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Emerging Minds response to Senate Inquiry

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

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About Emerging Minds

Emerging Minds is a non-profit organisation which has been dedicated to advancing the mental health and social and emotional wellbeing of Australian infants, children, adolescents and their families for over 20 years. Emerging Minds develops mental health policy, services, interventions, training, programs and resources in response to the needs of professionals, children and their families. We partner with family members, national and international organisations to implement evidence-based practice in the Australian context. Emerging Minds is currently responsible for leading the National Workforce Centre for Child Mental Health.

Emerging Minds conceptualises child mental health in 10 Guiding Principles (next page). These are key elements which consider the child as a whole and underpin the work we do.

We recognise that the best way to support child mental health is through early intervention and prevention. We apply a public health approach to infant and child mental health through increasing child mental health literacy and workforce capacity building, which supports early intervention and prevention. The importance of a focus on the mental health of infants and children has been reinforced by contemporary research and there has been a gradual recognition that services need to better address mental health in the early years.

Emerging Minds has a focus on supporting workforces in both child- and adult-focused services. We recognise the importance of the parenting role for adults experiencing vulnerabilities, and the impact of adult vulnerabilities on children’s social and emotional wellbeing. Emerging Minds’ training and resources are freely available to help workers increase their skills, knowledge and confidence around supporting child mental health.

Relevance of this inquiry to Emerging Minds:

The range of difficulties which may be experienced by a child or parent with Fetal Alcohol Spectrum Disorder (FASD) mean the impact of the disorder is intrinsically linked with the mental health and wellbeing of children in families affected by FASD. These physical, emotional and cognitive difficulties can make it harder for a child to successfully negotiate their learning and social environments, negatively impacting their development.

Greater understanding, along with quality support for children in families affected by FASD can make it easier for children to experience positive and inclusive interactions within their broader social networks. Emerging Minds offers practitioners and organisations a suite of freely available workforce development resources on FASD.

Guiding Principles

1. **Children and their local ecology**
   The wellbeing of infants and children depends on their social and environmental contexts, more so than with any other age group. Infant and child mental health is best understood within a framework that accounts for individual child characteristics, family strengths and vulnerabilities, and broader social and economic factors.
2. **Relationships matter**
   Relationships play a central role in children's social and emotional development and mental health. From the time of birth, children need stable and responsive relationships with caring adults.
3. **Prevention and early intervention**
   A focus on preventing or intervening early in the progression of mental health difficulties not only benefits infants and children but also creates a solid foundation for health outcomes later in life, making it a long-term investment in the future of Australian society.
4. **Strengths and vulnerabilities**
   At any point in time, children's mental health is influenced by a mix of strengths and vulnerabilities. Effective practice focuses on enhancing and promoting strengths, while accounting for vulnerabilities.
5. **Resilience**
   Resilience is the ability to recover, adjust to, or grow after an adverse event or period of adversity. The single most important factor for developing resilience in children is the presence of at least one committed and supportive relationship with a parent, caregiver or other adult.
6. **Trauma informed**
   Trauma involves experiences that overwhelm a person's ability to cope. Trauma-informed care is a framework for service delivery based on an understanding of the effect of trauma on individuals, their coping skills and service needs.
7. **Developmental perspective**
   Children are not small adults; they have particular emotional, social and physical capacities and needs. To be effective, service delivery must be designed around infant and child developmental stages.
8. **Cultural and spiritual identity**
   For some children and families, cultural and spiritual identity is central to health and wellbeing. Service provision is more effective if it respects and incorporates service users' cultural and spiritual understandings.
9. **Children's rights**
   Upholding and protecting children's rights is essential to promoting their mental health. It is every adult's responsibility to uphold and fulfil the rights of children.
10. **Child, family and practitioner voice**
    Services designed collaboratively with children, families and practitioners tend to be more effective, more acceptable to the individuals and families using the service, and more relevant to their local context.

10 Guiding Principles of Children's Social and Emotional Wellbeing taken from Keeping child mental health in mind: A workforce development framework for supporting infants, children and parents.

Summary of recommendations

Workforce Development – Ensuring workers in child protection, AOD services, primary healthcare and other sectors can:

- ask women about alcohol and pregnancy in non-judgmental ways that support honest reporting and ongoing retention with the service
- provide clear messaging and information
- be confident to provide best practice responses to women who are pregnant or planning pregnancy (and their partners) and who use alcohol.

Workers in child mental health services, disability, child protection, health care, education, and other sectors working with children and families, including post-diagnosis have:

- a clear understanding of the range of impacts and needs of children with FASD
- improved capabilities in regards to supporting children with FASD
- specific approaches for working with parents who have intellectual disability, FASD or other neurodiversity
- skills and knowledge on how to interact and communicate with children with neurocognitive and language difficulties, and intellectual disability.

Workforce development resources around supporting people with FASD will ideally be co-designed with children and their families and advocates.

Consistent data and record keeping in child protection about maternal alcohol use, and in AOD services about pregnancy to facilitate diagnosis. Nationally consistent data collection to inform population level interventions.

Public awareness messaging – campaigns with clear messaging about alcohol and pregnancy and FASD, to directly inform women of childbearing age, as well as men in the general public. Clear messaging also provides clarity for workforces such as primary health professionals, child protection staff and drug and alcohol workers, delivering appropriate information, routine screening, treatment and support.

Collaborative and integrated multidisciplinary care models which recognise the lifelong nature and range of impacts of FASD; the need for children and adults with FASD to engage in multiple services; and the value of multidisciplinary evaluation to identify the difficulties and shape accommodations for children with FASD. An adequately funded key worker model as a means to coordinate ongoing multi-systemic support needs of children after diagnosis.

Recognise and further explore the role of men in exposure to alcohol during pregnancy and integrate men as a target audience for prevention and reduction approaches. Men are provided with accurate messaging around alcohol in pregnancy and their role in supporting pregnancy outcomes.

Further research, understanding and collaboration with communities around alcohol in pregnancy and FASD among Aboriginal communities.

Policy as a driver for practice change and public awareness– recognise FASD as a disability. NDIS models which support therapeutic relationship building and collaborative multidisciplinary care. Recognise in the National FASD Action Plan the broader range of roles where understanding and responding appropriately to FASD has potential to improve child mental health.

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Response to selected Terms of Reference

We have responded below only to items of the Inquiry's Terms of Reference which are relevant to Emerging Minds. Our responses are framed with a focus on child mental health.

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

Emerging Minds will not be responding to this item from the Terms of Reference.

(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

- Research indicates that public health messaging in Australia has not been clear enough about alcohol consumption during pregnancy. Women are still not consistently and clearly being given the health message:

  "If you're pregnant, breastfeeding or planning to have a baby, the safest option is to not drink alcohol at all." (Foundation for Alcohol Research & Education, 2014).

- This has resulted in health and social service professionals not adequately exploring or screening for alcohol use with pregnant women, women who are planning a pregnancy or those who are breastfeeding (Breen, Awbery & Burns, 2014). These women are also not receiving appropriate information, treatment and support (Foundation for Alcohol Research & Education, 2014).

- Studies show that integrated care and a multi-agency approach are key in supporting pregnant women who continue to use alcohol at risky levels. These strategies can facilitate early access to pregnancy care, which is correlated with positive pregnancy outcomes (National Institute for Health Care Excellence (NICE), 2019; Taplin, Richmond & McArthur, 2014).

- Many unintended pregnancies could be avoided simply by providing women who use alcohol at risky levels with up-to-date information about contraception. Information about contraception, sexual health and pregnancy, and parenting support are not routinely offered; yet women who drink alcohol during pregnancy are less likely to have planned the pregnancy (Breen, Awbery & Burns, 2014).

- Decisions about alcohol use during pregnancy planning and pregnancy are currently seen as solely the responsibility of women. However, growing evidence suggests that paternal alcohol use also has various impacts on these decisions, as do broader societal messages Taplin, Richmond & McArthur, 2014; McBride & Johnson, 2016a).

Implications for child mental health:

FASD is a lifelong disability that is caused by foetal exposure to alcohol in utero and can be completely prevented. Accurate health messages and advice are required to assist women to make informed choices.

Recommendations:

- Clear public messaging and workforce development to ensure primary health professionals, child protection staff and drug and alcohol treatment services staff can provide appropriate information, routine screening, treatment and support.
- Systems change to facilitate integrated care and coordinated care plans between drug and alcohol treatment services, maternal health, pharmacological support and child protection. This will help to support positive pregnancy outcomes and facilitate diagnosis if FASD is suspected.
- Information about contraception to be routinely provided to women of childbearing age who attend drug and alcohol treatment services, to mitigate the higher risk of unplanned pregnancy in this group.
- Men to also be provided with clear messaging about alcohol use in pregnancy and strategies around how they can modify their behaviour to support their pregnant partner.

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

- Stigma, shame, guilt and fear of judgement are significant barriers to women seeking treatment for alcohol dependence and/or pregnancy care (Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG), 2018; Burns & Breen, 2013).

- Practitioner judgement, attitudes and lack of expertise/confidence in engaging, retaining, supporting and making linkages to pregnancy care for pregnant women who drink at high risk levels are also significant barriers (Burns & Breen, 2013; National Drug and Alcohol Research Centre, 2019).

- Fear of child protection referrals and of infants and perhaps other children being removed at birth can prevent women from seeking pregnancy care and/or substance use treatment early in pregnancy. Sometimes this means the first presentation is when women are in labour (Burns & Breen, 2013).

- Complex psychosocial issues such as family and domestic violence (FDV), mental health difficulties and post-traumatic stress disorder (PTSD), intergenerational disadvantage/trauma, financial disadvantage and housing instability are also frequently significant barriers for women who continue to drink in pregnancy (Burns & Breen, 2013; RANZCOG, 2018).

- Partner alcohol use is another barrier. Male partners play a significant role; studies have found that women who drink at risky levels often have male partners who also drink heavily. Men can also be influential in whether or not women seek and attend treatment; the risk of domestic violence increases with increasing levels of alcohol consumption (Taplin, Richmond & McArthur, 2014 p.14; McBride & Johnson, 2016a; Swan, Farber & Campbell, 2000 cited in Braaf, 2012; McBride & Johnson, 2016b).

Implications for child mental health:

When women experience barriers to seeking support for alcohol use and pregnancy, they are less likely to receive the health care and support that they need. This can directly impact their children through negative pregnancy outcomes such as FASD.

Recommendations:

- Workforce development to ensure that primary health professionals and drug and alcohol treatment practitioners provide non-judgmental support, and are confident in being able to provide a best practice response to pregnant women who use alcohol.
- Better exploration of male partners’ role in supporting pregnancy outcomes, and workforce development to ensure that men are also provided with accurate messaging around alcohol use in pregnancy and how they can support women.

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

Emerging Minds will not be responding to this item from the Terms of Reference.

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

- Recent estimates on the prevalence of FASD in Western societies range from 1 per 100 live births (Stade et al., 2008; Thanh, Jonsson, Salmon, & Sebastianski, 2014) to as high as 2-5% of the population (May et al., 2009; Roozen et al., 2016), with the most recent estimate placing the prevalence in Western communities at 4% (Flannigan et al., 2018).

- FASD is associated with a range of mental health difficulties (McLean, 2019a). The most recent edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM V) has flagged the neurodevelopmental impact of prenatal alcohol exposure as a condition that warrants further consideration for inclusion as a mental health condition in its own right (American Psychiatric Association, 2013).

- FASD appears to occur at a similar rate to many other mental health conditions – for example, the prevalence of anxiety disorders has been estimated at 6.9%; depression at

2.8%; and attention deficit hyperactivity disorder (ADHD) at 7.4% (Lawrence et al., 2015). It appears to be more common than developmental conditions such as autism spectrum disorder (ASD) (estimated to occur in 1.52% of the population) and 28 times more common than Downs Syndrome (estimated to occur in 0.14% of the population) (Flannigan et al., 2018; Nash & Davies, 2017; Popova et al., 2017).

- FASD is associated with a range of cognitive vulnerabilities that can contribute to mental health conditions if appropriate accommodations are not in place (McLean, 2019).

- FASD co-occurs with a range of mental health disorders and shares common features with other childhood mental health concerns (Anderson et al., 2017; APA, 2013; Nash, Koren, & Rovet, 2009; Nash et al., 2006). It is associated with high rates of mental health comorbidity. The profiles of many children suspected of having FASD could also meet the screening criteria for conditions such as ASD, ADHD, oppositional defiant disorder (ODD), language or communication difficulties, or learning difficulties (Anderson et al., 2017; APA, 2013; Nash, Koren, & Rovet, 2009; Nash et al., 2006).

- A study of 547 foster and adoptive children referred to a FASD clinic found that 80.1% met the criteria for FASD, but the diagnosis had previously been missed (Chasnoff, Wells, & King, 2015). In this same study the rate of misdiagnosis (i.e. children that had been incorrectly diagnosed with another mental health condition) was 6.4%. The flow-on implications of misdiagnosis may be considerable, as diagnosis will often determine the level and type of support offered to children and families throughout their lives (Anderson et al., 2017).

Implications for child mental health:

FASD is a significant issue for child mental health workers. Early support is needed for children who are living with FASD and emerging mental health and behavioural concerns.

Recommendations:

- Workforce development for child mental health specialists to build capacity to recognise FASD; to deliver evidence informed mental health supports; and to develop their capacity for differential diagnosis.

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

- FASD is a condition that can affect all aspects of cognitive development. It is characterised by its impact on multiple developmental domains, including physical- cognitive domains, language development and capacity for sensory regulation (Bower & Elliot, 2016; McLean, 2019b).

- Children who are living with FASD are best supported by a multidisciplinary assessment and diagnostic team (Bower & Elliot, 2016; McLean & McDougall, 2014). A multidisciplinary approach ensures a comprehensive assessment and understanding of how all aspects of a child's cognitive, language and physical development are affected by prenatal alcohol exposure. Comprehensive multidisciplinary assessment is needed in order to develop support that is tailored to the child's unique developmental profile and strengths (McLean & McDougall, 2014).

- FASD is a condition that is characterised by a diverse range of neurocognitive and behavioural difficulties. This variability in behavioural and neurocognitive functioning means that, at this stage, screening tools based on behavioural presentation are potentially problematic (e.g. may lead to possible false positives; aren't sufficiently linked to direct practice recommendations). At present, multidisciplinary assessment represents best practice approach to this condition (Bower & Elliot, 2016; Mclean & McDougall, 2014).

- FASD is a condition where multidisciplinary support is indicated, and where the coordination of multiple service providers and systems is needed to support a child's development. FASD is a lifelong disability affecting many areas of the child's life. Therefore, the best outcomes for children are likely to occur when there is good coordination between medical, educational and community services and other professionals involved in the child's life (McLean & McDougall, 2014). Models that use a 'key worker' ecological approach to case-coordination show promise where these have been employed (Reid et al., 2015).

Implications for child mental health:

Early identification of children's areas of strength and difficulty is important. When communicated well, this information can help those around the child to understand the child's support needs and to offer more effective support with cognitive and social skills and vocational guidance.

Recommendations:

- FASD is a lifelong condition that can be characterised by multiple physical health, mental health, cognitive and learning difficulties. A comprehensive, multidisciplinary evaluation is the best way to identify the diverse range of difficulties that children living with FASD can experience. Adequately funded key worker models offer promise as a means to coordinate the ongoing multi-systemic support needs of children after diagnosis.

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

Emerging Minds will not be responding to this item from the Terms of Reference.

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

- The prevalence of FASD amongst children in out-of-home care settings is likely to be much higher than the general population. It is estimated that on average around 17% of children in all forms of out-of-home care placements are living with FASD (Lange et al., 2013). Around 6% of those children were diagnosed with Fetal Alcohol Syndrome (FAS) (Lange et al., 2013). Children in care settings have higher rates of mental health concerns and it may be more difficult for these children to access suitable supports (Royal Australian and New Zealand College of Psychiatrists, 2015).

- It may be difficult to obtain comprehensive developmental histories for these children due to placement instability and lack of documentation. Child protection practitioners should ensure that history of maternal alcohol use in pregnancy is recorded and this information transferred to a child's file to facilitate accurate diagnosis (McLean, 2019c).

- Children and adolescents living with FASD are more likely to come into contact with the legal system, either as perpetrators or victims (Parkinson & Mclean, 2013). Between 11-23% of youth justice residents meet the criteria for FASD (Fast and Conry, 2011); and more recent research suggests that this figure may be as high as 36% (Bower et al., 2018). Children and adolescents living with FASD were 19 times more likely to have been incarcerated compared to those without FASD (Popova, Lange, Bekmuradov, Mihic, & Rehm, 2011).

- This population also displays significant mental health concerns. A recent study of lower risk juvenile offenders on diversionary programs found that 17.1% had a current mood, anxiety or psychotic disorder (Kang et al., 2017). It is reasonable to assume that difficulties with emotional regulation associated with FASD may underpin mental health issues in some youth.

- The cognitive, language and mental health difficulties of children with FASD may mean that they are unable to participate effectively in legal decision making; and neurodevelopmental impairments may predispose them to ongoing contact with the forensic and youth justice systems (Bower et al., 2018; Lansing et al., 2014; Parkinson & Mclean, 2013).

- The rates of reported alcohol consumption in pregnancy are higher for non-Aboriginal women but Aboriginal women are more likely to consume alcohol at harmful levels (Dudgeon et al., 2014).

- The reasons why pregnant Aboriginal women consume alcohol at harmful levels are complex. Contributing factors identified in The Lililwan Project include lack of knowledge about harms to the fetus; unemployment; having a partner who drinks; family violence; loss of land and culture; and the intergenerational trauma effects of the Stolen Generations (Fitzpatrick et al., 2012).

- A recent study conducted in the remote community of Fitzroy Valley identified high rates of neurodevelopmental disorders that will adversely impact upon educational outcomes, participation in community life, and productivity. Social and economic costs are significant and will affect communities for generations (Fitzpatrick et al., 2017).

- Williams, Percival, Hewlett, Cassady, & Silburn (2018) highlighted the need for the development of resources which specifically focus on the important role that men, grandmothers and aunties can play in supporting pregnant women to make positive decisions around their alcohol, tobacco, and other drug use.

Implications for child mental health:

The cognitive, language and mental health difficulties of these children in out-of-home care and youth justice populations may mean that they are less able to participate in decision making. In addition, neurodevelopmental impairments may predispose them to placement instability and ongoing contact with the forensic system (Bower et al., 2018; Lansing et al., 2014; Parkinson & Mclean, 2013).

For Aboriginal children, a leading cause of intellectual disability is prenatal alcohol exposure. Aboriginal children are twice as likely to be ‘developmentally vulnerable’(Fitzpatrick et al., 2017).

The interplay of cognitive and language difficulties may make children more vulnerable to mental health concerns; and systems that are poorly suited to neurocognitive difficulties may exacerbate children’s difficulties.

Recommendations:

- Workforce development in relation to communicating and interacting with children with neurocognitive and language difficulties and intellectual disability (ID).
- Child protection workers to be mandated to record AOD in maternal pregnancies as part of child protection risk assessment, using standardised instruments.
- We found that research on FASD and the impacts of alcohol exposure during pregnancy among Aboriginal communities was very limited. Further research into the experience of FASD among Aboriginal families would aid in understanding its impact on communities, and inform culturally relevant and safe prevention and early intervention approaches.

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

Emerging Minds will not be responding to this item from the Terms of Reference.

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

Emerging Minds will not be responding to this item from the Terms of Reference.

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

- Children under the age of 7 with a diagnosis of FASD are eligible for core, capital and capacity building supports and services. These supports allow these children to complete daily living activities; work towards their goals; be supported by any equipment; and to build their independence and skills.

- FASD is a condition where the coordination of multiple service providers and systems is needed to support outcomes. The creation of a competitive market within the NDIS can impact on collaborative efforts between providers, with implications for care integration and coordination (Green et al., 2018).

- The structure of the NDIS can also result in short episodic treatment, where there is less time to build relationships with families and other treating professionals, and less opportunity to strengthen the system around the child (Hayes, et al., 2018).

- National Disability Insurance Agency (NDIA) planners, local area coordinators and Early Childhood Early Intervention (ECEI) partners have a responsibility to work with children and families affected by FASD to understand their 'reasonable and necessary' supports. This workforce can lack the skills, experience and resources to assess or adequately advise families on appropriate supports and services for these children (CYDA, 2019; Einfeld et al., 2017; Hayes et al., 2019). This can have a significant impact on the level and type of support offered to children and families (Anderson et al., 2017).

Implications for child mental health:

Children with FASD require long term, multidisciplinary support which fosters therapeutic relationships. A system which falls short of these needs impacts directly on a child's overall social and emotional wellbeing. Furthermore, a lack of workforce skills, experience and resources in the area further impacts the likelihood of mental health promotion, prevention or early intervention initiatives.

Recommendations:

○ FASD is a lifelong condition that is characterised by contact with multiple services and professionals. Therefore, support/case coordination (along the lines of the key worker model) may be the most appropriate model of post-diagnostic support. This kind of role should be supported under the NDIS.

○ Improving outcomes for children with FASD requires a workforce who have a clear understanding of the cohort's needs. It is recommended that workforce development initiatives aim to improve workforce capability in supporting children and young people with

FASD. These will ideally be co-designed with children, their families and advocates (CYDA, 2019).

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

- As a whole, the impact of FASD on parenting capacity, and on the associated support needs of parents who are living with FASD is an under-explored area (Gomos, 2015). Given our understanding of FASD as a life-long disorder that can be characterised by difficulty with one or more aspects of new learning, adaptive skills, flexible thinking, social decision making, emotional regulation and possible intellectual disability, this strongly suggests that parents who are living with FASD will need ongoing and individualised support to manage the demands of parenting in a consistent way.

- Related research on parents with learning disabilities in the UK suggests that provision of practical support, a focus on increasing skills and competencies, and support that is tailored to people with learning disabilities is likely to be most effective (University of Hertfordshire, 2019). Support that is most effective in this population includes specific strategies such as modelling and rehearsal; providing concrete instructions; providing physical demonstrations and guidance; breaking tasks into smaller steps; overlearning routines; and extensive use of pictorial aids (e.g. McGaw, Ball & Clarke, 2002; Baum, Gray & Stevens, 2011). Parents with learning disabilities may also have trouble with generalising learned skills, suggesting that parental supports should be delivered in homes and other relevant settings (University of Hertfordshire, 2019).
- The extent of support required by parents living with FASD will vary according to the severity of their functional impairment. Psychological assessment can provide a foundation for understanding parental support needs. Tools such as the Parenting Assessment Manual may also contribute to an overall understanding of family need (e.g., McGaw, 2007). Some of the resources developed for working with families living with learning disabilities may also be useful in supporting parents living with FASD (e.g. resources from CHANGE and the Working Together with Parents Network, or the *Good Practice Guidance on Working with Parents with a Learning Disability*).

- Without support, parents living with learning disabilities are more likely to have their children removed due to lack of ongoing support (University of Hertforshire, 2019). Research suggests that although professionals may justify removal based on parental capability, the lack of ongoing skilled support provision, and presence of other factors such as poverty and relationship difficulties may be more salient (University of Hertfordshire, 2019).

Implications for child mental health:

Children who are living with parents affected by FASD may be more likely to experience removal and to remain in care once removed. In some cases, this removal may be based on untested assumptions about parental capability and reflect lack of workforce capacity for working in the specialised and ongoing way that may be necessary for this group of parents (University of Hertfordshire, 2019).

Recommendations:

- Workforce development in the specific approaches needed when working with parents who have intellectual disability and other neurodiversity is needed. Programs modelled after the *Enabling Parenting with Support* (Chinn, 2012) program may have value in this area.

(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

‘Recommendation 17 The Committee recommends that the Commonwealth Government develop educational material to raise awareness about Fetal Alcohol Spectrum Disorders (FASD). These materials should be monitored and informed by the FASD Reference Group. In particular, targeted training and materials should be developed for:

- special education teacher aides and class teachers;
- parents, foster carers and foster care agencies;
- police and court officials;
- youth workers and drug and alcohol officers; and
- officers in correctional facilities and juvenile detention centres.’

‘Recommendation 18 The Committee recommends that the Commonwealth Government include Fetal Alcohol Spectrum Disorders in the List of Recognised Disabilities and the Better Start for Children with a Disability Initiative.’

- The list of professions for whom targeted training and materials be developed in Recommendation 17 does not include key workforces in a position to support the prevention of FASD, as well as others whose clients or patients may be living with FASD in addition to their primary presenting condition. These include child protection workers; health practitioners supporting women who are pregnant or planning pregnancy (and their partners); and specialist child mental health practitioners.

- Recommendation 18 has not been achieved. FASD does not appear in the Guide to List of Recognised Disabilities, last updated 2014, on Australian Government Department of Social Services website. Neither does it appear in Disability Types and Descriptions on the National Disability Services website (as at Nov. 2019). Despite calls for FASD to be recognised as a disability in Australia, FASD is not included in the List of Recognised Disabilities or as an eligible condition with Better Start for Children with a Disability scheme.

  Recognition in policy is important for developing awareness of the nature of FASD and accommodations that can help support children in families with FASD. Recognition in policy is also an important implementation driver, supporting efforts for prevention of disability and early intervention for emotional and behavioural difficulties associated with FASD, including professional development among existing and emerging workforces.

Implications for child mental health:

Broadening the recommendations would improve understanding of FASD and workforce development among those workforces in a position to contribute to better primary prevention of FASD; as well as support early intervention for the flow on impacts of FASD in children. The benefits of this recommendation can be significantly boosted by providing a policy framework that recognises FASD as a lifelong condition causing disability, which is acknowledged in support and justice systems.

Recommendations:

- Expand the concept of work-roles for whom targeted training and materials be developed and implemented.
- Support implementation of professional knowledge and practice which is FASD-aware by recognising FASD as a disability.

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

- Significant gap exists in addressing the workforce development needs of child protection practitioners, child mental health professionals and AOD services.
- Child protection professionals need to accurately record alcohol consumption during pregnancy as part of routine assessment procedures. The child protection workforce are likely to be working with parents and children living with FASD; therefore, they should be a priority workforce.
- Child mental health practitioners are likely to encounter children living with FASD, given the high levels of comorbidity. It is important for the child mental health workforce to be included as a priority workforce for strategic focus (Brown et al., 2017).
- AOD counsellors have potential to intervene early to support children’s mental health by supporting a harm minimisation approach, helping parents living with AOD issues with parenting appropriate to the needs of affected children.
- The Australian Human Rights Commission (2019) has called on the Australian Government to support implementation of the National Fetal Alcohol Spectrum Disorder Strategic Action Plan 2018–2028 and address the recommendations made by the Senate Inquiry into Effective Approaches to Prevention, Diagnosis and Support for Fetal Alcohol Spectrum Disorder (p.34).

Implications for child mental health:

Include a focus on mental health by supporting the workforces that have the potential to shape supportive interventions for children living with FASD.

Recommendations:

- Expanding the strategy to include significant workforces that have the potential to shape children's mental health.

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

- Currently there is no consistency in capturing data on alcohol (or other drug) use in pregnancy. Collection of this data relies on self-reporting via the National Drug Strategy Household surveys, or midwifes asking a general question about alcohol use in the pregnancy record (Australian Institute of Health and Welfare (AIHW), 2017a). This could mean that there is significant under-reporting, particularly bearing in mind the stigma and fear of losing children to child protection.

- Only two of the jurisdictions that collect perinatal data use the validated AUDIT-C tool to screen for alcohol use. If used consistently, this could be a valuable source of information and would support future diagnoses of FASD (AIHW, 2017a).

- Despite pregnancy being flagged as a time of increased risk in the National Drug Strategy, drug and alcohol treatment services are not required to ask about pregnancy when collecting data on alcohol or other substance use. This data would provide clarity on how many women were already in treatment for AOD use when they became pregnant and conversely, how many women accessed pregnancy care first and were then referred for AOD treatment (National Drug and Alcohol Research Centre, 2019; AIHW, 2017a). It would also provide a clearer picture on the number of pregnant women who access AOD services, the substances they are using (including alcohol) and the chronicity of use – previous alcohol use is a strong predictor of prenatal alcohol use (Taplin, Richmond & McArthur, 2014). It would also facilitate exploration of how long it then takes for these women to access pregnancy care. This data could be used to explore the gaps in integrated care pathways nationally.

- If drug and alcohol treatment services were required to collect this data on the National Minimum Data Set (NMDS) for Alcohol and Other Drug Treatment Services (AODTS), it would provide an authorising environment to support best practice around working with pregnant women in drug and alcohol treatment services. Screening for alcohol use using the AUDIT-C could be part of this. Current funding agreements include KPIs such as 'Ensure your service meets the specific needs of target groups (such as women, youth, families with children, and Aboriginal and Torres Strait Islander people)'. However, services set their own performance measures around these KPIs and since pregnancy is not being collected as part of overall data, it could be argued that working with pregnant women is not a key focus (Ritter et al, 2014, pp. 211, 217).

- A recent AIHW study that explored asking pregnant women about their alcohol use as part of maternity care found that midwives did not have any training in this area. It also found that women understood that high levels of alcohol use were dangerous but were not sure about low levels of consumption. Women reported that an open conversation about pre-pregnancy alcohol use would be more beneficial, and that they believed it to be important that this data is collected and reported upon at a national level to help them make informed decisions (AIHW, 2017b).

- The Australian Human Rights Commission (2019) has indicated that the lack of national data on incidence and prevalence of FASD is a major impediment to developing effective policy responses (p.15).

Implications for child mental health:

When pregnant women are not asked about and screened for alcohol (and other substance) use in ways that support them to report this honestly, the infant is rendered ‘invisible’ to the health system that is supposed to be supporting it, putting its health and development at risk of lifelong disability.

Recommendations:

- Nationally consistent data collection is required to better capture alcohol (and other substance use) in pregnancy. Data could also be enhanced by requiring the collection of data on pregnancy and alcohol and other substance use on the National Minimum Data Set for Alcohol and Other Drug Treatment Services.

- Workforce development to train practitioners in the skills required to ask women about substance use in ways that will support honest reporting and ongoing retention in treatment.

(p) any other related matters.

Emerging Minds has no other matters to add.

Concluding comments

Emerging Minds has the platform and reach to increase understandings of neurodevelopmental differences and skills to respond effectively to children and families in a broad range of workforces.

We bring a unique lens on child mental health as a vital component of child development, which can and should be considered within the role of anyone working with children, or with adults who are parents/caregivers.

Early intervention and prevention approaches which foster the health and wellbeing of infants and children are not only an investment in productivity and responsible citizenship of future generations; they also demonstrate children as valued citizens and consumers of public policy, whose experience during childhood is equally as important as that of their future adult selves.
FASD is an entirely preventable disability. However once identified, appropriate early intervention responses can help to support children in families with FASD.

Early intervention means action early in life wherever possible – early in the life of the problem and early in connection with services – to reduce the impact of illness or adverse exposure. For children with FASD, this means real understanding of their differences, as well as accommodations that ensure they are able to learn, participate and contribute to their potential.

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Additional Material

Appendix A: Emerging Minds National Workforce Centre for Child Mental Health – Fetal Alcohol Spectrum Disorder workforce development resources

Webinar

Working to support children and families living with Fetal Alcohol Spectrum Disorder webinar

Podcast

Fetal Alcohol Spectrum Disorder (FASD) Podcast

Practice papers by Dr Sara McLean

What is Fetal Alcohol Spectrum Disorder (FASD)?

Understanding the impacts of Fetal Alcohol Spectrum Disorder (FASD) on child mental health

How to support children living with Fetal Alcohol Spectrum Disorder (FASD)

How to support caregivers and families living with Fetal Alcohol Spectrum Disorder (FASD)

Systems and service supports for children and families living with Fetal Alcohol Spectrum Disorder (FASD)