

Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

27 November 2019

Dear Committee Secretary

Inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder (FASD)

Thank you for the opportunity to make a submission to this inquiry into effective approaches to prevention, diagnosis and support for FASD. We make this submission in our personal capacity, and are solely responsible for the views and content contained herein.

Our submission addresses items (d), (h), (i), (j), (l) of the Terms of Reference. It is informed by research we have conducted as a team for the Australian National Advisory Council on Alcohol and Drugs (ANACAD) Secretariat on FASD and the criminal justice system. Our submission also draws on research we have undertaken separately in Western Australia:

- with First Nations communities in Perth and the South West region examining best practice relating to FASD interventions, cultural security, and supporting children and families with FASD (Dr Robyn Williams). This is the first Australian FASD study to include case studies of Aboriginal relative carers and is the largest consultation with First Nations people with a total of 180 Aboriginal people and six families.
- with First Nations communities in the West Kimberley region to develop culturally secure diversionary alternatives to the criminal justice system for Aboriginal youth with FASD (Professor Harry Blagg and Dr Tamara Tulich).
- on the first Australian study examining the feasibility for screening and diagnosing FASD and impairment in youth detainees in Banksia Hill Youth Detention centre in Perth (Dr Raewyn Mutch and others at the Telethon Kids Institute).
- examining the awareness of lawyers and justice professionals of FASD (Dr Raewyn Mutch and others at the Telethon Kids Institute).

If you have questions about this submission, please do not hesitate to contact Tamara Tulich

Sincerely

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

FASD is characterised by severe, pervasive neurodevelopmental impairment due to prenatal alcohol exposure. Impairment in executive function, memory, language, learning and attention in young people with FASD can result in a range of difficulties including diminished understanding of cause and effect, poor learning from past experiences and vulnerable decision making. These impairments can, in turn, lead and contribute to problems at school and with employment, mental health, social exclusion, substance misuse and early and repeated engagement with the law (Streissguth & Kanter 1997; Fast & Conroy, 2000).

However, the majority of individuals with FASD will never be diagnosed mainly due to associated diagnostic costs, and continued lack of awareness by health professionals. This means that most individuals are unlikely to be diagnosed by the age of 18, when they may already be enmeshed, or vulnerable to enmeshment, in the justice system.

In Australia health practitioners should use the most recent iteration of the *Australian FASD Diagnostic Guidelines* to determine developmental ability. However, there are still some practitioners who elect to use original diagnostic methods commonly employed in North America such as the Canadian or University of Washington guides. Few of the recommended assessment measures are specific for the effects of prenatal alcohol exposure and all reliable assessments have been derived among populations which do not include non-Indigenous Australians.

If there is ever a suspicion that a young person may have FASD then a referral for a comprehensive assessment should be made. A comprehensive assessment needs to be completed by a multidisciplinary team of health professionals including as a minimum: (i) paediatrician or physician experienced in normal development and psychosocial assessments, (ii) a speech and language pathologist, (iii) a clinical psychologist or neuropsychologist able to complete measures of executive function, cognition, memory and learning and (iv) an occupational therapist. In a fully funded venture the assessment should also have a cultural navigator for young people from regional and remote communities and a social worker experienced in determining and building the risk and protective factors for social and emotional wellbeing (SEWB).

Key submissions:

- *Increased public funding for comprehensive FASD assessment and diagnosis (including cultural navigators).*
- *A specific medicare item number for a FASD assessment.*

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

While data in Australia is limited, estimates of FASD in non-Indigenous populations range from 0.14 to 1.7 per 100 children, with rates in First Nations communities indicatively higher. In 2015, rates of FASD or partial FASD of 12 per 100 children were reported in Fitzroy Crossing in the West Kimberley region of Western Australia (Fitzpatrick et al, 2015). This is the highest reported prevalence in Australia and on par with the highest rates internationally.

A recent study undertaken in the Banksia Hill Detention Centre in Perth, the only youth detention centre in Western Australia, found 89% of youth detainees had a severe neuro-developmental impairment and 36 % were diagnosed with FASD (Bower et al, 2018). This is 'the highest reported prevalence of FASD in a youth setting worldwide' (Bower et al, 2018, p. 7). Thirty four of the 36 young people assessed as having FASD identified as Aboriginal, amounting to a prevalence of 47%.

The ongoing impact of intergenerational trauma on First Nations peoples is well documented, resulting in many medicating their trauma with alcohol without awareness of the harm to their unborn child (Atkinson J, 2002). From the 1960s, medicating trauma with alcohol has included drinking at harmful levels and binge drinking which significantly increases the risk/prevalence of FASD within the Aboriginal community. This pattern of drinking continues to the present day.

Research highlights that interventions on FASD must be decolonised for First Peoples in view of the historical and social context (Tait, 2003; Baldry & Wight; Felske, 2013). Further, international evidence shows that the historical context of trauma requires that interventions on FASD for Aboriginal peoples be decolonised and delivered by the Aboriginal community.

Key submissions:

- *'Decolonisation' of FASD interventions and including on-country programs, designed by Aboriginal people and FASD professionals for Aboriginal offenders with FASD, to prevent reoffending and promote meaningful community engagement.*
- *Funding for Aboriginal organisations to deliver FASD interventions.*

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

The impairments associated with FASD are relevant to each stage of the criminal justice process – from participating in police interviews and instructing lawyers, to understanding the court process, the availability of certain defences, sentencing, complying with court orders, accessing appropriate treatment and management if imprisoned. The Banksia Hill study highlighted the breadth of impairment across '...language, executive function, memory and cognition may contribute to offending behaviours and/or difficulties in negotiating all aspects of the justice system.' (Bower et al. 2018: 8).

There is a growing collection of parliamentary reports, case law and academic research highlighting the inadequate accommodation of FASD-associated impairments within the criminal justice system. In summary, this indicates:

- Failure to appropriately recognise and accommodate FASD within the criminal justice system can lead to an individual with FASD having repeated, negative contact with the justice system. This contact raises the likelihood of people with FASD experiencing adverse secondary consequences (sometimes referred to as 'secondary disabilities' associated with FASD), such as substance abuse and mental illness, which, in turn, increases their susceptibility to further contact with the justice system (as victims and offenders) (Streissguth & Kanter 1997).
- The assumptions of free will and individual responsibility that underpin Australian criminal law are largely incompatible with the impairments associated with FASD (Roach & Bailey 2009: 3).
- Poor identification (and therefore specialist assessment) of individuals with FASD and referral for specialist assessment (Mutch et al. 2013).

- A lack of awareness of police, prosecutory authorities, lawyers and justice professionals of FASD (Douglas et al. 2012; Mutch et al. 2013) remains a serious concern.
- The suggestibility of a person with FASD means they are more likely to gratuitously concur with propositions put to them by police in interviews (Parliament of Western Australia 2012: 75; Parliament of Australia 2017).
- Difficulties with memory place persons with FASD at a disadvantage when trying to explain behaviour, give instructions to lawyers, or give evidence (Parliament of Western Australia 2012: 75; Parliament of Australia 2017).
- The legislative regimes for fitness to stand trial, as they apply to persons with FASD, have been criticised, most notably the WA regime (Blagg, Tulich, Bush 2016, 2017; Crawford 2010, 2014; Martin, 2015; Parliament of Western Australia, 2012; *State of Western Australia v BB (a Child)* [2015] WACC 2; *State of Western Australia v Tax* [2010] WASC 208), including the absence of appropriate accommodations (Gooding, McSherry, Arstein-Kerslake and Andrews (2017) Arstein-Kerslake Gooding, Andrews and McSherry (2017); Parliament of Australia 2017).
- The absence of appropriate diversionary alternatives, and in particular place-based 'on country' therapeutic diversionary alternatives for Aboriginal youth with FASD (Blagg, Tulich, Bush 2016, 2017; Blagg and Tulich, 2018; Parliament of Australia 2017).
- Sentencing responses to FASD have been criticised as inadequate and likely to be the cause of deeper enmeshment in the justice system (Milward 2014; Douglas 2010; Crawford 2015; Chartrand & Forbes-Chilibeck 2003; *Churnside v the State of Western Australia* [2016] WASCA 146; Freckelton 2016).
- The difficulties that persons with FASD experience with memory and linking actions with consequences are likely to render diversionary alternatives such as fines, community-based orders, and good behaviour bonds, futile (Douglas 2010: 228).
- The imposition of community-based orders on persons likely affected by FASD was recently criticised as 'unrealistic' by the Court of Appeal of the Supreme Court of Western Australia in the case of *AH v Western Australia* [2014] WASCA 228. A person with FASD may be unable, rather than wilfully unwilling, to comply with court orders.
- Challenges to the effective management of people with FASD in the justice system, including lack of appropriate treatment programs (Mutch et al. 2013; *Churnside v the State of Western Australia* [2016] WASCA 146; Freckelton 2016; *AH v Western Australia* [2014] WASCA 228).
- Concerns about persons with FASD in prison, where difficulties with memory and linking actions with consequences may mean they are unlikely to be able to comply with prison rules, and may be victimised, exploited and manipulated due to their suggestibility (Douglas 2010: 228; Chudley et al 2007: 269; Fast & Conroy 2009: 252; Institute of Health Economics, 2013: 25).
- Incarceration in prison can worsen or exacerbate the condition of an offender with FASD (*AH v The State of Western Australia* [2014] WASCA 228).

International research and best practice support a *multidisciplinary and community-focused approach, that maximizes therapeutic outcomes and responds to the needs, including cultural needs, of people with FASD who come into contact with the justice system.* This would involve:

- **Training of justice professionals**

Australian studies have found that justice professionals require more training on FASD. A 2011 study (Douglas et al, 2012) looking at the knowledge and practices of barristers and solicitors in Queensland around FASD, highlighted that 82% of surveyed professionals wanted guidelines on how to deal with a person diagnosed with (or suspected of having) FASD. Suggestions were made that undergraduate legal training include FASD education, as well as for law societies and bar associations to develop training for their members (Douglas et al, 2014: 158, 164). A 2011-12 Western Australian study conducted by the Telethon Kids Institute examined the awareness and knowledge of FASD amongst justice professionals (judges, magistrates, lawyers, Department of Corrective Services staff and police), including the perceived impact of FASD on their practice and their information needs in the area. 1873 West Australian justice professionals were surveyed, including judicial officers, police and lawyers; 23% responded. This study found 'deficits in the treatment of individuals with FASD within the [Western Australian] justice system' on par with studies conducted in Queensland and Canada (Mutch et al. 2013: 39). This study (2013: 39) identified a number of challenges to the effective management of persons with FASD within the justice system, and that there existed a need for training and education to improve awareness of the specific impairments associated with FASD that impact on the treatment of individuals with FASD across the justice system of WA.

The North Australian Aboriginal Justice Agency and the Central Australian Aboriginal Legal Aid Service (2014: 2) have recommended urgent targeted training of the judiciary, lawyers, prosecutors, police and corrections officers to increase their awareness of FASD and facilitate early identification, referral and assessment in the NT. Internationally, the Canadian Consensus Statement on Legal Issues and FASD (Institute of Health Economics, 2013: 7) recommends ongoing mandated training for all stakeholders in the legal system both in courts and corrections; and in the community.

FASD is increasingly recognised in youth detention but largely unacknowledged in adult custody, as one senior policy officer told researchers 'sufferers are magically cured on reaching 18' (Blagg and Tulich, 2018). Creating culturally secure, trauma informed, non-punitive, enclaves in prisons and detention facilities is a difficult ask. Comprehensive training and education on FASD, however, should be mandatory for all staff in the correctional settings. Awareness of FASD may, at the very least, prevent custodial staff from having unrealistic expectations of what inmates with FASD can achieve in terms of following instructions and conforming with regulations. Literature also identifies that intensive case management and mentoring is best practice in working with child and adult clients with FASD. In a custodial setting throughcare planning is essential. Tubex et al (2019) undertook research with Aboriginal service providers and clients in the Kimberley region of WA, they found that poor planning for release and lack of follow up post-release meant that vulnerable released prisoners (staff at the Men's Outreach Service in Broome believed that roughly 80% of these had a FASD like disability) was a key reason for recidivism.

Key submission:

- *Funding for multidisciplinary educational training for judicial and legal professionals, correctional staff, police, health, schools and other professions that intersect with the justice system, about FASD and its medical, social and legal implications.*
- ***Programs to enable timely identification, assessment and diagnosis of FASD in court***

While judicial officers may recognise FASD in their courts and be willing to adjust their sentencing practices to better accommodate the needs of those affected, the court can only rely on the information presented to it. Canadian Justice Melvyn Green (2006) explains:

...judges only know (or are permitted to know) what counsel, by way of evidence and submissions, are prepared to tell them. My seat may be the best in the courtroom, but I can only see what counsel allow me to see...In too many cases, I suspect, judges are hamstrung because

they're denied the information they need. This doesn't serve the interests of justice or the public or, perhaps most importantly, the interests of defendants with FASD who, far too often, find themselves in conflict with the law...Crown as well as the defense – whose job it is to inform judges when a defendant is FASD compromised. A FASD-educated judge will then have the information to ask the salient questions: How impaired? What history of therapeutic intervention and with what success? What alternatives to jail are available? How effective are they likely to be *in this one, single, individual case?* Judges are at the far end of the forensic food chain. Please give us the tools to do our job.

As we noted in our response to (d) above, a full assessment of FASD can require input from a team of clinicians, including a developmental paediatrician, a speech pathologist, a neuropsychologist, an occupational therapist and a psychologist. The process can be slow (around 6 months), and expensive (between \$1500 - \$6000). This delay is clearly of significant disadvantage to both the individual being sentenced and the court, which is unable to take FASD into consideration without a report that provides evidence of it.

International best practice examples of timely identification, assessment and diagnosis of offenders with FASD within the court system include:

- The *FASD Youth Justice Program in Manitoba Canada* which functions to ensure that young people with FASD who have come in conflict with the law receive a timely diagnosis and makes recommendations to the court regarding sentencing dispositions; builds capacity within families and communities while enhancing supports and services; and implements meaningful multidisciplinary intervention and reintegration plans for youth following custody (Longstaffe et al. 2017).
- The *New Zealand Youth Court list days* which involve specialist mental health, alcohol and drug services assisting the court by screening and assessing offenders for mental health, intellectual disability and alcohol and drug issues; officer liaison services; treatment and clinical care; and the provision of specialist consultation for health and justice staff. Education Officers in Youth Justice Courts also provide the court with information about the education history of the young person including poor attendance or performance, prompting screening for FASD and earlier intervention, which can be taken into consideration by judicial officers when sentencing (Crawford, 2015: 71-72).

Programs like this, if resourced appropriately, could assist Australian courts by expediting multidisciplinary assessments to ensure judicial officers have the requisite information to be able to make sentencing dispositions which are responsive to needs and capabilities of offenders.

Key submissions:

- *Funding for programs with expertise to facilitate expedited assessments and reports of offenders suspected of having FASD, including recommendations for effective management, for courts to consider before sentencing;*
 - *Standardised screening, diagnosis and individualised support for young people and adults coming in contact with police, legal practitioners, courts and the justice system with suspected or diagnosed FASD; and*
 - *Greater public funding for FASD assessments (preferably reflected in Medicare item numbers).*
- ***Prioritising diversion***

Developing strategies at the front end of the criminal justice system will necessitate a lowered threshold for identifying potential FASD cases. It offers an opportunity for a support pathway but avoids the stigma of the formal justice system. The involvement of Aboriginal peoples in the diversion process may be a critical factor in ensuring that interventions are culturally competent. Diversion 'on country' and deeper involvement with Elders and others of significance to the child, may be a good way of constructing 'relational scaffolding'.

A successful diversionary approach requires investment in community structures. Currently, criminal justice budgets are consumed by prisons and detention centres: it is estimated that taxpayers pay \$3.8 billion a year to keep people in prison (The Australia, December 2016): over \$300 per night, it cost around \$30 per day for community supervision. This has increased demands for an alternative strategy where there would be investment in community alternatives. *Justice Reinvestment* is an evidence led strategy in which money currently spent on incarcerating people will be diverted into building community supports. Research in a locality would identify clusters of vulnerability and there would be local strategic plan involving all relevant agencies and community organisations. Over time there would be a transfer or resources away from prison building to community building. Evidence based FASD programs run by community organisations would be an obvious focus for investment. The model is being trialled in Bourke New South Wales (see <http://www.justreinvest.org.au/what-is-justice-reinvestment/>, also Brown et al 2016).

Key submissions:

- *Greater focus on diversion from the criminal justice system by the police, supported by local communities.*
- *Greater investment in diversionary multi-agency teams and capacity building/resourcing for local Aboriginal agencies to provide services.*
- ***Improving Outcomes in Court: Fitness, Sentencing and Rehabilitation***

FASD, along with other cognitive impairments, is relevant to whether an accused person is fit to stand trial. An accused person's mental fitness to stand trial relates to his or her ability to comprehend the proceedings and communicate at the time of a criminal trial, and is crucial to the fairness of the trial process. While differences exist between the Commonwealth, state and territories, a person found unfit to stand trial in Australia may be detained – often indefinitely and in a custodial setting – for a longer period than if they had plead guilty to the offence. This has been roundly criticised by international bodies, state and federal parliamentary committees, the judiciary, disability advocates and researchers.

Australian and international commentators have called for sentencing courts to adopt an approach that maximises therapeutic outcomes and is community based (Roach and Bailey, 2009; Freckleton, 2016). The 2013 Canadian Consensus Statement on Legal Issues of Fetal Alcohol Spectrum Disorder (FASD) (Institute of Health Economics 2013: 20-22) recommended sentencing courts take into account the challenges faced by those with FASD by giving primary consideration to the objective of rehabilitation and imposition of a community sanction by deeming FASD as a mitigating factor in sentencing. Traditionally, the term 'rehabilitation' is understood as a process that relies on the ability of a person to understand, learn, remember and make choices, which may be contrary to the abilities of people with FASD. However, the Statement recommends 'rehabilitation' be defined in relevant legislation to include 'a reasonable prospect of managing the offender in the community', which is a shift in goal from the neurodevelopmental ability of the individual, to an achievement facilitated by family, community and organisational support. In determining alternative sentencing options to prison, the Statement recommends (20-22) a focus on 'those measures most likely to provide opportunities for the offender to be rehabilitated and reintegrated peacefully into society'.

It is important that the unique circumstances of Aboriginal offenders with FASD are recognised in the sentencing process. The Canadian Supreme Court in *R v Gladue* [1999] 1 SCR 688 para 68 have well expressed this:

[T]he circumstances of aboriginal offenders differ from those of the majority because many aboriginal people are victims of systemic and direct discrimination, many suffer the legacy of dislocation, and many are substantially affected by poor social and economic conditions... Aboriginal offenders are as a result of unique systemic and background factors, more adversely affected by incarceration and less likely to be rehabilitated by it, because imprisonment is often culturally inappropriate and facilitates further discrimination towards them.

The newly established *FASD Court in Winnipeg, Manitoba Canada* (which began as an expansion of the *Manitoba FASD Youth Justice Program* discussed above) is an example of a justice innovation to improve sentences and outcomes for people with FASD who come before the criminal courts. It has been [described](#) as a 'game changer'. The court was established in 2019 for youth and adults who have been diagnosed with FASD, with judicial officers who understand FASD and support workers who can advise and connect people with FASD with community programs. The Chief Judge of the Provincial Court of Manitoba, Margaret White, explained in a [Notice](#) on 14 March 2019:

One of the goals of these dockets is to provide the accused with a court environment that takes into account the specific deficits identified in the FASD assessment report and how they might be related to the offender's moral blameworthiness or degree of responsibility for an offence. If there is a link between the deficits resulting from FASD and the offending behaviour, the Court would explore how the sentence imposed would best reflect and respond to that link.

Provincial Court Judge Mary Kate Harvie has [explained](#):

It's important for us to know what it is that's contributing to any offender's behaviour and whether or not there is some deficit which we should be taking into account. Because FASD is often, not always... a hidden disability and is sometimes masked by other behaviour, it's really critical for us to know whether or not that is a contributing factor to their offending behaviour and whether or not there are supports out there that might assist in ensuring they don't get into trouble again.

Consideration should be given to a similar court innovation in Australia. This could be built around innovations already in existence such as Neighbourhood Justice Centres and Aboriginal Courts with a focus on triage, co-located services, a no wrong door approach, trauma informed practice and strong engagement with Aboriginal communities as justice partners and service providers. For Aboriginal persons with FASD who come into contact with the justice system, the establishment of culturally secure and community owned alternatives to prison is essential.

Key submissions:

- *Funding for community education and community based or owned service provision to support community-based orders, with Aboriginal organisations funded to provide support services for Aboriginal people with FASD. That is:*
 - *Specialist community based programs for offenders with FASD that focus on the development of daily living skills and provide activities to support the maintenance of people in the community on community based orders.*
 - *On-country programs, co-designed by Aboriginal people and FASD professionals for Aboriginal offenders with FASD to prevent reoffending and promote meaningful community engagement.*

- *Community based secure, supervised separate accommodation for juveniles and adult offenders with FASD, to be used by courts as alternative sentencing options to prison.*
- *Programs to enable timely identification, assessment and diagnosis of offenders with FASD in court; standardised screening, diagnosis and individualised support is needed for young people and adults coming in contact with police, legal practitioners, courts and the justice system with suspected or diagnosed FASD.*
- *Provision for courtroom accommodations such as support persons, and training of justice professionals;*
- *Abolish indefinite detention of unfit accused with FASD, and ensure that detention is only used as a last resort.*
- *Expansion of existing court innovations such as Neighbourhood Justice Centres and Aboriginal Courts with a focus on triage, co-located services, a no wrong door approach, trauma informed practice and strong engagement with Aboriginal communities as justice partners and service providers.*

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

(a) Social costs

Incarcerated young people in Australia are amongst the most disadvantaged of our community with common backgrounds of risk and vulnerability, repeated early life and intergenerational trauma. They have an elevated frequency of health problems when compared to those young people not incarcerated and commonly report impaired development, early school failure, early engagement in health risk behaviours, decreased social and occupational opportunities, increasingly poor physical, mental and material health, and repeatedly unmet therapeutic needs; the confluence of these many and complex risks drives offending behaviour and sustains social disadvantage.

Juvenile incarceration of itself is an important determinant of health and likely correlates with worse health and social functioning across the life course, highlighting the substantial challenges to delivery of equitable care in detention facilities. There is no doubt that the social, emotional and behavioural problems that are symptomatic of a young person's neurodevelopmental health and mental health can have pervasive consequences and even further damage the architecture of the developing adolescent brain. It is imperative that the SEWB of young people be assessed when they come into contact with justice services, and the assessment of risk and protective factors for SEWB should be mandatory and routine practice.

The likely high prevalence of adults with undiagnosed FASD is an indicator of widespread systemic failure despite considerable resources dedicated to FASD diagnosis and promoting awareness. Notably, there are missed opportunities of preventing further cases of FASD amongst sibling groups within the same family (Elliot, 2014). Individuals are born with FASD through no fault of their own, and literature supports a predictable pathway in life:

- Living with undiagnosed FASD and comorbidity, varying in range of serious health conditions
- Not being raised by biological parents
- Raised in out-of-home care, and subsequent multiple placements in the system

- Not diagnosed as a child, and no early interventions to prevent secondary disabilities
- Vulnerable to bullying and sexual abuse
- Onset of secondary disabilities; disengaging with school, mental health, alcohol and drugs; involvement in the criminal justice system
- Likely to also have either a parent, or siblings with FASD

Widespread systemic failure means that many with undiagnosed FASD rarely receive appropriate attention, until youth and adults end up incarcerated.

(b) Economic costs

The expense of FASD diagnosis still presents as an impediment for referral to FASD diagnosis (Tait, 2018). Within FASD literature, the economic costs of FASD to society across the lifespan, is well documented (Thanh, et al, 2011). In 2009, the annual cost of FASD in Canada was estimated conservatively at 6.2 billion dollars. However, *significant expenditure may be saved by investing in early FASD diagnosis and intervention with the child and family*. FASD is a lifelong disability, children with FASD will tend to become adults with FASD who will need support for the rest of their lives. Early intervention determines the overall quality of life they will have as an adult in terms of being able to live independently. This directly impacts on the financial costs associated with the person throughout their life. Without support and diagnosis, individuals with FASD will face a life marked by extreme adversity, poverty, incarceration, poor health, vulnerability to suicide, violence, early mortality, and are likely to become parents themselves (Hellemans, et al, 2010; Herrick, et al, 2011).

Investment in early FASD intervention with the child and family, is likely to result in significant financial savings across the life of the person. The economic costs over the lifetime for a person born with FASD have been estimated at over CAD \$1 million (Popova et al 2016), or more recently over AUD \$33,000 per year (Greenyer 2018). These figures are likely underestimates as they don't include all associated costs including the high social and emotional burden. As noted above, the Banksia Hill Detention Centre Study (Bower et al, 2018) found that 36% of youth detainees had FASD. The approximate cost of incarcerating a young person in WA is \$250,000 per annum. By providing support (full-time support carer and therapy at \$120,000/year) rather than incarcerating those young people with FASD in youth detention in WA, 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.

Since 2014, the Australian Government has provided around \$20M in direct funding for FASD-related activities, along with another \$7.2M associated with the 2018-2028 FASD Strategic Action Plan. However, the budget allocated does not come close to funding suggested plans. We support the submission of the Telethon Kids Institute that key elements of the strategic plan should be costed and budgeted for as long as FASD exists within the Australian population. 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.

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

Australia remains well behind countries such as Canada in service delivery and training in FASD, and this has a serious ongoing impact on individuals and families living with FASD. In a recent study, Nyoongar scholar Dr Robyn Williams (2018) concluded that:

- The lack of knowledge and awareness of FASD was widespread among those caring for children with FASD.

- Having to navigate the lack of awareness of the wider community was a serious issue.
- Learning to understand behaviours of children with FASD took considerable time and energy.
- No carers/family was provided access to any FASD training during the years they have cared for their children.

A carer who raised two siblings with FASD describes the lack of training provided on FASD:

The only training that was offered was from Yorgonup, but it wasn't to do with FASD, it was about children in care. How to deal with things, but there was nothing specific on FASD, which I would have loved.

The lack of awareness of FASD by previous carers for this young child contributed to multiple placements by the age of five, Carer states:

She has had three homes, the first people had no idea, never heard of FASD, had limited experience dealing with any children let alone a child with disabilities. The second people clearly knew about FASD, and clearly recognised there was a problem and were trying to do something about it, but then became very frustrated because of their inability to know where to go or how to go about it to get any help for her, because they were told she didn't have any issues. They got this child with highly emotional issues plus the FASD, with no help at all, and it actually broke them, and it was very sad when it broke their family. That is how Lana ended up with us.

Advocating for a young adult is made more difficult by society having no awareness of FASD. A carer describes some of the challenges that have confronted her young adult son recently in his full time job:

Where he's working, I've had to argue with them a lot of times, because they don't understand what fetal alcohol syndrome is, and they say we treat all our staff the same, and I told them he's not the same. They have been arguing for him to get his manual license so he can drive the cars around the grounds. They won't listen to me about what fetal alcohol is, so it is difficult for him to get his license.

The authors recommend the National Disability Insurance Agency (NDIA) update their references to FASD, recognising the full spectrum and also the need for therapy and support for individuals with neurodevelopmental impairment with or without a formal FASD diagnosis. There is no 'one size fits all' management plan for an individual with FASD. Services and management therapies for a person living with FASD needs to be tailored to the individual's specific difficulties and strengths. Comprehensive neurodevelopmental diagnostic services can inform individualised reports that highlight a person's strengths and difficulties and best practice services/supports they require. All individuals with FASD should have access to these therapeutic services through the NDIS with additional funding to provide diagnostic revision and assessment to be available across a person's life.

Australia's First Nations People have a rich understanding of health and healing. Importantly "disability" is not a word in the Aboriginal lexicon. The Australian FASD diagnostic tool needs to give specific attention to these differences. The authors suggest the Australian FASD diagnostic tool which is scheduled for revision needs to newly include specific cultural competencies to be woven across all aspects of the tool. Cultural competencies for the recommendations of diagnostic tool, interpretations of testing outcomes, informing diagnostic formulations and ensuring culturally-safe therapeutic recommendations for best social and emotional wellbeing.

There also needs to be an agreement to acknowledge the effects of intergenerational trauma (<https://youtu.be/vlqx8EYvRbQ>; the Healing Foundation, <https://healingfoundation.org.au/healing-portal/>) on neurocognitive development.



Adapted from Menzies School of Health Research – Aboriginal and Islander Mental Health Initiative.

First Nations people are living with the effects of colonisation and genocide including intergenerational, early-life and iterative lived-trauma, and cross-sector structural racism. The overrepresentation of Aboriginal and Torres Strait Island children and adolescents in detention is a serious consequence of the intergenerational, unmitigated and complex structural harms seeded at colonisation. The authors together with the Royal Australasian College of Physicians' (RACP) agree with the Uluru Statement from the Heart:

that our nation's health inequities are closely related to powerlessness, racism and a slow process of reconciliation alongside limited recognition of human, land and sovereign rights. This is of deep concern to health professionals and health organisations who strive for healing and contentment in the families and communities they serve.

Given the over-representation of Aboriginal children in detention, the definition of health for this submission aligns with the statement from the Aboriginal and Torres Strait Islander Health Committee of the Royal Australasian College of Physicians' (RACP):

To us health is so much more than simply not being sick. It's about getting a balance between physical, mental, emotional, cultural and spiritual health. Health and healing are interwoven, which means that one can't be separated from the other.

Accounting for each determinant of health as outlined by the RACP, redressing specific inequities, evaluating inherent and structural risks through the lens of colonisation and dispossession, identifying and meeting individual needs, can inform and support the delivery of restorative health and wellbeing initiatives especially among children, adolescents, adults and families living with FASD.

Key submissions:

- *the NDIA update their references to FASD, recognising the full spectrum and also the need for therapy and support for individuals with neurodevelopmental impairment with or without a formal FASD diagnosis.*

- *the Australian FASD diagnostic tool be revised to include specific cultural competencies to be woven across all aspects of the tool and an acknowledgment of the effects of intergenerational trauma on neurocognitive development. This should include: cultural competencies for the recommendations of diagnostic tool, interpretations of testing outcomes, informing diagnostic formulations and ensuring culturally-safe therapeutic recommendations for best social and emotional wellbeing.*

FASD training package for workforces and families

There is no consistent FASD training available in providing tools for families or workforce in Western Australia. Williams' discussions with families caring for FASD relatives found frustration at the lack of understanding of FASD by the general workforce, including health professionals: leading to high levels of frustration and increased anxiety.

Slowly, there are groups offering training services for communities and agencies.

Nyoongar woman, Dr Robyn Williams, developed a training package on FASD informed by: an international study tour in 2014 (including Canada); a literature review; results of interviews with Nyoongar families and the inclusion of the results of the survey, "Our Gurlongas, our Future".

The key components of the FASD training package were as follows:

- An overview of FASD as an irreversible lifelong disability, and how it affects children and adults who are living with FASD and the implications for their families and the wider community;
- Approaches for intervention, management and treatment;
- An understanding of the urgent need for ongoing professional advocacy and raising awareness in the community; and
- Understanding issues of stigma that confront adults and children living with FASD.

Training must be delivered in a culturally secure environment where adults are able to express views and feelings freely and without negative judgement. Aboriginal people have been constantly judged and put down by white authority; training should be embedded in Aboriginal community settings and run, as far as feasible, by Aboriginal workers. Further, in being informed by cultural security; Indigenous approaches and the literature on FASD; this training promotes understanding and highlights the stigma associated with FASD, and promotes a nonjudgmental approach in understanding FASD. An Aboriginal approach may highlight historical factors peculiar the experience of Aboriginal families since colonisation, and not simply offer a decontextualized clinical account. In particular, training on FASD should be trauma informed and centre the role of inter-generational trauma in creating the context within which FASD and like conditions thrive.

According to Millians (2015) carers of children with FASD need to receive training on the educational needs of their children. This would provide carers with more confidence to advocate for the children at school. Further, Millians (2015) argued that school based interventions were critical in supporting children with FASD cope with the academic, behaviour and social demands of the schooling system.

Aside from Dr Robyn Williams, The Russell Family Fetal Alcohol Disorders Association (rffada) is a not-for-profit ensuring that individuals affected prenatally by alcohol have access to diagnostic services, support and multidisciplinary management in Far North Queensland. The Telethon Kids Institute in Perth offers training on prevention, diagnosis and intervention to reduce the burden of FASD.

Key submission:

- *Funding for training packages and support for carers and families of persons with FASD. For Aboriginal carers and families, this training must be culturally secure and delivered by Aboriginal people.*

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