have recently been updated. [Access the eLearning modules](#)

NSW Health resources : Stay Healthy in Pregnancy

NSW Health has developed resources for women, families and health and professionals addressing alcohol use in pregnancy and FASD. The resources – Stay Healthy in Pregnancy, it's worth it – were developed with input from a clinician researcher from *FASD Research Australia* and the University of Sydney, who also provided information sessions State-wide. They are freely available and include videos for youth, men, women, families and clinicians. [Access the resources.](#)

NHMRC Partnership Grant: improving the management of alcohol use in pregnancy

Hunter New England Health have led a practice changes initiative with the University of Newcastle, University of Sydney, FARE and researchers from *FASD Research Australia* to embed the Audit-C into e-maternity records to enable maternity service providers to ask about alcohol in a standardised way and provide advice and referral according to the estimated level of risk to the unborn child. Training and education on alcohol use in pregnancy and its harms was offered to all maternity staff in three health districts. Evaluation of the intervention is underway and preliminary data suggest that these interventions have informed and altered clinician practice. Data collection is ongoing for the primary outcome, namely receipt of information by pregnant women and resultant reported behaviour change. (Kingsland, 2018)

Make FASD History: a multi-site prevention program

This program takes a multifaceted approach to FASD prevention, supporting organisations and communities to use consistent information and messages about drinking in pregnancy and FASD utilising existing national and regional FASD prevention resources. It is funded by the Australian Government.

Telethon Kids Institute and *FASD Research Australia* staff are working with partners in two sites (Alice Springs and Newcastle) to address the risks associated with women's alcohol consumption, especially while pregnant. Based on local priorities and identified needs, this work involves:

- developing localised “models of care” for referral and support pathways
- delivering targeted localised health promotion activities
- providing community education opportunities
- facilitating workforce development opportunities, focused on screening and brief interventions during pregnancy.

Results from the research components of this project have yet to be published. Outputs will be available in 2020, and will contribute new knowledge about FASD prevention, particularly in relation to the justice sector and the alcohol and other drug sector; medical workforce (including AUDIT-C use) and community health promotion messaging for pre-natal alcohol exposure and FASD prevention.

Alcohol and breastfeeding

In conjunction with *FASD Research Australia*, a survey of 240 health professionals in Australia found that although most were aware of the 2009 [NHMRC Australian Guideline to reduce health risks from drinking alcohol](#) that specifically relates to alcohol and breastfeeding (Guideline 4B), there was little evidence of comprehensive adoption of the Guideline into everyday practice. Higher adoption rates were reported by child health nurses, midwives and GPs than by obstetricians and paediatricians (Giglia 2018). This study (and another of in-depth telephone interviews with maternal health practitioners (Giglia 2019) suggest that having a national policy guideline for safe alcohol consumption during lactation has not sufficiently promoted awareness of this topic among maternal health professionals to be useful as a potential strategy to support long-term breastfeeding. The new NHMRC Alcohol Guidelines, to be released in 2020, will provide an opportunity to improve guideline dissemination to health professionals, and provide advice about alcohol use both during pregnancy and breastfeeding.

Recommendations:

There is a need for ongoing education and training of a wide range of health professionals to ensure they have the skills and confidence to ask and advise about alcohol use in pregnancy and manage and refer women as required.

National endeavours including the FASD Hub Australia, Australian Guide to the Diagnosis of FASD and accompanying e-modules require sustained funding as recommended in the National FASD Action Plan.

Recommendations on pregnancy and breastfeeding from the revised NHMRC Alcohol Guidelines for Australia (expected release 2020) should be adequately disseminated and their reach evaluated.

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

There are recognised barriers to the implementation of clinical guidelines for the management of maternal alcohol consumption. These may prevent women receiving accurate, timely and culturally appropriate information and advice on alcohol use in pregnancy. Barriers identified in a survey of 31 antenatal service providers and managers in NSW included stress, aspects of the clinic environment, expectations of others, confidence, and difficulties in adapting to change. (Doherty 2019b)

Similarly, qualitative research conducted with 53 Australian health professionals (France 2010) found various barriers to the provision of accurate information existed. A number of these barriers were centred around presuppositions of the health professionals, namely, the assumption that the majority of women already know to reduce their consumption or to abstain and therefore don't require advice. Additionally, the decision of health professionals to provide advice was influenced by the specific socio-economic circumstances of each patient, with those of lower socio-economic status erroneously thought to be more likely to need advice. An additional barrier to discussing alcohol use in pregnancy with patients was the perception that consumption at higher, problematic levels is typically associated with extenuating circumstances which are beyond the capacity of health professionals to address, for example, socio-economic disadvantage, domestic violence and/or other substance use.

In another interview study, maternity clinicians also identified that there is a lack of resources, such as pamphlets, support staff, "history alerts" and "referral systems", which would be required if provision of information about alcohol consumption was to become routine. Further, they felt that depending on how long ago formal education was concluded, different clinicians believed in different alcohol messages, which were sometimes outdated. Midwives identified a lack of ongoing professional development to enable them to understand the current evidence in his area and concluded that this results in confusing messages for clinicians and pregnant women alike. (Muggli 2016) National data collection on alcohol use in pregnancy: A qualitative study. Report commissioned by the Australian Institute of Health and Welfare. Murdoch Children's Research Institute, 2016.)

In a study from Newcastle, NSW, which includes researchers from *FASD Research Australia*, less than two thirds (64.3%) of pregnant women at their initial antenatal visit, reported that they received an assessment of their alcohol consumption and just over one third (34.9%) received advice and referral

appropriate to their self-reported level of alcohol consumption since pregnancy recognition. Less than 10% of women received appropriate care at subsequent antenatal visits. Characteristics that significantly increased the odds of receiving all guideline elements at the initial antenatal visit included: less than university attainment (OR = 1.93; 95% CI:1.12, 3.34), not residing in an advantaged area (OR = 2.11; 95% CI:1.17, 3.79), first pregnancy (OR = 1.91; 95% CI:1.22, 2.99) and regional/rural service location (OR = 2.38; 95% CI:1.26, 4.48); and at subsequent visits: younger age (OR = 0.91; 95% CI:0.84, 0.99) and Aboriginal origin (OR = 3.17; 95% CI:1.22, 8.24). Each of the recommended care elements were highly acceptable to pregnant women (88.3–99.4%). (Doherty 2019b). A systematic review of implementation strategies to improve preconception and antenatal care for alcohol consumption is underway (Doherty 2019).

Audit of a child development service in Perth by researchers from Telethon Kids Institute showed that high time pressure, perceived low priority of alcohol use in pregnancy, lack of knowledge about how to ask, and a concern that raising the topic of alcohol use in pregnancy could damage the client relationship are additional barriers to asking about alcohol use in a prior pregnancy and the provision of advice. (Mutch 2013)

Recommendation:

Provision of evidence-based care should be addressed through use of evidence-based implementation strategies that identify and address barriers and improve patient-centred outcomes.

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

Australian Guide to the diagnosis of FASD

Clinical researchers from *FASD Research Australia* led development of the Australian Guide to the Diagnosis of FASD and the training in its use, and several have developed and provided clinical service in diagnostic clinics.

The [Australian Guide to the diagnosis of FASD](#) (and accompanying e-learning modules) was published in May 2016 by the Co-Directors of *FASD Research Australia* (Bower & Elliott 2016). In the development of the Guide there was an extensive systematic review, consultation, and discussion with organisations responsible for international guidelines. The Australian Guide to the diagnosis of FASD is harmonised with the Canadian Guidelines and similar to those used in Scotland and include some diagnostic tools developed by the University of Washington Guideline for the 4-digit diagnostic code which is widely used in the USA. (Astley 2004)

Based on the Australian Guide to the diagnosis of FASD, the diagnosis of FASD requires evidence of prenatal alcohol exposure and severe impairment in three or more neurodevelopmental domains. There are two diagnostic sub-categories:

1. FASD with three sentinel facial features
2. FASD with less than three sentinel facial features

FASD Research Australia through the University of Sydney subsequently received funding to disseminate and provide training on the use of the Australian Guide to the diagnosis of FASD to a range of health professionals, particularly paediatricians, psychologists, speech and language pathologists and occupational therapists. This work was funded by the Australian Government Department of Health. As part of this project, FASD Australia has developed a training package for FASD diagnosis that will be freely available and includes a comprehensive support document, a slide set, videos and access to other resources including the e-learning modules. This is modelled on the training provided nationally by *FASD Australia* and will enable clinicians throughout Australia to conduct health professional training themselves and hence increase capacity for diagnosis using the Australian Guide to the diagnosis of FASD.

Additional training in use of the Australian Guide to the diagnosis of FASD was led by *FASD Research Australia*, predominantly in Western Australia, Queensland and New South Wales. Some of this training was funded by Commonwealth and State governments. Similar training was provided by *FASD Research Australia* researchers from the University of Sydney in Auckland and sponsored by the New Zealand Ministry of Health.

Health professionals who complete this training are encouraged to register their clinic or service on the [FASD Hub Service Directory](#). The Service Directory can be searched by state/territory or type of health professional – opportunity for referral from another health professional or parents trying to find a service as part of management or therapy strategies.

University of Western Australia Graduate Certificate in FASD Assessment and Diagnosis:

In 2019 the Graduate Certificate in the Diagnosis and Assessment of FASD was launched through the University of Western Australia, as part of a FASD Models of Care grant provided by the Australian Government Department of Health, and administered by PATCHES Paediatrics. The course is delivered mostly online, allowing flexible delivery of course material. Many of the areas that need more clinicians trained in FASD are often least able to access workshops and training clinics (e.g. rural towns). The Graduate Certificate provides an avenue for clinicians to build their skills and become more confident in assessing and diagnosing FASD. This includes the provision of foundational material on FASD, assessment tools relevant to each discipline. and ethical and cultural considerations for diagnosis. The course builds on the e-Learning modules and other community workshops by utilising a multilayered approach to teaching , which provides a good opportunity for students develop a deeper understanding of FASD. The interactive lecture format allows for students to discuss the content with clinicians across varied disciplines.

There has been large interest in the course to date with over 80 unique expressions of interest, including 30 formal applications made in the last 12 months. In 2019, seven students completed the online lecture and assessment program of the course. Students were from metropolitan and regional WA, NT, QLD and Canada. The students come from a range of disciplines including Psychology, Speech Pathology, Occupational Therapy and Nursing. The students started placement activities in October 2019, joining multidisciplinary clinics through PATCHES (WA, Outreach and NT), Gold Coast and the Asante Centre in Vancouver.

The students who completed the coursework components of the unit have indicated that the course was beneficial for furthering their understanding of the complexity of FASD and has enabled them to feel more confident in supporting and managing clients with FASD in future¹.

3D facial imaging and epigenetic studies: potential tools for future diagnosis

Researchers from the University of Sydney and *FASD Research Australia* are currently contributing to research on 3D imaging for facial dysmorphology in FASD in projects led by Murdoch Children's Research Institute (Muggli 2017) and Curtin University and collaborating on epigenetic and genetic research in children with prenatal alcohol exposure and/or FASD (Fransquet 2016, Loke 2018). These novel approaches to diagnosis will likely contribute to earlier, more accurate diagnostic tools for future use.

Barriers and enablers to FASD diagnosis:

The diagnosis of FASD is complex, and ideally a multidisciplinary team of clinicians will assess individuals for prenatal alcohol exposure, neurodevelopmental impairment, dysmorphology and general physical health.

There are several dedicated FASD assessment services in Australia, some which run within broader child development services – Child Development Service FASD Clinic (Gold Coast), Sunshine Coast Child Development Service FASD Clinic, NSW FASD Assessment Clinic (CICADA) at the Children's Hospital at Westmead, Developmental Paediatrics at Monash Children's Hospital, PATCHES Paediatrics which has a clinic in Perth and outreach and justice diagnostic services across WA, NT, SA, Victoria and Tasmania, Central Australian Aboriginal Congress Child Development and FASD clinic, Goulbourn Valley Health FASD clinic, and SA Women's and Children's Health Service FASD clinic .

The Australian and New Zealand FASD Diagnostic Network was established in 2015 to coordinate, expand capacity and standardise the approach relating to FASD referral, diagnosis and management in Australia. A FASD Diagnostic Consortium has been operating since 2017 as part of a FASD Models of Care grant provided by the Australian Government Department of Health. This consortium has been successful in developing FASD referral and diagnostic pathways in WA, NT (Top End and Central Australia), Shepparton (VIC), Women's and Children's Health Service (SA), and Tasmania.

Funding for FASD assessment and diagnostic services in Australia is variable and often short term. Some clinics (Gold Coast and CICADA) receive State government funding, and Gold Coast has also received Australian Government support. Monash has recently received an Australian Government Grant for a year-long pilot program. Access is problematic and inequitable, with some clinics providing a free service open to any child and others incurring a significant fee, restricting access for some families. Most services are located in metropolitan settings, but some of these provide telehealth. Diagnostic multidisciplinary team (MDT) assessment for FASD is time-consuming and the current clinics, many of which do not have a full time MDT, have limited resources to cope with demand and have long waiting lists. For example, at the CICADA clinic, which has a full multi-disciplinary team present only one day per week, the predicted wait till first appointment is approximately one year. In addition to service provision some clinics e.g. CICADA have a remit for state-wide training and research.

¹ Further information and Alumna Story available at <https://www.uwa.edu.au/study/courses/graduate-certificate-in-the-diagnosis-and-assessment-of-fetal-alcohol-spectrum-disorders-fasd>

Clinicians from state-wide child development services across Australia have received training on assessment and diagnosis for FASD using the Australian Guide to the diagnosis of FASD from *FASD Research Australia*. There are also long wait times for children to access an initial assessment through such child development services. Individual health professionals have also participated in training programs and have registered their service (general and community paediatrics, speech therapy, psychology services) on the FASD Hub Service Directory. Patients managed by individual health professionals often face long waits for the psychology and other allied health assessments required to establish or refute a diagnosis.

Delayed diagnosis is stressful for families and during the wait for a clinic appointment a child's health and behavioural problems may escalate and impact significantly on their behaviour and academic performance with potential for contact with the justice system.

Data about the FASD diagnostic process were obtained from *FASD Research Australia* researchers at the University of Sydney for 42 families attending the NSW FASD assessment service (CICADA). The average time between symptom onset or parental concerns and diagnosis was 4 years and 72% had seen three or more doctors during this time. Of the children, 45% had been given an incorrect diagnosis and 27% received unnecessary tests or interventions. Many (73%) thought the diagnosis could have been made sooner and most attributed the delay to lack of health professional knowledge. The majority (98%) were satisfied with how they were told about the diagnosis but less than half were informed about parent support groups and 64% were offered psychological counselling while 69% believed this should always be offered (E Elliott, personal communication).

Recommendations:

Australia requires a nationally coordinated strategy to allow transparent, sustainable funding for FASD diagnostic services that will ensure equitable access and timely and comprehensive assessments for all young people at risk of FASD, at no or low cost to the family.

A sustained program of education and training is required to develop diagnostic and management capacity among a wide range of health professionals to work within and outside specialised FASD diagnostic services. This could be made available through a range of educational opportunities.

The current funding models and market mechanisms for Autism diagnosis may provide a helpful framework within which to increase diagnostic activity. These include national adoption of approaches to diagnosis, Medicare rebates through MBS that allow comprehensive assessment of children with complex neurodevelopmental disorders (including for medical, clinical/neuropsychological, speech and language assessments), and access to therapy. Individuals diagnosed with FASD and with significant functional impairment should be eligible and to apply for NDIS support.

To remain current and evidence based, the Australian Guide to the diagnosis of FASD, which has been in use since 2016, requires review and revision.

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

In a systematic review, 428 conditions co-occurring in individuals with FASD were identified, the most prevalent being congenital abnormalities and mental and behavioural disorders. The five comorbid conditions with the highest pooled prevalence (between 50% and 91%) included abnormal results of functional studies of peripheral nervous system and special senses (e.g. hearing and vision impairment), conduct disorder, receptive language disorder, chronic serous otitis media, and expressive language disorder. (Popova 2016a)

In Australia, national, prospective surveillance for FASD is facilitated by the [Australian Paediatric Surveillance Unit](#) and cases reported by paediatricians are entered into a National FASD case Register. The surveillance is ongoing, and the register is led by *FASD Research Australia* at the University of Sydney and funded by the Australian Government. In preliminary data from January 2015 to December 2017 we identified 280 children aged less than 15 years and diagnosed with FASD using the Australian Guide to the Diagnosis of FASD. Of these, 22% had 3 Sentinel Facial Features (SFF) and 78% had fewer than 3 SFF. All children had severe functional impairment in at least three neurodevelopmental domains. The two most commonly impaired domains were Executive Function, including Impulse control or Hyperactivity (81%) and Attention (79%). Impairment was found in Adaptive function, social skills or social communication in 73%; academic achievement in 73%; and speech and language in 70%. Cognition was impaired in 48%, Memory in 43% and Affect Regulation in 36%. In addition, 23% had microcephaly (head circumference < 3rd percentile) indicating a severe structural brain injury. A child diagnosed with FASD in Australia during the study period was most likely to be male (63%), aged 8.5 years (median), Indigenous (59%) and have past or current involvement with child protection services (74%). They were more likely to be living in an area within the middle two quartiles for socio-economic status (62%) and in foster/adoptive care (54%) rather than living with their birth parents (20%) or grandparents (15%). These data illustrate the chronic, complex clinical picture associated with FASD, the need for accurate and timely diagnosis, and the need for capacity building to enable ongoing medical, educational and allied health management (Zimmet et al, unpublished).

A chart review of 31 families seen in a FASD clinic in Australia found that, 26 children (84%) had a comorbid diagnosis, with 19 (61%) having a comorbid diagnosis of attention deficit hyperactivity disorder (Reid et al 2017a).

Researchers from the University of Sydney and *FASD Research Australia* are currently undertaking systematic reviews on structural and functional abnormalities associated with the ear and eye following prenatal alcohol exposure and in individuals with FASD.

In a study of fostered and adopted children undergoing a comprehensive multidisciplinary diagnostic evaluation, of the 156 with a diagnosis of FASD there was a 6.4% misdiagnosis rate. (Chasnoff 2015)

In the NSW FASD Assessment Service (CICADA), 45% of families said their child had previously been given an incorrect diagnosis and 27% had received unnecessary tests or interventions.

Recommendation:

As recommended in the National FASD Action Plan ongoing infrastructure funding is required for national surveillance and the National FASD Register to monitor trends in epidemiology, outcomes and co-morbidity in FASD.

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

Prevention

A scoping review (Adebiyi 2019) identified 32 prevention interventions for FASD internationally: 10 facility-based; 3 school-based; and 19 community-based. Three Australian studies were included (Payne 2011a, Payne 2011b, France 2014). Motivational interviewing was the most common strategy used in these studies, for reducing prenatal alcohol exposure and reducing FASD. All but two of the interventions were shown to be effective or showed promise.

A systematic review of randomised controlled trials of behavioural support interventions amongst women to prevent or limit prenatal alcohol exposure (Fergie 2019) found nine international studies. No Australian RCTs were identified. Four of the studies indicated positive results utilising a range of behaviour change techniques. Behaviour change techniques identified to be of a high level of efficacy included; action planning, behavioural contract, prompts/cues, self-talk, and provision of written materials.

A critical review of public health interventions (Crawford-Williams 2014) identified 7 studies for inclusion in the review, none of which was Australian. All but one study reported an increase in knowledge levels of participants following exposure to the intervention. Only four studies used consumption as an outcome measure, two of which found statistically significant decreases in alcohol consumption during pregnancy. However, the overall quality of the studies was assessed to be low to moderate and the methods utilised in the design of the public health messages were not described.

A systematic review of prevention interventions to reduce prenatal alcohol exposure and FASD in Indigenous communities conducted by *FASD Research Australia* (Symons 2018) found 10 studies; nine from the US and one from Australia. There was little evidence that the interventions were effective in reducing risk of prenatal alcohol exposure or FASD, primarily due to methodological limitations in all studies.

A narrative review (currently underway by researchers at Telethon Kids Institute associated with *FASD Research Australia*) of FASD prevention activities in Australia, aims to identify the processes program developers use to address prenatal alcohol exposure. This review will suggest recommendations and frameworks for future work.

Recommendation:

Development and evaluation of programs for FASD prevention (national/state and local), based on sound research, is needed, particularly given the methodological limitations of many of the studies included in the systematic reviews reported above.

Diagnosis

There is no international consensus on diagnosis of FASD, however the key elements (prenatal alcohol exposure, sentinel facial features and neurodevelopmental impairment) are common criteria. The Australian Guide to the Diagnosis of FASD is harmonised with the Canadian guideline (Cook 2016), and the 2019 [Scottish national clinical guide](#) is based on both the Australian and Canadian guides. The Australian Guide recommends use of some diagnostic tools developed by University of Washington, including the lip philtrum guide and facial software (Astley 2004).

The National Institute on Alcohol Abuse and Alcoholism (NIAAA) has recently convened an international expert group to establish consensus criteria for FASD for research purposes. This will likely ultimately lead to internationally agreed diagnostic criteria. The group, which includes *FASD Research Australia* Co-Director Elliott, met recently in Washington DC and is due to report in 2020.

Recommendation:

The Australian Guide to the diagnosis of FASD has been in use since 2016. It needs review and revision to incorporate new findings, ensure currency and adherence to best practice internationally.

Endorsement of the Australian Guide to the diagnosis of FASD by NHMRC should be sought at this time.

Management

The review by Adebisi (Adebisi 2019) also identified 41 management interventions for FASD internationally: 13 facility-based; 16 school-based; and 12 community-based. One Australian study was included (Reid 2017). A variety of management interventions were used in these studies, including those addressing social skills, educational skills, cognitive and motor performance and problem behaviours. Very few were focussed on early intervention, when opportunity for benefit is likely to be greatest. All but two of the management interventions were shown to be effective or showed promise.

Given the high rates of FASD identified in the Fitzroy Valley region of Western Australia, a self-controlled cluster randomised trial of the Alert Program to improve self-regulation and executive function in Australian Aboriginal children was implemented (2015-2018) by researchers at Telethon Kids Institute and *FASD Research Australia* (Wagner 2018). This research directly responded to a call to action from local stakeholders and families to implement and evaluate contextually and culturally relevant interventions to support affected individuals. It is the first time the Alert Program has been evaluated with an Australian or with a majority Indigenous population anywhere in the world. Locally, 74 school staff received self-regulation and Alert Program training with results showing significant improvements in school staff knowledge of these concepts. Thirty-two teachers from nine of the ten Fitzroy Valley primary schools delivered the program to all students in their classroom with 76% of children ($n = 296$) participating in data collection with parental consent.

While results of teacher and parent-rated questionnaires assessing changes to students' self-regulation and executive functioning skills were mixed, the project had a positive impact on most teachers involved in the research according to results of a teacher survey. Following the study, the majority of teachers who completed the follow-up survey reported being confident and effective at managing student needs and behaviours and changing their teaching and behaviour management practices after learning about the Alert Program. Moreover, most teachers agreed there were benefits to teaching the program to students at both a whole school and individual level and would recommend Fitzroy Valley schools adopting the program into the future. Data for the primary outcome, behaviour change in children, are not yet available.

In response to the high rates of FASD and associated challenging behaviours identified in remote Aboriginal communities during the Lililwan Project, a community-initiated project to implement the Triple-P (Positive Parenting Program) was conducted in the Fitzroy Valley by Marninwarntikura Women's Resource Centre (MWRC) in Fitzroy Valley and members of *FASD Research Australia* from the University

of Sydney (Andersson 2019). In the project (named Jandu Yani-U or for all families), delivery of Indigenous Triple P (including components of Stepping Stones) was demonstrated to be feasible in a very remote community context. 38 local 'parent coaches' were trained to deliver the program to parents and families and 38 families completed the program and almost 530 community members received informal skill training. Using validated measures, we demonstrated empowerment of parent coaches, parents and family members receiving the program. Benefits to parents and children included a significant: decrease in the parent-reported intensity and frequency of their child's challenging behaviours; increase in parenting skills and confidence; decrease in the number of parents or family members using dysfunctional parenting styles (such as over-reactivity); and a significant decrease in the number of family members who reported clinically significant symptoms of anxiety. The success of the program depended on it being community initiated and led; having a prior trusting relationship between the lead organization and the research team; adaptation of the coach and parent training and resources; two-way program delivery to include Aboriginal trainers; flexible program delivery; ongoing community consultation; and the provision of ongoing supervision and mentorship. This program is an integral component of a suite of programs led by MWRC to support healthy communities across the life span and is an entry point into engagement with other services. It is likely transferrable to similar settings. In the Fitzroy Valley 80 more families have requested access to the program following completion of the research project, which was delivered as part of an NHMRC grant and now requires ongoing funding.

An audit of child health services in remote communities with high rates of FASD and early life trauma suggests that services there are inadequate to address the chronic, complex needs of children with FASD and that better co-ordinated services and strategies to attract, train and retain health professional are required (Dossetor 2019).

Members of *FASD Research Australia* have recently received an NHMRC Partnership grant for a collaboration between the University of Sydney, Royal Far West and MWRC to develop and evaluate a model of care for FASD and Early Life Trauma that integrates telehealth and trauma-informed care.

Recommendation:

Management of FASD must be evidence-based and there is an ongoing need internationally for high quality trials of interventions to generate such evidence. Efficacy and cost-effectiveness of new interventions must be assessed before they are funded and/or recommended for use in Australia.

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

While educational contexts represent a key setting for early intervention and support for FASD, little is known about the way that FASD is recognised and managed within the Australian education system. The study being conducted by *FASD Research Australia* staff, entitled 'Fetal Alcohol Spectrum Disorder in the Australian Education System: Knowledge, attitudes, needs, and practices', aims to provide insight into the current understanding and practices regarding FASD in schools in Australia, as well as the needs of students living with FASD and the educators who work with them. Using an online survey, data were collected from a national sample of 343 school administrators and educators (teachers, specialist support staff, and ancillary support staff) and analysis is currently underway. Understanding the

knowledge, practices and needs of educators will inform the development of resources for educators as well as the implementation of management strategies in educational settings.

A scoping review, also being conducted by *FASD Research Australia* researchers, aims to synthesise all data on the experiences of people with FASD and their parents within the education context and included the screening of 2107 papers. Most of these focused on school-based interventions, academic outcomes/academic comparisons with other students, educators' knowledge and attitudes, and information for educators. 22 papers were identified, focused on the experiences of people with FASD and their parents within the education context. The majority of papers came from Canada and/or the USA. Recurring themes related to a positive educational experience included: the need for carers to advocate for their child, implementation and access to accommodations and services, communication between carer and teacher and a focus on the child's strengths.

The WA Department of Education has developed a web-based FASD resource Hub for WA education staff, to which *FASD Research Australia* researchers have contributed.

Fetal alcohol spectrum disorder (FASD) and complex trauma: A resource for educators for educators on FASD and early life trauma and its consequences was originally published in 2014 and updated in 2018 by experienced educators with some input from *FASD Research Australia*. The resource is intended to increase teacher's awareness of FASD and its management in the school system. The resource is freely available online and [downloadable](#) (Weston J & Thomas S 2018).

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

A systematic review estimated that the prevalence of FASD was 10-40 times higher in studies of children in care, correctional facilities, special education, specialised clinics and Aboriginal populations, than the general population. (Popova 2019). This systematic review included two Australian studies relating to Aboriginal populations: (Fitzpatrick 2015, based in a remote region of WA, finding a prevalence of FASD of 19%, and Harris 2003, reporting a prevalence of FASD of 4.7 per 1000 births in the NT). The systematic review also included a study conducted in the only youth detention centre in WA, which found a prevalence of FASD of 36% (Bower 2018).

To our knowledge, there have been no Australian prevalence studies among migrant communities or children in care, although the proportion of Aboriginal children and children living in out-of-home-care was high in a national FASD surveillance study (Elliott 2008). Current Australian Paediatric Surveillance Unit data show that of 280 children identified with FASD in a two year period, 59% were Indigenous and 74% had past or current involvement with child protection services. They were more likely to be living in an area within the middle two quartiles for socio-economic status (62%). Over half lived in foster/adoptive care (54%) rather than with their birth parents (20%) or grandparents (15%).

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

Individuals with FASD are disproportionately involved with the criminal justice system. A recent systematic review determined that the prevalence of FASD among adults in the criminal justice system is 19 times higher than the estimated global prevalence (Popova, 2019). A second systematic review concluded young people with FASD are 19 times more likely to be incarcerated than young people without FASD (Popova 2011).

Our recent research in Western Australia (funded by NHMRC and affiliated with *FASD Research Australia*) determined the highest known prevalence of FASD among young people in the justice system worldwide. Over one third (36%) of a representative sample of sentenced young people in detention (n=99) diagnosed with the disorder (Bower 2018). This prevalence rate is a conservative estimate, and would likely be higher if there weren't such challenges with collecting information about prenatal alcohol exposure and other relevant aspects of development for youth in the justice system (Freeman, 2019). Notably, only two young people had been diagnosed prior to the study, suggesting a critical lack of recognition and identification of FASD both within the justice system and community. In addition, 89% of all young people assessed met criteria for severe impairment in at least one area of neurodevelopment, regardless of whether they had FASD or not. Prior to this study, the highest identified prevalence of FASD among youth in custody internationally was 23.3% (Fast, 1999). With regard to FASD and adult justice populations, a recent Canadian study found 17.5% of a sample of adults in the criminal justice system (n=80) met criteria for a FASD diagnosis (McLachlan 2017). A further 13.8% of this sample were likely to have FASD however further case information was required to confirm these (McLachlan 2017). Among adults in the Australian criminal justice system, there is currently no published evidence regarding the prevalence of FASD.

Identification of FASD among people involved with the justice system is challenging, with no routine screening or assessment processes for FASD currently in place. A lack of awareness that an accused has FASD has implications for legal proceedings of the accused, as well as any mediation programs undertaken with victims (Fraser 2008). There is an urgent need to recognise FASD at the first point of engagement with the justice system, and ideally much earlier through their engagement with health, education and child protection services (Bower 2018). Information gained through a comprehensive neurodevelopmental assessment, such as that conducted by a multidisciplinary team as required for a FASD diagnosis (Bower & Elliott 2016), can be used to develop informed responses to an individual's immediate and future needs within both the justice system and community. As with other developmental disorders, children and adults with FASD are also at high risk of being complainants or witnesses of crime (Fraser 2008). While FASD prevalence among this population is not known, their needs in legal processes are also important to identify and respond to. They may struggle to comprehend concepts, such as 'victim', be reluctant to seek help, and have compromised communication and cognitive skills to provide a testimony and understand legal outcomes (Fraser, 2008). It is likely that they will require supports, such as intermediaries, to help facilitate their participation in legal and court proceedings (Hepner 2015).

Among individuals with FASD, a small but growing body of research has demonstrated that interventions targeted at specific areas of need can lead to improved skills that support daily living. These have included skills of language, literacy, social communication, attention, self-regulation and parenting, as

well as managing one's own health issues, and obtaining stable housing (Reid 2015). For justice-involved individuals with FASD, recent research has identified that interventions related to the development of communication skills (Kippin 2018) and fine motor and visual motor integration skills (Safe 2018) should be provided to enhance education and behaviour change programs. Interventions targeting communication, literacy and social cognition have been successfully trialled in justice settings in Australia (Martin 2018, Snow 2016), the United Kingdom (Gregory 2011) and the United States (Noel 2014).

Research has found that professionals who provide interventions with people with FASD for sex offences require specific training about FASD and the increased risk of inappropriate sexual behaviours, as well as approaches and resources for providing more effective interventions (Brown 2019). Adapting existing interventions, such as drug and alcohol programs, for individuals with FASD who are involved with the justice system is also important to increase potential for desistance (Currie 2016). Community partnerships and comprehensive multi-disciplinary team approaches with justice services are important for planning and implementing much needed interventions for those with FASD (Longstaffe 2017, Reid 2019 under review).

In our Western Australian research, comprehensive assessments for FASD were viewed by rehabilitation staff as a necessary, yet absent, aspect of service provision (Hamilton 2019a). Among staff caring for youth with high neurodevelopmental needs, it was noted that insufficient resources, inadequate staffing, inconsistent access to information about young people in their care and poor practices for information sharing result in staff not having the information they needed to plan services and interventions conducive to rehabilitation and consistent throughcare between detention and the community (Hamilton 2019b). Further research is required to better understand the adequacy of justice-related rehabilitation responses both in detention and in the community for people with FASD.

Research from Western Australia and Queensland has determined a need for justice, police and community services workforces to receive FASD training as part of their routine inductions and ongoing professional development (Douglas 2012a, Douglas 2012b, Hamilton 2019a, Mutch 2013, Passmore 2018). In Western Australia, our recent training intervention, *Reframe*, was developed as a response to this need, and was trialled and evaluated with over 100 justice professionals in 2018 (Passmore, 2019). The training significantly improved staff knowledge and attitudes regarding FASD, and increased their intent to use appropriate management strategies when engaging with someone who might have FASD or another neurodevelopmental impairment. In addition, over 93% of participants reported the presentation of information was easy to understand, the training was relevant to their needs, attending the training was time well spent, the training format was helpful, and they would recommend the training to others (Passmore 2019). Requests to access this training have been received from several state and federal government agencies, and community services who engage with young people and adults involved in the justice system.

Diagnosing FASD in the criminal justice system is complex, time consuming and expensive. In Western Australia and the Northern Territory there has been a substantial increase in court-ordered FASD assessments, for the purpose of informing sentencing, and informing therapy and support approaches to reduce reoffending. The WA Department for Communities funds FASD assessments through a FASD Assessment Tender process, and in the Northern Territory FASD assessments are funded by Territory

Families. Since October 2019, individuals involved in the justice system, who have been deemed eligible for NDIS funding, have received tailored FASD and trauma-informed therapy services in WA and the NT.

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

FASD is a preventable life-long neurodevelopmental disorder caused by alcohol exposure during pregnancy. The economic costs over the lifetime for a person born with FASD have been estimated at over CAD \$1 million, (Popova 2016b) or more recently over AUD \$33,000 per year. (Greenmeyer 2018) A recent study in Banksia Hill Youth Detention Centre in WA found that 36% of the young people there have FASD. (Bower 2018, Thanh 2015)) Approximate incarceration costs are \$250,000 per person per year just in WA. These figures are likely underestimates as they don't include all associated costs including the high social and emotional burden.

Given there is no cure, and existing therapies are in the development stage, this makes FASD one of the most expensive preventable diagnoses across the lifespan.

The recent FASD Strategic Plan outlines a series of policies for the prevention, diagnosis and management of FASD. Although the Government has provided around \$20M in direct funding for FASD-related activities since 2014, and another \$7.2M associated with the 2018-2028 FASD Strategic Action Plan, the budget allocated does not come close to funding the suggested plans. We recommend key elements of the strategic plan should be costed and budgeted for as long as FASD exists within the Australian population. This will take a concerted, long-term approach as well as significant initial investment. However, it should be clear that this would be an investment in health and well-being, as any prevention of FASD, or mitigation of the consequences, will have a substantial flow-on reduction of costs to government in the long term.

We recommend that funding be made available to complete key research projects critical for ensuring that future spending on prevention or services is evidence based and cost-effective. We provide a few key examples that might be considered:

1. Given the prevalence of FASD in Australia is unknown, a comprehensive prevalence study with active case-ascertainment in a general population would provide critical knowledge for planning future budgets for prevention, diagnosis and treatment, as well as for research. An informative prevalence study producing the highest level of evidence is likely to cost at least \$5 million.
2. The cost of FASD across the lifespan in Australia could be estimated using the unique opportunities provided through data linkage in WA and would allow better cost-effectiveness estimates in the future. This research could be completed with \$2 million.
3. Women who have long-term addiction to alcohol are at higher risk of having children with FASD. The Parent-Child Assistance Program provides three years of case-managed outreach support for these high-risk women. It has proven efficacy and is provided at over 50 centres in the US and Canada. Economically, it saved \$7 million CAD per year with 366 clients. (Thanh 2015) Based on the success of a small recent pilot in Perth we recommend a roll-out to state capitals and five major rural centres with associated research evaluation. At a cost per centre servicing 30 clients of around \$250,000 per year, and associated research evaluation, 12 centres (360 clients) would

require approximately \$3.5 million per year. Not counting improvements in client health, employment, legal situation etc., if more than one case of FASD was prevented for each 100 clients then this program would likely reduce government spending.

4. The evidence supporting the most effective public health approaches to prevention is generally not strong and further research in this area is needed.
5. By providing support (full-time support carer and therapy at \$120,000/year) to young people incarcerated in youth detention in WA with FASD (costing \$250,000/year), given 36% were diagnosed with FASD, cost savings of \$4.6 million/year could be realised in WA alone without taking into account potential benefits of being housed and treated in the community.

Recommendations:

Given these few examples, which cover only some of the proposed actions in the FASD Strategic Action Plan, we strongly recommend that proper costings and benefits be made for each of the area of the plan, and significant budgetary investments made by Government to reduce the impacts of FASD given the resulting economic and social benefits that would accrue.

While the methodological rigour of studies identified in systematic reviews is often poor, very little information has been offered to explain how program developers get to a solution about what is needed. Allocating appropriate time and resources with an emphasis on process is necessary to understand what approaches are most effective.

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

Fetal Alcohol Syndrome (a term which has not been used in Australia since the publication of the Australian Guide to the diagnosis of FASD in 2016) can be found in [List B of conditions eligible for support from the NDIS](#): Permanent conditions for which functional capacity is variable and further assessment of functional capacity is required. Congenital conditions – cases where malformations cannot be corrected by surgery or other treatment and result in permanent impairment but with variable severity.

The outdated term ‘Fetal Alcohol Syndrome’ which can be equated to the sub-category ‘FASD with three sentinel facial features’ is only part of the spectrum and probably omits two-thirds or more of individuals with FASD who, due to the timing of prenatal alcohol exposure, have severe neurodevelopmental problems in the absence of sentinel facial features.

Recommendation:

We urge the NDIA to update the reference to Fetal Alcohol Syndrome in List B and recognise the full spectrum of FASD. We also support the need for therapy and support for individuals with ongoing severe neurodevelopmental impairment with or without a formal FASD diagnosis.

Health professionals should be trained to ensure that FASD diagnosis is accurate and that assessment and management fully describe the ongoing impairments in the individual and the and services/supports required, to assist individuals and families to access support through the NDIS.

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

Support for parents and carers of children with FASD and for adults with FASD is provided through Australian support groups, such as NOFASD Australia and the Russell Family Fetal Alcohol Disorders Association.

Two Australian studies have reported on parent and carer challenges, health, and need for support (Reid 2019, McRae 2019).

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

Progress has been made in full or in part on many of these recommendations, although much remains to be achieved, most of which is reflected in the FASD Strategic Action Plan 2018-2028.

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

The [National FASD Strategic Action Plan](#) was developed following extensive and comprehensive nation-wide consultation with stakeholders, including health, justice, education and child protection professionals, consumers and community members, and government agencies. The Plan contains priority objectives relating to prevention, screening and diagnosis, support and management and priority groups. There is a governance framework and an evaluation framework.

The [Plan](#) was released in November 2018, with a promise of \$7.2M for its implementation. This funding is to be directed to: prevention (\$1.47M); screening and diagnosis (\$1.2M); inform schools and workplaces and support the justice and policing sectors (\$1.2M); solutions tailored to local communities (\$1.27M); to continue existing activities including continued development of the digital hub for information, tools, research and consumer support (\$1.55M).

In the 12 months since its release, a national FASD Advisory Group has been established and had their first meeting on 7 November 2019. To our knowledge, no funding has been allocated to the plan to date, although tenders have closed for the continuation and expansion of the FASD Hub, and grant opportunities were announced on 21 November for: FASD Consumer resources; review and dissemination of the FASD Diagnostic Tool; FASD employment services and criminal justice system resources; and an early childhood FASD identification guide. Additional announcements have since been made for grants on: FASD teacher and educational setting resources; Best practice resources for priority groups; and the Australian FASD Register. Allocation of this funding should be transparent, fair and

equitable. It is important to note that to address all the priority objectives listed in the Plan will require considerably more than \$7.2M.

Recommendation:

We strongly recommend that proper costings and benefits be provided for each of the priorities of the FASD Strategic Action Plan, and significant budgetary investments be made by Government to reduce the impacts of FASD given the resulting economic and social benefits that would accrue.

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

Mandatory inclusion of data on maternal alcohol use in the national perinatal data collection has been recommended for many years. Alcohol is a teratogen and we should routinely and comprehensively collect national data on its use in pregnancy, as a means of surveillance of exposure and to monitor prevention efforts. At the end of 2018, we understood that prenatal alcohol exposure was to be included in the National Minimum Perinatal Dataset, but more recent information suggests that three variables on alcohol use in pregnancy have been agreed for inclusion in the Perinatal Best Endeavours Data Set from July 2019 – i.e. not formally mandated. In Western Australia, collection of prenatal alcohol use has been a mandatory item on the Midwives Notification System since July 1, 2017.

The Hunter New England study (NHMRC Partnership) is trialling a practice change intervention that includes health professional education and inclusion of the Audit-C in electronic maternity records (Kingsland 2018, Doherty 2019b). Clinicians recording alcohol consumption in pregnancy are then provided with evidence-based management strategies and local referral pathways. If successful in improving antenatal practice and/or changing maternal behaviour during pregnancy this initiative will likely be introduced more widely in NSW and beyond.

(p) any other related matters

SUMMARY OF RECOMMENDATIONS

Priorities for research and research translation

In addition to the recommendations made above in relation to the Terms of Reference for the Inquiry, we have made recommendations regarding some priorities for research and research translation.

- National, state and local evidence-based, health promotion campaigns to raise awareness of the risks of alcohol consumption during pregnancy and promote behaviour change. These campaigns must be based on reviews of available research evidence, should incorporate only strategies found to be effective, and must be fully evaluated.
- Ongoing education and training of a wide range of health professionals to ensure they have the skills and confidence to ask and advise about alcohol use in pregnancy and manage and refer women as required.

- Recommendations on alcohol use in pregnancy and breastfeeding from the revised NHMRC Alcohol guidelines for Australia should be adequately disseminated and their reach evaluated.
- Ongoing education and training of a wide range of health professionals to ensure they have the skills and confidence to recognise those at risk of FASD, to diagnose FASD or refer for diagnosis, and to manage the harms of prenatal alcohol exposure including FASD.
- The Australian Guide to the Diagnosis of FASD, which has been in use since 2016, requires review and revision.
- Nationally coordinated strategy to allow transparent, sustainable funding for FASD diagnostic services that will ensure equitable access and timely and comprehensive assessments for all young people at risk of FASD, at no or low cost to the family. This will require evaluation of current services for the diagnosis and management of FASD across the lifespan.
- Capacity building of the education, justice and child protection workforce to better work with and meet the needs of individuals with FASD.
- Sustainable funding for national resources including the FASD Hub Australia and the Australian FASD Register and related surveillance.
- Provision of evidence-based care should be addressed through use of evidence-based implementation strategies that identify and address barriers and improve patient-centred outcomes.
- National funding models to increase diagnostic activity, including Medicare rebates for assessments by multi-disciplinary health and allied health professionals for individuals with complex neurodevelopmental disorders including those with prenatal alcohol exposure.
- NDIA to update the references to FASD as FAS and recognise the full spectrum of the disorder and also the need for therapy and support for individuals with neurodevelopmental impairment with or without a formal FASD diagnosis. Health professionals to be trained in appropriate formulation of reports that highlight the ongoing impairments and services/supports required by individuals with FASD through the NDIS.
- Comprehensive costings and benefits be calculated for each of the areas of the FASD Strategic Action Plan, with significant budgetary investments made by Government to reduce the impacts of FASD given the resulting economic and social benefits that would accrue.
- A comprehensive research project to estimate the economic costs of FASD in Australia, based on identified cases of FASD and their morbidity, mortality, service use, educational outcomes, and justice and child protection engagement over their lifespan. Such a study could be conducted in WA, using record-linkage.
- Assessment of the adequacy of justice-related interventions for youth and adults with FASD.
- Intervention trials of therapies with individuals with FASD who are in school or the justice system.
- Evaluation of case-managed outreach support for woman at high risk of alcohol use during pregnancy
- A study of FASD prevalence in a nationally representative general population.

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