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Effective approaches to prevention, diagnosis and support for fetal alcohol spectrum disorder

Senate Standing Committee on Community Affairs

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Contents

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Introduction

For more than a century, The University of Queensland (UQ) has maintained a global reputation for delivering knowledge leadership for a better world. The most prestigious and widely recognised rankings of world universities consistently place UQ among the world's top universities.

UQ has won more national teaching awards than any other Australian university. This commitment to quality teaching empowers our 52,000 current students, who study across UQ's three campuses, to create positive change for society. Our research has global impact, delivered by an interdisciplinary research community of more than 1500 researchers at our six faculties, eight research institutes and more than 100 research centres. Centres that have contributed to this submission include:

The Child Health Research Centre brings together researchers from a range of specialist areas to tackle some of the big issues in child health. We are working in partnership with doctors, nurses, health specialists, and parents to find new and better methods for promoting child health and for treating common childhood conditions, illnesses and injuries.

The Perinatal Research Centre is committed to improving perinatal health through world class biomedical and clinical research. Our multidisciplinary research team aims to translate research advances into clinical practice and better health outcomes for mothers and babies.

The TC Beirne School of Law brings together leading national and international scholars, distinguished Alumni and leaders of the legal profession. We are recognised as one of the top law schools in Australia through our commitment to the rule of law, dedication to excellence in research, the education of outstanding, socially responsible lawyers and the improvement of the law and legal institutions through our extensive and valued government, professional and industry relations.

The Centre for Chronic Disease is focused on chronic non-communicable diseases, with emphasis on disadvantaged, transitional and high-risk populations. We embrace clinical sciences, epidemiology, population health, genetics, morphologic students, as well as evaluations of potential preventative and therapeutic interventions.

The Primary Care Clinical Unit is involved in a wide range of teaching, clinical and research activities. The multidisciplinary team of General Practitioners and Primary Care Researchers are dedicated to improving the quality of care provided to patients in the community. One stream of research within our unit is focussed on addressing the health and social needs of urban Aboriginal and Torres Strait Islander peoples.

The Centre for Online Health investigates the potential role of new models of service delivery within the healthcare system. We assess the feasibility, efficiency and clinical effectiveness, patient satisfaction and economics of telemedicine in a range of settings.

The Queensland Brain Institute is focused on two of the greatest challenges of modern science: understanding brain function and the prevention and treatments of disorders of brain function. Our excellence in the field has played a key role in UQ attaining the highest possible score for neuroscience, one of only two universities in Australia to achieve this.

The Poche Centre for Indigenous Health brings together First Nation health expertise across the university and works collaboratively with First Nation organisations and health providers on improving health outcomes for First Nations people.

The Centre for Policy Futures aims to enhance the University's position as a key source of ideas and insights on the policy priorities that matter to Australia and the Pacific region. We provide policy engagement studies, as well as executive education involving academics across UA and beyond.

This submission represents the opinions of the contributing authors listed in this document. It does not necessarily represent an official position of The University of Queensland.

Summary and recommendations

Australia has some of the highest rates of prenatal alcohol use in the world (i.e. 36%).[1] One potential, and serious unintended consequence of this is fetal alcohol spectrum disorder (FASD), a lifelong disability. Prenatal alcohol exposure results in structural and functional alterations in fetal brain development and this is associated with a range of impairments, including cognition (i.e. general intelligence), learning and memory, executive functions and everyday life skills.[2] The earlier a child obtains an accurate diagnosis the better their long-term outcomes.[3] However, current misconceptions around FASD, combined with a lack of services, lack of practitioner confidence, and time it takes to complete a FASD assessment, contributes to under-diagnosis in Australia.[4] In the words of one caregiver, *"It shouldn't take years to get a diagnosis when we could have been helping our kids and not wasting time. An early diagnosis can change things for us.[5]"* Notably, not only does earlier diagnosis improve outcomes for children with FASD, every diagnosis increases awareness of the risks associated with prenatal alcohol use and prevents future alcohol-exposed pregnancies from occurring.

We thank the Senate Standing Committee on Community Affairs for establishing this inquiry into FASD, an under-recognised and consequently, under-diagnosed neurodevelopmental condition. The recommendations outlined in this document are:

1. Broader more inclusive messaging regarding the prevention of FASD across the whole of Australian society.
2. Development of any preventative approaches should follow the four key recommendations provided by Professor Nancy Poole, (1) do no harm; (2) take a gender transformative approach; (3) tailor initiatives to the audience; and (4) aspire to quality practice.
3. Increased resources to promote prevention with women and men of reproductive age.
4. Increased training and support for all antenatal care providers.
5. Increased access to continuity of midwifery care.
6. Increased access to specialist holistic support services for women who are experiencing difficulties with alcohol use during pregnancy.
7. Increased provision of FASD assessment and diagnostic services.
8. Expansion of FASD assessment and diagnosis beyond specialist clinics into a range of public settings, including community health, primary health and mental health services.
9. Inclusion of FASD content in university curriculums of all relevant health professionals.
10. Increased professional development opportunities, including mentoring and clinical supervision.
11. A wide-ranging review of the Australian Diagnostic Guidelines, to enable the development of a robust evidence-based, culturally and clinically relevant tool.
12. Given the high prevalence of co-morbid conditions routine screening for the presence of prenatal alcohol exposure is required in patients presenting with some of the frequently occurring comorbid conditions.
13. Children undergoing assessment for FASD should receive holistic assessment of their physical health, alongside assessment of their neurodevelopmental functioning.
14. Increased research is required regarding co-occurring physical health conditions, including valid direct assessments and monitoring over time to understand health trajectories.
15. Increased access to evidence-based prevention approaches.
16. Increased access to assessment and diagnostic services, incorporating more innovative ways to provide services, including those outside of traditional health settings and the use of tele-health.
17. Increased access to evidence-based intervention approaches and evaluation of outcomes with regard to our Australian communities.
18. Increased training and professional development for education professionals regarding FASD and how to effectively teach and support students.

19. Recognition of FASD as a verifiable disability within the education systems of Australia.
20. Significantly increased resources to meet the needs of children in out of home care. This must include routine screening for prenatal alcohol exposure and developmental concerns and access to timely and appropriate assessment, diagnostic and support services.
21. Promote First Nations leadership and partnerships to co-create programs to prevent the occurrence of FASD and support individuals, families and communities who experience FASD.
22. Prevention program development must not only focus on individual risk factors for FASD, but address discrimination in the system and aim to eliminate social factors such as poverty.
23. Interventions must be holistic and focus on supporting families to create a sense of belonging for those experiencing FASD.
24. Increased access to timely and appropriate neurodevelopmental assessments in the justice system, which can support effective judicial decision making regarding individuals with FASD.
25. Effective health, child protection and justice partnerships are urgently required to facilitate access to neurodevelopmental assessments.
26. Increased training and professional development for judicial professionals, particularly regarding how impairments associated with FASD can impact on engagement in the legal process.
27. Extension of Australian models of best practice in the justice system, including the neighborhood justice center and the Koori/Murri court models.
28. Uptake of international models of best practice in the justice system, including the Manitoba Youth Justice Program, the New Zealand Courts and widespread access to intermediaries.
29. More timely provision of assessment and diagnostic services, to facilitate access to NDIS.
30. Provision of training to NDIS providers to increase their ability to provide appropriate supports for individuals with FASD and their families.
31. Increased access to assessment, diagnostic and support services for adults with FASD.
32. Increased support for caregivers of children with FASD, including access to regular respite and interventions to support caregiver mental wellbeing and family functioning.
33. Significantly more research into all three of the key aims of the National Action Plan.
34. An additional prevention objective needs to be included in the Plan, focused on increasing the provision of evidence-based prevention approaches, including for individuals of reproductive age.
35. An additional objective needs to be included regarding priority groups of interest, to focus on improving outcomes for children in out-of-home care who are at significantly increased risk of experiencing FASD.
36. Given the high individual and societal costs associated with FASD, increased funding is required to effectively implement the National Action Plan.
37. Harmonization of prenatal alcohol use data across research and clinical settings to inform prevention efforts.
38. Investigation of data linkages to capture FASD diagnostic rates more efficiently and effectively.

Terms of reference

i. The level of community awareness of risks of alcohol consumption during pregnancy.

There continues to be a lack of understanding in Australia regarding the risks of consuming alcohol during pregnancy and consequently, a lack of awareness about FASD.[6] This is particularly concerning, given as aptly stated by previous Australian researchers, “women’s drinking behaviours during pregnancy are embedded in their broader cultural contexts[7]” (p.7). Recent Australian research indicates that although there may be increased general awareness that drinking alcohol while pregnant could be harmful, there are ongoing misconceptions. For example, that there are ‘safe periods’ to consume alcohol[6] and that different types of alcohol are safer than others.[6,7] These findings are consistent with reports from biological parents who have attended our diagnostic clinic in the past 12 months who stated that although they knew that ‘perhaps it was not a good idea to drink’ they were not aware of the extent of the potential negative impacts, including that they were not aware of FASD. Consequently, significantly more work is needed to increase understanding regarding the risks of consuming alcohol during pregnancy and specifically, educating the community about FASD.

When developing effective prevention approaches, four key ingredients have been suggested by Professor Nancy Poole, an international leader in FASD prevention:

1. **Do no harm**
   - Prevent further stigmatization, avoid negative gender and ethnic stereotypes and support dignity.
2. **Take a gender transformative approach**
   - Gender transformative approaches have dual goals of improving gender equity at the same time as improving health. Engaging and empowering men, women and other family members encourages shared responsibility in the prevention of FASD. Notably, research clearly indicates that women who have partners and family members who consume alcohol are more likely to consume alcohol while pregnant.[8]
3. **Tailor initiatives to the audience**
   - For example, tailoring to different age groups and communities. An example of this was the “be her pre-testie bestie” social media campaign that was tailored to connect with young people in New Zealand.[9]
4. **Aspire to quality practice**
   - For example, an important consideration is the content of the message. A previous Australian study assessed the impacts of different styles of prevention messages (i.e. threat appeal, threat appeal combined with self-efficacy and self-efficacy alone). Although the addition of self-efficacy was not found to increase the effectiveness of the message; it was found to decrease the negative impact of the message and therefore, decrease the potential for unintended effects. Therefore, a combination of self-efficacy and threat-based messaging was recommended. [10]

Recommendations:

1. Broader more inclusive messaging regarding the prevention of FASD across the whole of Australian society.
2. Development of any preventative approaches should follow the four key recommendations provided by Professor Nancy Poole, (1) do no harm; (2) take a gender transformative approach; (3) tailor initiatives to the audience; and (4) aspire to quality practice.

ii. 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.

iii. Barriers that may prevent women receiving accurate, timely and culturally/ethnically appropriate information on alcohol and pregnancy.

A major barrier to the prevention of FASD is that many women of child-bearing age are not getting access to timely prevention information. Currently, the majority of preventative efforts in Australia focus on women who are planning a pregnancy or women who are already pregnant. Given the high rates of unplanned pregnancies in Australia (i.e. 40%),[11] significant prenatal alcohol exposure can occur before a woman even knows that she is pregnant. This is supported by previous Australian research that documented high rates of prenatal alcohol exposure between the period from conception to pregnancy recognition (i.e. 60.6%).[12] This is also illustrated in the case stories of many of the biological mothers whose children have attended our clinic for FASD assessments. They reported that although they stopped consuming alcohol once they found out they were pregnant, unfortunately, given the binge drinking culture in Australia,[12] significant levels of alcohol exposure had already occurred.

Recent research indicates that Australian women are continuing to receive inconsistent messages regarding the potential risks regarding alcohol consumption during pregnancy.[13,14] This is both from their healthcare providers and their family and friends. Consequently, more work needs to be done to educate both health professionals and the community, as discussed in the previous section. As a woman's decision to continue consuming alcohol during pregnancy are influenced by both health professionals and the broader community it is imperative to draw upon evidence-based counters to these influences.[7,13] A previous Australian study concluded that "if an honest and factual message is delivered by an expert and supportive source, along with an acknowledgement of the uncertainty surrounding risk to the fetus following low to moderate alcohol exposure in utero, then the message is likely to be persuasive as well as minimise counter-argument" (p. 11).[10]

A major barrier reported from recent research for pregnant women, is the lack of access to individualised antenatal care that can facilitate appropriate and supportive discussion regarding alcohol use.[13,14] To date, caseload midwifery models (i.e. care from a known midwife throughout pregnancy, labour, birth and into the postnatal period) have been overlooked in the prevention of FASD.[15] Despite significant evidence regarding the benefits of caseload midwifery, access in Australia to this model of care is still limited. As stated in a previous publication on this topic "expecting women to change their health behaviour during pregnancy without continuity of care is akin to expecting improvements in mental health by visiting a different psychologist every time a person attends an appointment" (p.2).[15]

Additionally, midwives who we recently interviewed regarding this topic reported a lack of training in their university curriculums regarding asking about sensitive topics such as prenatal alcohol exposure and a lack of ongoing support and professional development in their workplaces. They also highlighted a range of other barriers to prevention, including a lack of effective services for women who are experiencing alcohol use issues during pregnancy.[14]

Recommendations:

- Increased resources to promote prevention with women and men of reproductive age.
- Increased training and support for all antenatal care providers.
- Increased access to continuity of midwifery care.
- Increased access to specialist holistic support services for women who are experiencing difficulties with alcohol use during pregnancy.

iv. Provision of diagnostic services in Australia including capacity, training, integration and diagnostic models in current use.

Provision of FASD assessment and diagnostic services in Australia has increased over the past few years, particularly the past five years.[4] However, significantly more are needed. A recent publication documented some of the challenges that Australian practitioners are currently experiencing implementing FASD assessments into their practice following training. Specifically, time constraints and the complexity of the assessment process hinders timely assessment.[4]

Given the high prevalence of FASD,[1,16-18] assessment and diagnostic services need to extend beyond specialist clinics and become part of routine practice across a wide range of settings. For example, a range of assessments for other neurodevelopmental conditions are provided by health professionals (e.g. autism spectrum disorder, attention deficit hyperactivity disorder). Then the specialist services can be appropriately reserved for the most complex cases. This could be facilitated through the inclusion of FASD content into the university curriculums of all relevant professionals (e.g. medical, psychology, social work, occupational therapy, speech and language pathology) and increased professional development opportunities for current health professionals, including access to mentoring and clinical supervision. Notably, at UQ we are currently developing a set of innovative clinician support tools, which can help inform the diagnostic process making it more easily accessible for health professionals working outside of specialist diagnostic settings.

The recently announced Commonwealth Department of Health funding to undertake a revision of the 2016 Australian Diagnostic Guideline[19] is welcomed and will provide an important opportunity to update and improve the guideline. This will provide the chance to improve the scientific rigour of the diagnostic process. The previous guide was based on the Canadian diagnosed guidelines,[20] without incorporation consideration of other approaches to diagnosis. Some areas for improvement of the Australian Guideline reported in a recent publication[4] included:

- The domains considered as part of the diagnosis for FASD
- Lack of a diagnostic spectrum (i.e. only children with severe impairments are identified, missing the majority of children who have moderate impairments).
- Assessment of people from culturally and linguistically diverse backgrounds.

Recommendations:

- Increased provision of FASD assessment and diagnostic services.
- Expansion of FASD assessment and diagnosis beyond specialist clinics into a range of public settings, including community health, primary health and mental health services.
- Inclusion of FASD content in university curriculums of all relevant health professionals.
- Increased professional development opportunities including mentoring and clinical supervision.
- A wide-ranging review of the Australian Diagnostic Guidelines, to enable the development of a robust evidence-based, culturally and clinically relevant tool.

v. The prevalence and nature of co-occurring conditions and of misdiagnosis of FASD.

Individuals with FASD experience a very high prevalence of co-occurring conditions, given that prenatal alcohol exposure can impact all the developing organs and biological systems. A previous systematic review and meta-analysis identified over 428 comorbid conditions.[21] We have recently undertaken four systematic reviews, documenting the increased risk for individuals with FASD of experiencing a range of chronic health conditions. There was evidence from preclinical studies that prenatal alcohol exposure was associated with poor metabolic health (including elevated blood glucose and insulin resistance),[22] cardiovascular problems (e.g. hypertension, cardiac dysfunction),[23] renal dysfunction (impaired electrolyte excretion)[23] and immune related outcomes (e.g. hypersensitivity following postnatal challenge).[24] However, there is currently a lack of clinical research, with only 5 out of the 128 studies that we included across all four reviews included children with a diagnosis of FASD.

We have recently undertaken an international survey of caregivers to ascertain up to date information regarding health problems that children with FASD are experiencing. Compared to caregiver data taken from the National Health Survey 2017-2018[25], caregivers of children with FASD reported significantly higher rates of eye conditions (e.g. congenital vision impairments), heart problems (e.g. congenital malformations, heart murmurs, tachycardia); eczema/dermatitis; kidney problems, thyroid problems, high blood pressure and urinary incontinence.[26] Consequently, caregivers are reporting that children are experiencing a wide range of health problems at higher rates than the general population. Given the wide range of possible comorbid conditions and complexities experienced by individuals with FASD this urgently requires increased research attention and a more holistic and integrated approach to clinical care.

Recommendations:

- Given the high prevalence of co-morbid conditions routine screening for the presence of prenatal alcohol exposure is required in patients presenting with some of the frequently occurring comorbid conditions.
- Children undergoing assessment for FASD should receive holistic assessment of their physical health, alongside assessment of their neurodevelopmental functioning.
- Increased research is required regarding co-occurring physical health conditions, including valid direct assessments and monitoring over time to understand health trajectories.

vi. International best practice in preventing, diagnosing and managing FASD.

There are a range of international examples of best practice that could be adopted in Australia to improve, prevention, diagnosis and management of FASD.

Prevention

The four part framework to prevention, is an evidence-based overarching approach that considers all the components that are required to facilitate effective prevention. This includes:

- *Level 1: Broad public awareness building, health promotion, linked to alcohol policy initiatives*
- *Level 2: Discussion of alcohol use and related risks with all women of childbearing years and their support networks.*
    - An example of best practice for this level of prevention is the highly effective CHOICES Program (Changing High-Risk Alcohol Use and Increasing Contraceptive Effectiveness Study). Numerous studies support the effectiveness of this program[27] and it has now been successfully piloted as an online intervention.[28]
- *Level 3 Specialised, holistic support of pregnant women with alcohol and other health/social problems.*
    - An example of best practice for this level of prevention is a multi-year (2017-2020) co-creating evidence program currently underway in Canada. These programs utilise harm reduction approaches and are relational, culturally appropriate, trauma-informed and holistic (i.e. set up as 'one stop shops' for services).[29]
- *Level 4: Postpartum support for new mothers and support for child assessment and development.*
    - An example of best practice for this level are nurse home visiting programs and/or paraprofessional advocacy or mentorship approaches such as the Parent-Child Assistance Program (PCAP). Women who engaged in these programs demonstrated a reduced risk of future alcohol-exposed pregnancies.[30]

Diagnosis

- We require increased access to diagnostic services. For example, in 2011 there were 44 multi-disciplinary clinics in Canada providing FASD assessment and diagnostic services,[31] this has likely increased now.
- More innovative and creative ways to expand the provision of assessment and diagnosis into a range of different settings (e.g. youth justice and chid protection) is needed. Additionally, the use of tele-health to undertake assessments has been utilised in Canada for approximately 10 years,[32] facilitating increased access to services in rural and remote areas.

Management

- There are a number of evidence-based interventions that have been developed internationally that could be adapted and implemented in Australi.[2,33] See Petrenko and Alto[34] for specific guidance regarding facilitating implementation of interventions. This includes: spreading awareness, reducing stigma, more diagnostic clinics, more professionals trained, systems should be revised to include FASD and help families qualify for services, increased dissemination of programs, which should be integrated into existing systems of care. Evaluating the use of international evidence-based practices will be important to ensure they meet the needs of our Australian communities.

Recommendations:

- Increased access to evidence-based prevention approaches.
- Increased access to assessment and diagnostic services, incorporating more innovative ways to provide services, including outside of traditional health settings and the use of tele-health.
- Increased access to evidence-based intervention approaches and evaluation of outcomes with regard to our Australian communities.

vii. Awareness of FASD in schools and the effectiveness of systems to identify and support affected students.

Awareness regarding FASD in schools varies. There are some examples of excellent practice, but overall our experience has been that there is limited awareness and understanding regarding FASD in the education system. Children with FASD can experience extensive difficulties in the school setting, due to their wide range of neurodevelopmental challenges (e.g. learning and memory, executive functions, attention and cognition). This has been found internationally[35] and in relatively recent Australian research.[36] For example, Australian caregivers of children with FASD reported a lack of knowledge and support from the education system and systematic discrimination through the absence of recognition of FASD as a disability.[36]

Without understanding and adaption in the school setting children with FASD are at high risk of disengagement or exclusion from the education system. There is urgent need for education systems in Australia to recognise FASD as a verifiable disability, so that children and young people can access the appropriate supports they need in the school setting to facilitate success.

Recommendations:

- Increased training and professional development for education professionals regarding FASD and how to effectively teach and support students.
- Recognition of FASD as a verifiable disability within the education systems of Australia.

viii. The prevalence of, and approaches to, FASD in vulnerable populations, including children in foster and state care, migrant communities and Indigenous communities.

Research suggests the prevalence of FASD may be higher in some specific populations, including children in out-of-home care (OOHC).[18,37] Children who enter OOHC need to be understood in ways that lead to positive outcomes. They have often experienced multiple forms of adversity, including poverty, neglect and abuse and their behaviour can be challenging. Ensuring caregivers are knowledgeable about FASD and its neurological impacts has been found to lead to better outcomes, including placement stability.[38] However, unfortunately in the current system in Australia foster caregivers are provided with limited information and support, which restricts their ability to effectively meet the complex needs of children in their care. Currently there is a significant lack of services in this sector, which is contributing to the ongoing trauma when the causes of misbehaviour are misunderstood. If initiatives were to be prioritised, FASD diagnostic and support services in the OOHC system must currently be considered as the most important.

Previous research has indicated a higher prevalence of FASD in some First Nation populations.[18] However, context is important and this prevalence must be considered within historical and ongoing frameworks of trauma and colonisation.[39,40] Alcohol use in First Nations populations vary greatly and binge drinking may be associated with increased prevalence of trauma and subsequent grief and depression.[41] Maternal alcohol use during pregnancy has been associated with social factors such as poverty, violence and stress all of which are associated with colonisation and corresponding trauma.[42,43]

Trauma that is attributable to colonisation must not only be considered as ‘historical’ because current systems also create ongoing trauma within First Nation populations.[44] Consideration of FASD in First Nation communities must include a ‘multi-dimensional perspective’ that focuses on intergenerational rather than individual risk factors of FASD.[39] Initiatives must focus on reducing inequity in the accessibility and responsiveness of health, education and social services as well as acknowledging ‘unresolved grief’ as a causative factor in alcohol use.[39]

Recommendations:

- Significantly increased resources to meet the needs of children in out-of-home care. This must include routine screening for prenatal alcohol exposure and developmental concerns and access to timely and appropriate assessment, diagnostic and support services.
- Promote First Nations leadership and partnerships to co-create programs to prevent the occurrence of FASD and support individuals, families and communities who experience FASD.
- Prevention program development must not only focus on individual risk factors for FASD, but address discrimination in the system and aim to eliminate social factors such as poverty.
- Interventions must be holistic and focus on supporting families to create a sense of belonging for those experiencing FASD.

ix. The recognition of, and approaches to, FASD in the criminal justice system and adequacy of rehabilitation responses.

There is persuasive evidence that individuals with FASD are over-represented within the justice system. This includes a study published in 2018 in Western Australia, which found 36% of young people met criteria for FASD.[45] But, the requirement to confirm prenatal alcohol exposure for the diagnosis renders this a likely underestimation. Of great concern, only two of the 36 children who met criteria in this study had a previous diagnosis.[45] The impairments individuals with FASD experience impact on their engagement with all areas of the justice system, including at the point of arrest, participation in interviews, fitness to plead, court proceedings, sentencing considerations, compliance with community-based orders, including bail and parole and the effectiveness of interventions.[46-48] Australian research has identified the urgent need for diversionary pathways in the context of FASD,[49] especially regarding young people who are from First Nations backgrounds.

In general there has been limited responsiveness in the Australian justice system regarding the needs of individuals with FASD. Of particular concern is the lack of knowledge, understanding and training received about FASD by justice professionals, including police, police prosecutors, lawyers, judicial officers and correctional service officers.[47] An additional limiting factor is the inadequate availability of timely assessments, to support court decision making processes. Without timely assessment, individuals are denied appropriate supports, which contributes to the cycle of re-offending. Importantly, to advance access to timely assessments and appropriate supports, effective health, child protection and justice partnerships are urgently required. There are a range of Australian and internationally models of best practice, which generally follow a solution-focused approach. Given that this type of approach aims to address the underlying causes of an offender's behaviour it has the potential to be more effective for individuals with FASD.[46]

Examples of best practice in Australia and internationally:

- Australia: Murri/Koori courts – operate in many parts of Australia. This court model ensures Elders and culturally respected First Nation people contribute to the court decision making in relation to sentencing and bail, leading to alternative responses that can respond to the needs of the person.[50]
- Victoria, Australia: Neighbourhood Justice Centre – Has been operating successfully for 12 years.[51] The magistrate takes a solution-focused approach, with various services co-located at the court (e.g. drug treatment, employment and housing) and the offender can be diverted to social support programs.
- *Canada: The Manitoba Youth Justice Program*[52] – is an example of a comprehensive approach to FASD in the justice system. This program has been in place since 2006. It ensures that young people get access to diagnostic services, provides recommendations to the judiciary, builds capacity within the family and community to enhance support for the young person and implements meaningful multi-disciplinary treatment plans.[52]
- *Canada: Manitoba FASD court* – A new court has opened this year for individuals with FASD.
- *New Zealand Youth, Rangatahi and Pasifika Courts:* Have implemented solution-focused approaches.[53] A key mechanism of these courts are Family Group Conferences, which include key family and support people alongside justice, health and educational professionals.[54]
- *New Zealand approach to fitness to plead:* The *Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003* (NZ) (IDCCR Act) and the *Criminal Procedure (Mentally Impaired Persons) Act 2003* (NZ) apply to both adults and children and govern fitness to plead. This legislation ensures that, if possible a person's family must be fully engaged in decision making and also provides a legislative framework for the court to order a needs assessment.
- *United Kingdom and New Zealand:* Access to communication assistants or intermediaries, often speech and language pathologists who help individuals to understand and effectively communicate during the legal proceedings. In Australia, intermediary schemes have been inconsistently implemented.

Recommendations:

- Increased access to timely and appropriate neurodevelopmental assessments in the justice system, which can support effective judicial decision making regarding individuals with FASD.
- Effective health, child protection and justice partnerships are urgently required to facilitate access to neurodevelopmental assessments.
- Increased training and professional development for judicial professionals, particularly regarding how impairments associated with FASD can impact on engagement in the legal process.
- Extension of Australian models of best practice in the justice system, including the neighborhood justice center and the Koori/Murri court models.
- Uptake of international models of best practice in the justice system, including the Manitoba Youth Justice Program, the New Zealand Courts and widespread access to intermediaries.

x. 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.

The current major barrier for families is access to timely assessment and diagnosis, which can then facilitate access to NDIS. Once families have been able to access assessments, anecdotal reports currently indicate that access to NDIS is variable, with some families reporting success and others not. However, a major current concern is the lack of availability of NDIS providers who are aware of FASD and therefore able to provide effective services for children and families. Caregivers are reporting a lack of knowledge and skills from NDIS providers they have attempted to engage with. Given the complexity and the range of impairments that individuals with FASD can experience, training is required to support NDIS providers to be able to effectively individualise their treatment approaches to meet the needs of those with FASD and their families.

The experiences of caregivers regarding NDIS providers, is consistent with previous research we have undertaken regarding health professionals more broadly, which indicates a significant lack of knowledge and skills regarding FASD screening, assessment, diagnosis and support.[5,36,55] For example, one caregiver reported *"do not write off mothers as being neurotic and that they wouldn't know what they are talking about because we are not professional or because you haven't heard about FASD so there is no such thing.[55]"* Another caregiver stated *"If you said to me do you think the medical profession has let our child down I would say totally.[55]"*

Recommendations:

- More timely provision of assessment and diagnostic services, to facilitate access to NDIS.
- Provision of training to NDIS providers to increase their ability to provide appropriate supports for individuals with FASD and their families.

xi. Support for adults with FASD and for parents and carers of children with FASD.

There is currently severely limited services for adults with FASD. This is also true internationally, with the majority of the intervention efforts to date focused on children.[2] Two examples of successful interventions provided internationally include the Step-by-Step program,[56] a mentoring based program and the PCAP program,[57] which was modified to accommodate the needs of clients with FASD. Investigation of the needs of the adult population with FASD, and subsequent service support is needed.

Increased attention is required regarding supporting caregivers of children with FASD. Through our clinical work, we frequently hear heartbreaking stories from caregivers regarding the negative impacts and the high level of distress they experience caring for children with FASD. Families are overwhelmed and present with relationship and family breakdowns, which can lead to children (biological, adoptive and foster children) being placed into residential care. These experiences of Australian caregivers are replicated in research that has documented the significant burden of care, including increased levels of stress, significant challenges, unmet needs and impacts on their quality of life.[58]

Of note is Canadian research that compared stress experienced by parents of children with autism spectrum disorder (ASD; i.e. a known stressful disability for parents) to parents of children with FASD, with the latter reporting significantly more overall stress. It has been suggested that the increased stress caregivers experience could be partly attributed to the lack of understanding and awareness regarding FASD in the community, which results in caregivers having to constantly explain their child's behaviour and advocate for their needs in every single context of their lives.[58,59]

The health and wellbeing of caregivers and families are clinically important factors leading to positive outcomes for children with FASD. As such, support for caregivers is vital and is an imperative area to target for increased services. Access to practical supports such as regular respite and also access to interventions that can support caregiver mental wellbeing and family functioning are important areas for consideration.

Recommendations:

- Increased access to assessment, diagnostic and support services for adults with FASD.
- Increased support for caregivers of children with FASD, including access to regular respite and interventions to support caregiver mental wellbeing and family functioning.

xii. The effectiveness of the National FASD Action Plan 2018-2028, including gaps in ensuring a nationally co-ordinated response and adequacy of funding.

The three key aims of the plan

We currently have limited research in all areas of the three key aims. Specifically: (Aim 1) we do not know what the prevalence of FASD is in Australia;[60] (Aim 2) We have some initial research in Australia regarding associated impacts of FASD, but much more is needed, including research regarding the economic impacts of FASD; and (Aim 3) We have very limited research regarding the quality of life of people living with FASD in Australia. Researchers at UQ published the first study this year investigating this area.[58] Support for increased research efforts are required in all three of these key areas to understand the current needs and enable progress to be tracked.

Priority objective – prevention

Current objectives focused on reducing access to alcohol and increasing awareness also needs to include an objective regarding increasing the provision of evidence-based prevention approaches, including for people of reproductive age. It is stated in the summary Prevention section that many pregnancies in Australia are unplanned, but prevention in this area has not actually been addressed in the current objectives.

Priority groups

Children and young people in out-of-home care have been overlooked in the Plan. Research clearly demonstrates that this is a special population at significantly increased risk of experiencing FASD.[18] As described in a previous section of this submission, this is an area that requires urgent attention in Australia.

Funding

The funding for the Plan is grossly inadequate (i.e. $9.2 million over four years). We are yet to see economic evaluations for Australia regarding costs associated with FASD. International data suggests that the costs are substantial. For example, New Zealand estimated productivity losses due to FASD-attributable morbidity and premature mortality was $NZ49 million to $NZ200 million. These costs do not include costs related to the education, health and justice systems. A systematic review of all studies assessing economic impacts of FASD calculated an average annual cost for children with FASD of $US22, 810.[61] Applying this estimate to the Australian context, even utilising an underestimated FASD prevalence rate of 2% would put the costs at over $AUD16 billion per year.

Recommendations:

- Significantly more research into all three of the key aims of the National Action Plan.
- An additional prevention objective needs to be included in the Plan, which focusses on increasing the provision of evidence-based prevention approaches, including for individuals of reproductive age.
- An additional objective needs to be included regarding priority groups of interest, to focus on improving outcomes for children in out-of-home care who are at significantly increased risk of experiencing FASD.
- Given the high individual and societal costs associated with FASD, increased funding is required to support research in this area and effectively implement the National Action Plan.

xiii. The need for improved perinatal data collection and statistical reporting on FASD and maternal drinking.

Continued improvements in data collection in all areas are required. This includes:

- As described in the previous section of this submission we are in critical need for accurate data on the prevalence of FASD in the Australian population. There has only been one active-case ascertainment study undertaken in Australia, which estimated the prevalence in a single remote community in WA.
- As has been recommended in Canada, harmonization of the approach to prenatal alcohol use data across birth cohort studies would be a powerful research strategy to inform prevention strategies.[62]
- Standardised screening and recording of prenatal alcohol use using the AUDIT-C in all relevant clinical settings would facilitate the collection of accurate information for FASD diagnostic processes and enable comparisons between clinical settings and research data.
- Diagnostic rates of FASD in Australia currently rely on paediatricians reporting to the Australian Paediatric Surveillance Unit. This will evidently be an underestimation of the true rates of diagnosis. Given the availability of electronic health data, data linkages should be explored to capture diagnostic rates more efficiently and effectively.

Recommendations:

- Harmonization of prenatal alcohol use data across research and clinical settings to inform prevention efforts.
- Investigation of data linkages to capture FASD diagnostic rates more efficiently and effectively.

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