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# ***Senate Inquiry into effective approaches to prevention and diagnosis of Fetal Alcohol Spectrum Disorder (FASD)***

**Danila Dilba Health Service  
Submission**

**13 December 2019**

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## Introduction

Danila Dilba Health Service (**DDHS**) was established in 1991 as an Aboriginal community controlled organisation. Our aim is to improve the physical, mental, spiritual, cultural and social wellbeing of Biluru (and Torres Strait Islander) people in the Yilli Rreung (greater Darwin) region. DDHS is primarily funded by the Australian Government through the Department of Health. We provide services from eight locations, reaching more than 12,000 people, approximately 60 per cent of the Aboriginal population residing in the Darwin/Palmerston region. We employ over 130 people (over 70 per cent are Aboriginal and Torres Strait Islander).

Comprehensive primary health care encompasses the range of health care generally offered by general practice but extends beyond that to provide specialist and allied health professionals; health promotion and education; care coordination for clients with complex health needs; social emotional wellbeing (**SEWB**) and alcohol other drugs (**AOD**) services.

We note that the terms of reference of this inquiry focus on the prevention and detection of Fetal Alcohol Spectrum Disorder (**FASD**), which is a spectrum diagnosis with a range of presentations relating to severe neurodevelopmental impairment, resulting from exposure to alcohol in utero. DDHS provides a range of services to children and families relevant to this inquiry. These include:

- Family support and strengthening through the Australian Nurse Family Partnership Program (**ANFPP**) which is a nurse led, sustained home visiting program that supports women pregnant with an Aboriginal or Torres Strait Islander child to improve their own health and the health of their baby;
- A contraception clinic that helps women plan families and a collaborative midwife lead model of antenatal care. These are both integrated in primary health care services close to home.
- An assessment and planning clinic for children with behaviour and development problems (**The ABCD Clinic**). FASD diagnosis is part of the ABCD collaborative service model;
- Youth support services, including a youth social support team based six-days a week at Don Dale Youth Detention Centre (**Don Dale**), to provide social emotional wellbeing services and programs to children in youth detention; and
- We will also soon begin delivery of primary health care services to children in detention through a clinic at Don Dale.

DDHS and NT Legal Aid Commission (**NLAC**) started a health justice partnership in 2016 to assist DDHS clients to get better access to legal help if they need it. In 2018-19 this service expanded, providing lawyer appointments at Palmerston and Malak clinics in addition to services at the Darwin clinic, and into new areas of collaboration between our organisations. NLAC has provided training to doctors at DDHS about the National Disability Insurance Scheme (**NDIS**) and how to make effective referrals so our clients can get the disability services they need. We have also been expanding our collaboration in the youth justice space, exploring the best model to meet the needs of children in detention.

Our submission is informed by our experience delivering these services, and working directly with Aboriginal children and families affected by FASD and other forms of neurodevelopmental impairment in the NT. Our submission has also been developed with input from the NLAC civil team as well as reference to submissions developed by the Northern Australian Aboriginal Justice Agency, and Aboriginal Medical Services Alliance.

## Executive Summary

There has been a longstanding, discriminatory approach to discussions about FASD prevention and detection in the Northern Territory (NT). It is important to note that the non-indigenous population also suffers acutely from the harms of risky alcohol consumption in the NT, and FASD is not an issue confined to Aboriginal communities. Effective responses must be directed at the whole community, creating generational change and shifting societal norms about alcohol consumption to eradicate FASD.

DDHS is an Aboriginal Community Controlled Health Organisation (**ACCHO**), built by a community that empowered itself to establish, manage and deliver health services to its own people. Therefore, our submission will focus on the prevention, assessment and treatment of FASD in our Aboriginal communities. Moving forward necessitates a strengths based-approach, embedded in community control and empowerment.

Our submission focusses on the benefits of delivering a comprehensive primary health care model, integrating prevention, education, early assessment and intervention services into primary health care. Our experience demonstrates that Aboriginal Community Controlled Health Services are best placed to delivery these services - leveraging off existing relationships of trust in order to ensure continuity of care and support throughout the client journey. A holistic approach to FASD prevention, assessment and treatment, delivered by Aboriginal community controlled health services, is likely to produce the best outcomes for Aboriginal children and families.

Our submission highlights some of the challenges in this context, drawing attention to the complex needs of our clients, and to the staffing and funding challenges in providing a safe and effective service. We highlight the need for broad population focussed prevention strategies that encompass the reduction of demand, supply and consumption of alcohol across the community as a whole, noting that in the context of our clients, these strategies must recognise and address the social determinants underlying alcohol misuse and other overlapping vulnerabilities.

## Recommendations

1. The Commonwealth Government should encourage the Northern Territory Government through the COAG, to maintain its commitment to implement broad measures to limit alcohol supply and reduce alcohol related harm in the community.
2. Comprehensive, sustained awareness particularly among vulnerable groups to create generational change, shifting societal norms around alcohol consumption to eradicate FASD. In Aboriginal Communities, this education and information should be developed and delivered by local Aboriginal Community Controlled Health Services.
3. The Commonwealth Department of Health should provide increased funding in the Indigenous Australians Health Program to address emerging issues (like FASD). This will enable further impact in primary health care and child and maternal health services through an integrated service model.
4. The Commonwealth Department of Health either fund the expansion of the Australian Nurse Family Partnership Program (**ANFPP**) model into the early stages (first trimester) of pregnancy, or develop an alternative sustained, culturally-appropriate program to provide intensive supports including health education to women at the early stage of pregnancy.

5. The Northern Territory's Mandatory reporting requirements (particularly under s 26 of the *Care and Protection of Children Act*) should be reviewed. The impact requirements are having on women seeking support with alcohol cessation or ante-natal care should be considered.
6. The Commonwealth Department of Health and Northern Territory Primary Health Network collaborate to ensure funding to engage specialist services, including a paediatric neuropsychologist, in the DDHS Assessment Behaviour Child Development (ABCD) Clinic.
7. The Commonwealth Government should make the necessary directions under section 19(2) of the Health Insurance Act 1973 (Cth) to enable the payment of Medicare benefits for medical services provided to children and young people in detention in the Northern Territory.
8. The Commonwealth Government should ensure that the National Disability Insurance Scheme (NDIS) is made available in a consistent way to ensure support is provided for children in detention with FASD.
9. The Commonwealth Government should ensure that the National Disability Insurance Scheme (NDIS) is available to fund the provision of support for children in detention with FASD in a consistent way. In particular, the availability of providers of these therapeutic supports for children in detention should be reviewed to ensure that NDIS plans are actually implemented in detention.
10. Evidence-based FASD training should be developed and delivered to all staff working with children and young people in the Northern Territory's youth detention system.
11. Commonwealth and Northern Territory Governments should coordinate to provide funding for the development and implementation of a therapeutic secure facilities for children with high needs relating to their disabilities, including children in the justice system. These should be developed in partnership with local Aboriginal Community Controlled Health Services

## Northern Territory Context

The Northern Territory (**NT**) has the highest per capita consumption of alcohol in Australia.<sup>1</sup> In fact it is amongst the highest in the world.<sup>2</sup> In 2016, 28 per cent of people in the Northern Territory exceeded the lifetime risk drinking guideline and 36 per cent exceeded the single occasion risk guideline.<sup>3</sup>

Both Aboriginal and the non-indigenous populations suffer acutely from the harms of risky alcohol consumption in the NT. FASD is an issue confronting the whole community, however, there has been a longstanding, discriminatory approach to discussions about FASD prevention and detection in the NT. Derived from fundamentally racist policies of assimilation, alcohol policies in the NT have, since colonisation, been justified rhetorically by

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<sup>1</sup> Northern Territory Department of the Attorney General and Justice. (2017). Northern Territory Wholesale Alcohol Supply 2008 to 2015, p. 3.

<sup>2</sup> Loxely, W. et al 2016, National Alcohol Sales Data Project (NASDP) Stage Five Report 2016, national Drug Research Institute, Curtin University, Perth. World Health Organization 2014, Global Information System on Alcohol and Health (GISAH).

<sup>3</sup> Australian Institute of Health and Welfare, 'National Drug Strategy Household Survey 2016: Detailed findings, 88.

a discourse that, as academic Peter d'Abbs suggests 'counter poses "most Territorians" against "problem drinkers", thereby encoding racial distinctions in non-racial symbols'.<sup>4</sup> The rhetoric of needing to address the issue of 'problem drinkers' with clearly racial overtones has since become even more deeply embedded within dominant NT alcohol policy discourse, permeating fundamentally flawed policy and decision making in this area.

As d'Abbs further proposes:

*These changes mask an important continuity: Aboriginal alcohol problems continue to be defined not by the Aboriginal families and communities who directly experience them, but by non-Aboriginal people according to their perceptions and priorities.*<sup>5</sup>

In light of this, we believe that solutions in this area must be driven by Aboriginal people and communities. Aboriginal and Torres Strait Islander people account for 32 per cent of the NT population, the majority living in remote or very remote communities (80 per cent). National data indicates that overall, Indigenous Australians are more likely to abstain from drinking alcohol than non-indigenous Australians (31 per cent compared with 23 per cent respectively).<sup>6</sup> However, among those who do drink, a higher proportion of Indigenous Australians drink at risky levels (35 per cent compared with 25 per cent for non-indigenous Australians for single occasion risky drinking).<sup>7</sup> DDHS has found this national data is consistent with the AUDIT-C<sup>8</sup> scores for our client population.

Despite this, very little evidence has been gathered about the prevalence of FASD, a disorder caused by the effects of consuming alcohol during pregnancy. Researchers and authorities are, at this point, only able to assume a higher prevalence of FASD in the NT compared with other lower consuming jurisdictions. As the NT FASD Strategy noted:

*FASD prevalence in the NT is unknown, and there are no national estimates of the prevalence of FASD in Australia. Anecdotally, we know that many NT children are experiencing learning difficulties, have difficulty controlling their emotions and impulses, and many of our young people are coming into contact with the juvenile justice system.*<sup>9</sup>

Recognising the need for Aboriginal community control in this area, in May 2018, the Aboriginal Peak Organisations NT (**APO NT**) hosted a landmark Top End forum on FASD, bringing together Aboriginal leaders, FASD experts, Aboriginal community-controlled organisations, government representatives, medical professionals, and Non-Government organisations.<sup>10</sup> In his opening remarks at this forum, John Paterson, the CEO of the Aboriginal Medical Services Alliance NT (**AMSANT**) said:

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<sup>4</sup> D'Abbs, Peter. "Problematizing alcohol through the eyes of the other: alcohol policy and Aboriginal drinking in the Northern Territory, Australia." *Contemporary Drug Problems* 39, no. 3 (2012): 371-396, p. 381.

<sup>5</sup> Ibid p. 390.

<sup>6</sup> Australian Institute of Health and Welfare, 'National Drug Strategy Household Survey 2016: Detailed findings at 108.

<sup>7</sup> Ibid.

<sup>8</sup> AUDIT-C: Alcohol Use Disorder Identification Test – Consumption was introduced into the DDHS health check in 2018. The tool has three short questions that estimate alcohol consumption in a standard, meaningful and non-judgmental manner.

<sup>9</sup> Northern Territory Department of Health, *Addressing Fetal Alcohol Spectrum Disorder (FASD) in the Northern Territory 2018-2024 ('NT FASD Strategy')*.

<sup>10</sup> See <http://www.amsant.org.au/apont/fasd-forum-2018/>

*...Foetal Alcohol Spectrum Disorder, or FASD, has a devastating impact on Aboriginal women, their children, families and communities. The individual and community impacts of this entirely preventable disorder are compounded by the fact that FASD also places a heavy burden on our systems of health, education and justice.... It's important to acknowledge that while the burden of this disease weighs most heavily on the families who are directly impacted and must live with it every day, **the underlying causes of FASD are spread across our communities and demand of us collective action to find solutions.** (Emphasis added)*

## Prevention

### Addressing the social determinants

DDHS encourages the committee of this Inquiry to look beyond the Terms of Reference and not to ignore the underlying social determinants of alcohol misuse, and child vulnerability. The World Health Organisation defines the social determinants of health as:

*the conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries.<sup>11</sup>*

Data demonstrates that an Aboriginal family in the NT is more likely than any other family to experience negative factors related to these social determinants.<sup>12</sup> This is consistent with evidence submitted to the Royal Commission into the Protection and Detention of Children in the Northern Territory (**Royal Commission**) that many Aboriginal children in the NT experience developmental delays and an array of complex needs that require appropriate treatment and support, due to the circumstances of their upbringing.<sup>13</sup>

Widely available evidence also demonstrates that early life trauma is associated with family violence, physical or emotional abuse and neglect, removal from family or involvement in the care and protection system, that may disrupt a child's emotional development and is a significant risk factor for alcohol misuse, depression, suicide and anti-social criminal behavior.<sup>14</sup> Brain structures that regulate emotion, behaviour and impulsivity are also less developed in young people who have experienced trauma.<sup>15</sup> Unfortunately, Aboriginal people are statistically more likely to have been affected by these and other trauma-inducing events.

It is our view that addressing alcohol misuse and FASD cannot be uncoupled from recognising and addressing the experience of trauma and other complex social challenges. ACCHOs have a key role to play in driving change in Aboriginal Communities in this area. This was recognised by the Northern Territory Department of Health's FASD Strategy:

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<sup>11</sup> World Health Organisation, Social Determinants of Health, Accessed 12 December 2019 at [http://who.int/social\\_determinants/sdh](http://who.int/social_determinants/sdh)

<sup>12</sup> AHMAC 2017. Aboriginal and Torres Strait Islander Health Performance Framework. Canberra. <http://www.health.gov.au/indigenous-hpf>

<sup>13</sup> See Professor Sven Silburn, evidence to the Royal Commission <https://childdetentionnt.royalcommission.gov.au/NT-public-hearings/Documents/transcripts-2017/Transcript-19-June-2017.pdf>

<sup>14</sup> See, Professor John Boulton, Statement to the Royal Commission, 6 October 2016, 56 (ii). P 6

<sup>15</sup> Samantha Buckingham. Legal Studies Paper No. 2016-2017. 'Trauma Informed Juvenile Justice'. 53 American Criminal L. Rev. 641. 2016



## Therapeutic approach to alcohol harm minimisation

DDHS believes that broad population focused prevention strategies must encompass reduction of demand, supply and consumption of alcohol across the community as a whole, in a way that does not stigmatise or isolate women. This was echoed by the sentiment of delegates at the APO NT FASD Forum who agreed that there was an urgent need for action to prevent FASD in our Top End communities, and across the NT:

*It is essential that our responses do not stigmatise women or Aboriginal people. It is important that we don't lay blame, but instead work together, to support our women and young girls. Everyone is at risk of FASD, so everyone must be informed of the harmful effects of drinking while pregnant. Our men also need to step up and support our mothers, sisters, nieces and partners, to ensure that we give every child the best chance in life.*

As DDHS submitted to the The Alcohol Policies and Legislation Review 2018 (**The Riley Review**),<sup>17</sup> a true harm minimisation approach to alcohol policy and legislation must be situated within a therapeutic framework that:

- recognises both the strengths and disadvantages of the community in dealing with alcohol and its consequences;
- is based on evidence about the nature and causes of alcohol related harm;
- offers therapeutic pathways to those experiencing problematic alcohol use rather than punitive approaches that inappropriately criminalise the results of social disadvantage and trauma;
- offers a range of acceptable and effective treatments to those who wish to reduce alcohol use;
- incorporates primary health care into the process;
- improves the safety and well-being of people currently involved in risky alcohol use; and
- regulates supply of alcohol in an evidence based way.<sup>18</sup>

The Riley Review recommended a range of measures to reduce alcohol supply and consumption in the NT. These measures included:

- the need for a complete rewrite of the current Liquor Act to provide a coherent framework for the operation of the liquor industry within harm minimisation principles;
- addressing significant issues including the density of alcohol retail outlets, prohibiting all takeaway sales on Sundays, implementing an immediate moratorium on takeaway

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<sup>16</sup> This was recognised by the Northern Territory Department of Health's FASD Strategy: *Addressing Fetal Alcohol Spectrum Disorder (FASD) in the Northern Territory 2018-2024*.

<sup>17</sup> Danila Dilba Health Service, Submission to the Northern Territory Legislative Assembly Select Committee on Alcohol Policies and Legislation Review.

<sup>18</sup> See Gray, D. W. (2010). Reducing alcohol and other drug related harm. Resource sheet no. 3. Produced for the Closing the Gap Clearinghouse. Canberra: Australian Institute of Health and Welfare and Australian Institute of Family Studies. Retrieved from <http://www.aihw.gov.au/uploadedFiles/ClosingTheGap/Content/Publications/2010/ctgcrs03.pdf>



liquor licences, and phasing out store licences to reduce the number of corner grocery stores that sell alcohol;

- the introduction of a floor price for alcohol products to reduce the availability of dangerously 'cheap' alcohol; and for the government to continue to lobby the Australian Government for the introduction of a volumetric tax.

As the Northern Territory Government's Submission to this inquiry indicates, the implementation of these recommendations is underway. We recognise the promising early results of these reforms, including a 21 per cent decrease in domestic violence incidences in the NT between the floor price's introduction on 1 October 2018 and 31 July 2019.<sup>19</sup> We commend the Northern Territory Government for taking these steps to reduce alcohol supply and consumption, and recommend the sustained commitment to these measures.

**Recommendation (1)** The Commonwealth Government encourage the Northern Territory Government to maintain its commitment to implement broad measures to limit alcohol supply and reduce alcohol related harm in the community.

## Community education

Community education strategies present a key opportunity to both change individual behaviours, and shift societal attitudes, norms and myths surrounding alcohol consumption in pregnancy. Adequately addressing the root causes of FASD therefore necessitates a range of primary, secondary and tertiary prevention strategies, in order to effectively educate high-risk demographics, as well as challenge social norms around general alcohol consumption.

While secondary and tertiary strategies generally refer to those implemented by health professionals, primary prevention strategies present an opportunity to target not only pregnant women, but but people planning families, high-risk demographics and the general population from an early age.

The National Indigenous Drug and Alcohol Committee (**NIDAC**), the leading Indigenous policy agency in this field, recommends a range of actions in relation to prevention and community education. While it should be recognised that best-practice community education approaches to the prevention of FASD may differ between urban, rural and remote settings, DDHS operates in a primarily urban context, for which the following measures have been identified by NIDAC:<sup>20</sup>

- Targeted social marketing campaigns to continue being developed and delivered by the Australian Government. Tailored to different cultural contexts identified within high-risk groups, these should discourage of unsafe levels of alcohol consumption within the general population, and raise awareness in the community of the potential impact of alcohol on the developing fetus;

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<sup>19</sup> Chelsea Heaney 'Alcohol-related domestic violence and assaults drop dramatically one year on from floor price introduction' ABC News (Online) 18 October 2019, <https://www.abc.net.au/news/2019-10-18/domestic-violence-assualts-drop-alcohol-floor-price-nt/11619046>

<sup>20</sup> National Indigenous Drug and Alcohol Committee, *Addressing fetal alcohol spectrum disorder in Australia* (2012) <https://aodknowledgecentre.ecu.edu.au/healthinonet/getContent.php?linkid=575971&title=Addressing+Fetal+Alcohol+Spectrum+Disorder+in+Australia>

- Holistic integration of primary prevention strategies into the education system, incorporating measures to shift behaviours and attitudes at the individual level, in addition to community attitudes which uphold the current drinking culture and environment in Australia;
- The development of consistent health-promoting messages surrounding alcohol consumption which highlight the risk of alcohol consumption across the life cycle, but which particularly emphasise that no amount of alcohol consumption is safe during periods of pregnancy or breast feeding;
- Community education campaigns which are situated within the broader context of addressing harmful drinking, contributing to a societal shift in drinking culture, and ensuring that instead being stigmatised, expectant mothers feel supported to access and receive the assistance they need in order to adhere to such advice.

As AMSANT noted in its submission to this Inquiry, ACCHOs are well-placed to ‘*deliver education and community information locally ... in a culturally safe and effective way.*’<sup>21</sup> Through our community engagement and health promotion programs, DDHS implements a number of initiatives that improve health literacy, and encourage health-seeking behaviours across the life course. Taking place at community events and in schools, these programs equip individuals and communities with the knowledge, understanding, and access to resources that enables them to feel empowered about their health from an early age.

**Recommendation (2)** Comprehensive, sustained awareness particularly among vulnerable groups to create generational change, shifting societal norms around alcohol consumption to eradicate FASD. In Aboriginal Communities, this education and information should be developed and delivered by local Aboriginal Community Controlled Health Services.

## Holistic Approach to Primary Health Care

Primary Health Care is effective and important source of information, motivational and therapeutic counselling for Aboriginal women across their life cycle. While interventions to reduce alcohol use as part of antenatal care are critical (as discussed below), primary health care services should also be sufficiently funded to intervene earlier than this, screening for alcohol use and offering health information, advice and support for all women, particularly those of child-bearing age.

While primary prevention must be the focus, the ability to engage women of childbearing years to address anaemia, smoking, alcohol and other health issues specifically is the role of an integrated service. Through our primary health care services, DDHS strives to build relationships of trust with Aboriginal women, across the Darwin-Palmerston region. In light of this, our GPs, nurses, midwives and Aboriginal health practitioners are well-placed to provide brief interventions to support women (before, during and after pregnancy) and in the cessation of alcohol use.

The role of our family support workers and outreach teams are also crucial in this process, to build relationships of trust and support with women and their families both before and during pregnancy, and after childbirth. These interventions, at the individual level, are crucial to reducing risky alcohol use, and increasing health education.

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<sup>21</sup> Aboriginal Medical Services Alliance Northern Territory (**AMSANT**) Submission to Senate Inquiry into effective approaches to prevention, diagnosis and support for FASD, at p 3.

Primary health care is also an important entry point to antenatal care for the majority of pregnant women. It is well-known that pregnancy can be an effective time to offer brief interventions in relation to health behaviours as parents are receptive to health messages at this time. However, health professionals need to be well-equipped with information, and need to have the capacity to support these interventions and subsequent referrals.

DDHS recommends increased funding for ACCHOs to enable further impact in primary health care and child maternal health services through the provision of:

- An integrated clinical model to provide brief interventions to support women and make referrals for women seeking to cease alcohol use;
- Funding to increase outreach capacity across primary health care teams, and child maternal health services to take the services to the clients;
- Additional substance abuse treatment services suitable for pregnant women who identify as needing support for alcohol cessation, particularly those who already have children.

**Recommendation (3):** The Commonwealth Department of Health provide increased funding in the Indigenous Australians Health Program to address emerging issues (like FASD). This will enable further impact in primary health care and child and maternal health services through an integrated service model.

## Culturally Appropriate Antenatal Support

### *Australian Nurse Family Partnership Program*

The Australian Nurse Family Partnership Program (**ANFPP**) is a nurse led, sustained home visiting program that supports women pregnant with an Aboriginal or Torres Strait Islander child to improve their own health and the health of their baby. Clients receive continuity of care through regular home visits from a Nurse Home Visitor and a Family Partnership Worker from 16 weeks' gestation until the baby is two years old.

The team of four nurses and their managers are based at our clinic in Malak and about 80 per cent of DDHS's current pregnant and new mother clients are using the service. In 2018-19, 51 mothers were part of the DDHS ANFPP program. The program aims to:

- Improve pregnancy outcomes;
- Support parents to improve child health and development; and
- Support parents to develop a vision for their own future.

Service delivery embraces empowering client-centred principles. The ANFPP recognises the positive impact of culturally safe service delivery within Aboriginal and Torres Strait Islander communities, which is why a Family Partnership Worker contributes to our home visits. Our Family Partnership Workers and Nurse Home Visitors promote trust and respect between our clients and their family, the Aboriginal community and health providers.

### *Collaboration with Midwives*

Prevention efforts targeted at women as part of antenatal care are of key importance. Under the DDHS integrated service model of care, all antenatal services and services for mothers and children are integrated across DDHS clinics.

Women are referred to the ANFPP at 16-weeks' gestation, unfortunately it is usually 'too late' to prevent early in-utero exposure if the mother is currently drinking. The current ANFPP program can only really have an impact on FASD prevention in future pregnancies.

This collaborative model involving midwives, GPs, Aboriginal Health Practitioners and Obstetricians could be further strengthened by expanding the ANFPP program into the first trimester and integrating this into the service model. This may require a shift from the absolute fidelity of the model, in recognition of the different cultural context and challenges, as well as the context of our social support system.

**Recommendation (4):** The Commonwealth Department of Health either fund the expansion of the Australian Nurse Family Partnership Program (**ANFPP**) model into the early stages (first trimester) of pregnancy, or develop an alternative sustained, culturally-appropriate program to provide intensive supports to women at the early stage of pregnancy.

### *Mandatory Reporting Requirements*

The ANFPP team are able to develop meaningful therapeutic relationships through the quality time they get with mothers. They also have good working relationships with the DDHS midwives to support antenatal care. Through this approach they are able to identify early concerns and provide support for women during and after pregnancy. Our ANFPP team are able to leverage relationships of trust to talk to pregnant women about the risks of alcohol consumption, contraception methods and general health and well-being strategies.

However, our ANFPP team have raised their concerns that in some cases, the NT's broad mandatory reporting requirements<sup>22</sup> may be jeopardising the development of these relationships of trust, and to deterring women from help-seeking behaviour. In this context, some women may fear that disclosing drinking during pregnancy, even if it has ceased, places them at risk of a notification of risk of 'abuse' or 'neglect', which may lead to child removal. This fear likely exacerbated due to underlying fear and mistrust of the system - the legacy of the stolen generation.

There is a lot of confusion and misinformation, particularly in the community, about what types of harm need to be reported and the consequences of reporting.<sup>23</sup> This may be having unintended consequences, including preventing people from attending clinics or entering into the program. Our ANFPP team remain concerned that the broad mandatory reporting obligations erode or in some cases prevent a relationship of trust between the team and their pregnant clients.

Acknowledging the confusion regarding mandatory reporting requirements, the Royal Commission recommended that mandatory reporting guidelines be developed, and information seminars be held to assist notifiers in meeting these obligations.<sup>24</sup> This recommendation is a start, but also given the unintended consequences that mandatory reporting may be having, these requirements should also be further reviewed. Our ANFPP

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<sup>22</sup> S 26 of the Care and Protection of Children Act (NT) makes it a criminal offence for person who believes on 'reasonable grounds' that a child has suffered or is likely to suffer harm or exploitation.

<sup>23</sup> See feedback from community consultations in the report prepared by the Aboriginal Medical Services Alliance NT in 2018: Listening and Hearing are Two Different Things (2018) at p7. <http://www.amsant.org.au/wp-content/uploads/2018/07/Listening-and-Hearing-are-Two-Different-Things-Final-Report-6-July-2018.pdf>

<sup>24</sup> Royal Commission Final Report, Recommendation 32.4

team and clinical teams are well-placed to support pregnant women to stop or reduce consumption of alcohol while pregnant and are best placed to refer those clients to additional supports if required.

**Recommendation (5):** The Northern Territory's Mandatory reporting requirements (particularly under s 26 of the *Care and Protection of Children Act*) should be reviewed. The impact requirements are having on women seeking support with alcohol cessation or ante-natal care should be considered.

## Early Assessment and Diagnosis

There are multiple overlapping social factors that contribute to child developmental delay. As noted above, the impact of trauma and social determinants of health in this context must not be ignored. In light of this, we believe that taking a holistic approach to child health, integrating early assessment and intervention services into primary health care is likely to achieve the best outcomes for children and families. As AMSANT also submitted to this Inquiry, there needs to be a comprehensive screening and assessment process, beyond a narrow focus on FASD.

As with all complex learning and behaviour diagnoses, it is difficult to make a FASD diagnosis under the age of 7, however early assessment and intervention is important to long term outcomes and to ensure access to appropriate services. In particular, FASD and functional assessments are helpful in facilitating access to the NDIS, and in ensuring access to relevant supports for children and their families. Primary Health Care services play a key role in coordinating assessments and interventions in this space. This was recognised by the NT FASD Strategy:

*Within current resources, there will be a renewed focus on ensuring that primary health care staff are educated so that abnormalities can quickly be recognised and assessed. NT Health will increase the use of telehealth services for specialist advice when developmental concerns in children are identified, particularly in remote areas.<sup>25</sup>*

## Collaborative Assessment of Behaviour and Child Development Clinic

Over the past few years DDHS has worked in partnership with the Top End Health Service (TEHS) Paediatric Department to improve specialist services for Aboriginal and Torres Strait Islander children in the Darwin/Palmerston region. In 2014, we established our own paediatric specialist service at the Palmerston Clinic in partnership with the Royal Darwin Hospital (RDH), which hosted visiting registrars and specialists. By 2018, we recorded a 26 per cent increase in paediatric specialist referrals and it became clear that our paediatric clinic needed to be reviewed to develop a more sustainable model.

Building on learnings from the DDHS paediatric clinic, in February 2019, with the assistance of NT Department of Health funding,<sup>26</sup> and funding as part of a research project with PATCHES Paediatrics,<sup>27</sup> DDHS established an Assessment of Behaviour and Child Development Clinic (**ABCD Clinic**) to support families and children with learning, behavioural and development issues.

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<sup>25</sup> NT FASD Strategy at p 20.

<sup>26</sup> Arising out of the NT FASD Strategy.

<sup>27</sup> A nationally funded research and service development project, with a vision of building a private public assessment and planning service with sites across Australian. Funding for this research helped support an additional DDHS child health project officer position.

These assessment processes, including for FASD, are complex and multidisciplinary and, involve ruling out vision and hearing problems, neuropsychological assessment, as well as assessment by paediatricians, OT, physios and speech pathologists. For our clients, given the impact of trauma and overlapping vulnerabilities (as outlined above) we consider it critical that this process is embedded in a primary health care setting. The ABCD Clinic is holistic, and aims to strengthen continuity.

The existing service aims to:

- Support Aboriginal families, children and carers to establish diagnoses, and support plan for children with development and behaviour difficulties including FASD;
- Strengthen capacity of specialist and PHC staff in assessment and planning for children with development and behaviour difficulties;
- Engage children and their families in PHC and specialist follow up and to identify children who are eligible for NDIS funded services;
- Improve access to allied health services for DDHS child clients.

The collaborative model brings together the expertise of DDHS staff with knowledge of community and primary health care, paediatricians and registrars with an interest, knowledge and skill in development, behaviour, assessment and management. FASD assessment is also an integral part of the ABCD assessment process, particularly given the implication that a FASD diagnosis can have on availability of supports, particularly through the National Disability Insurance Scheme (**NDIS**).

As outlined above, there are multiple overlapping vulnerabilities affecting many of our clients and their families. Our ABCD clinic staff report that one of the major difficulties is keeping in contact with families and children throughout the assessment process. Factors such as poverty and homelessness make it difficult to complete the several assessments required to obtain a FASD or other diagnosis. DDHS finds it difficult to keep in contact with families who have to keep moving both within the Darwin area and outside of Darwin due to these factors. Unfortunately, it is also these families who are likely to suffer from the harmful effects of alcohol consumption and would be at higher risk of children presenting with FASD.

In light of this, our ABCD Clinic strives to ensure holistic engagement, assessment and case coordination, building on relationships of trust to assist families to navigate complex referral pathways and systems. This involves assisting children and families to access all relevant assessments and supports to meet the child's complex and overlapping needs (e.g vision, hearing, impact of trauma and other developmental concerns) as well as assisting with other challenges like accessing safe accommodation.

This ABCD clinic is based at the Palmerston clinic. Next year we are moving towards an even more integrated approach, with a view to having one ABCD model, with clinics alternating out of our Bagot Community and Palmerston. We hope to have the NT Government Child Development team better integrated in this service, as well as SEWB psychologists using the assessment to enable diagnosis.

### Case Study

Leanne\*, a DDHS client, is the carer for her three grandchildren. One of the children was suspected of having autism, one was suspected of having ADHD, and all three had a history of trauma and suspected in-utero alcohol exposure. The children all came into Leanne's care with foetal incontinence, difficulty learning and regulating behaviour. At this Territory Families were also involved as the school had made reports of concern regarding the children and



were particularly concerned about the children's behaviour. Leanne was terrified of losing the children, whom she loved and cared for dearly.

At this time the family came to the attention of the ABCD Clinic project officer through a referral from Leanne's regular DDHS clinic. Given the complexity of the case, it was decided that it was necessary to convene a case conference to develop an assessment and treatment plan. Through engagement with her local clinic, Leanne was supported to keep the assessment process on track, including referrals for hearing, vision and other relevant assessments. The children were engaged with several support services, including occupational therapy and play therapy to help address their complex trauma.

Working across the DDHS services, a social worker from our SEWB team was also engaged to assist Leanne with a range of other challenges, for example arranging furniture for the house.

While there is no formal collaboration with the Department of Education, Department of Housing or Territory Families, the collaborative model has strengthened our communication processes with these, and other relevant stakeholders. Our priority continues to be ensuring that children and families receive access to the therapeutic supports that they require, including where there is a diagnosis. Our work in this space is evolving, particularly in supporting clients to access supports under the NDIS.

## Challenges assessing for FASD

### Facilitating access to assessments

The process for children and their families can be complex and involve several assessments and several providers including schools. Despite GPs ensuring that they make all the necessary referrals and provide all the assessment tools to progress the child in the assessment process, families can find it challenging to organise appointments and follow up paperwork. As noted above, another difficulty is that many of our clients are very transient, so it can be difficult to arrange follow up appointments.

Our ABCD Clinic strives to ensure continuity of care, and so DDHS has prioritised the allocation of resources to engage and assist families through this process by building on relationships of trust. A project officer was recruited to organise appointments and provide clinical and family support on clinic days for the ABCD Clinic. Our paediatric registrars and paediatric nurse engage with the family to develop a relationship of trust and provide clarity about the processes.

### Staffing the model

One of the major challenges in providing a safe and culturally appropriate paediatric assessment service has been staffing the model. This is particularly so in relation to FASD assessment, which require a specialised multi-disciplinary team, including a paediatric neuropsychologist, OT, speech pathologist and Aboriginal health practitioner.

The ABCD clinic does not have all these services in-house, and so relies on referrals. We were hoping to engage a neuropsychology services (from the Charles Darwin University psychology department) however this did not end up being possible. We have been able to engage external providers of hearing, eye, speech, physio and occupational therapy (OT) services, however again, referrals to these services take time and can delay the process, which we aim to have completed within six months.

By way of comparison, the Central Australian Aboriginal Congress (**Congress**), an Aboriginal Community Controlled Health Service in Alice Springs has a Child and Youth



Assessment and Treatment Service team, which was established in April 2018. The team has grown substantially over this time and now includes a team leader, two neuropsychologists, two speech pathologists, one OT, one Aboriginal Family Support Worker and a Clinical Case Coordinator. This service is able to see six children over a six week period for a differential assessment.

Due to our resourcing restraints, and the focus on integrating services within primary health care, our ABCD model is more directed at process. This model could be significantly strengthened through additional funding to engage allied and specialist services on an ongoing basis. In particular, the model would really benefit from access to a qualified paediatric neuropsychologist to undertake FASD assessments.

**Recommendation (6):** The Commonwealth Department of Health and Northern Territory Primary Health Network collaborate to ensure funding to engage specialist services, including a paediatric neuropsychologist, in the DDHS Assessment Behaviour Child Development (ABCD) Clinic.

### Case load and time frames

Since establishing the ABCD Clinic, we have been inundated with referrals for assessment. In particular, in light of increasing awareness of FASD following the Royal Commission, we have seen a significant increase in referrals from Territory Families and legal services for children in the youth justice and child protection systems. The challenge with these referrals is that they often have to be turned around relatively quickly, for example with an upcoming Court deadline.

Our process (coordinating relevant referrals and assessments, building rapport and trust with the client) an 'all in one day' assessment model, like other provides such as PATCHES. Our model relies on the development of relationships of trust with children and families, to facilitate a process that is culturally strengthening and holistic. Based on our current resources, we strive to complete the assessment process within six months.

Given these current time frames, the ABCD clinic assessment process is not really suited to clients in the youth justice system, who generally require reports with a quick turn around. However, DDHS taking over the provision of primary health care in Don Dale Youth Detention Centre, presents a significant opportunity to increase the capacity of the service, and fast-track these processes, ensuring culturally appropriate assessment and support for children in the youth detention system.

This service would be significantly enhanced through the provision of Medicare funding, in line with recommendations of the Royal Commission.<sup>28</sup> The use of Medicare for young people in detention is a policy decision that can be accommodated under section 19(2) of the *Health Insurance Act*. Indeed, all community controlled Aboriginal health services and all remote state government Aboriginal health clinics already hold a section 19(2) exemption allowing billing under Medicare. These exemptions recognise the high level of health needs of Aboriginal people and the fact that Aboriginal people do not access Medicare through private general practice at the same level as the rest of the population. In this context, this is an opportunity to better support health among vulnerable young people.

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<sup>28</sup> Royal Commission Final Report, Recommendation 15.4.

**Recommendation (7):** The Commonwealth Government should make the necessary directions under section 19(2) of the Health Insurance Act 1973 (Cth) to enable the payment of Medicare benefits for medical services provided to children and young people in detention in the Northern Territory.

## Interventions and Support for Children and Families

### Multidisciplinary Assessments

A FASD diagnosis or functional capacity assessment can help children and families to better understand behaviours and challenges, and put in place strategies to manage these. Our clients often struggle to understand and get the support that they need, and do not understand the significance of assessments, and the impact these could have on their lives. As noted above, there are significant challenges in keeping in contact with these families and children throughout the assessment process.

Assessments of functional capacity and FASD are particularly important as they can help clients to gain access to relevant supports, including through the NDIS. At DDHS this process has been strengthened through our health-justice partnership with the Northern Territory Legal Aid Commission, through which we are able to work collaboratively to assist children, parents and carers to navigate the complex legal and other processes.

In his evidence to the Royal Commission, Dr James Fitzpatrick discussed the importance of ensuring access to multidisciplinary assessments to determine functional capacity. He noted at [20] that:

The neuropsychologist is in a good position to establish the functional implications of a child's unique profile to inform psychoeducation and facilitate a better understanding of the child's functioning, with the opportunity for ongoing review and assessment as the child develops. Such assessments are typically multi-faceted, and require an understanding of the complex neuropsychological, clinical, forensic and educational implications of neurodevelopmental conditions, often within a cross-cultural context.<sup>29</sup>

In light of increasingly available evidence regarding the prevalence and effects of FASD, Territory Families, the Courts and legal practitioners have increasingly recognised the utility of assessments, to identify neuro-disability and inform treatment or case management plans. In Darwin, individual assessments are becoming more readily available and accessible to children in the justice and child protection systems through referrals to private providers including PATCHES paediatrics. However for families with children that are not in these systems, these assessments are generally unaffordable, and so inaccessible. This is the gap that the ABCD clinic seeks fill, however as outlined above there are significant resource restraints that limit the availability of this service.

### Education and capacity building for families

Once a child has a FASD diagnoses, there is a need for education and capacity building for their family (or carers) to understand the condition, and help support the child's education, regulation, behaviour, and social skills going forward. There is often a particular focus on behaviour management, for example the Riley Review recommended that:

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<sup>29</sup> Dr James Fitzpatrick, Evidence presented to the Royal Commission into the Protection and Detention of Children in the NT (2017), at [20].

- 3.7.13 Additional funding be allocated to the development of more residential secure care facilities for the delivery of behavioural management programs to the cognitively impaired, including FASD individuals.
- 3.7.14 Community based health organisations and social service providers be funded to provide evidence based behavioural management programs for FASD individuals. The programs should be linked to the FASD support service.

In our view, we must extend the conceptualisation of the challenges for these children and families beyond behaviour management to include broader skills development. Whilst it is important to help parents and carers develop a different set of skills to work with these young people, it is not just about managing difficult behaviours, the risk being that difficult behaviours may become a single reference point for the support.

The parents and carers of children with FASD also need to be able to support them with the development of life and education skills, particularly in the context of challenges in daily activities including learning, attending, sitting still, regulating and impulse management.

It has been our experience that even where a young person is assessed and approved access to NDIS, outside major cities there is very poor access to allied health for treatment and other services. In many cases, once a FASD assessment is made NDIS may provide funding but access is still an issue, let alone culturally safe care. This issue is compounded in light of challenges facilitating access and continuity of care.

Furthermore, in his evidence to the Royal Commission, Dr James Fitzpatrick noted that it is important to understand how trauma and disrupted attachment affects a young person's development, particularly in the context of the overlapping social determinants of health.<sup>30</sup> Given the evidence of intergenerational trauma there clearly needs to be further research and exploration about how to build capacity in the context of trauma and other factors causing child vulnerability.

## Youth Justice and Child Protection Systems

DDHS has adopted a 'whole of life' approach to the health of our clients, meaning that we look to the social determinants which drive inequities in health outcomes in our work and advocacy to improve those outcomes. Looking at the beginning of a person's life, factors which contribute to becoming involved in the Youth Justice and/or care and Protection systems are also factors which impact negatively on health outcomes. This overlap and close links between health, disability and contact with justice and child protection have led to DDHS becoming involved in service provision and advocacy.

Following the Four Corners program, 'Australia's Shame' in July 2016, the former Northern Territory Department of Children and Families, now Territory Families, approached DDHS to develop a proposal to support the social and emotional wellbeing of 'youth detainees' at Don Dale and to provide an "observer" and information gathering role focusing on youth wellbeing while in detention (at Don Dale). DDHS's function at Don Dale has evolved over time and has developed an increasingly therapeutic focus to the program now known as the Youth Social Support Program (**YSSP**). The YSSP staff continue to provide social emotional wellbeing support and programs to young people in Don Dale, as well as limited post-release support. As noted above, we are also in the process of taking over provision of primary health care in a clinic at Don Dale. This presents a significant opportunity to improve the health and developmental outcomes of children in detention.

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<sup>30</sup> Dr James Fitzpatrick, Evidence to the Royal Commission, see also Pestell and Paul, 2015.

## Prevalence of FASD and availability of assessments

A recent study at Banksia Hill Detention Centre in Western Australia (**The Banksia Hill Study**) found that 89 per cent of young offenders have a severe neurodevelopmental impairment, and 39 per cent were diagnosed with FASD.<sup>31</sup> Though a similar study has not been undertaken in the NT, it is likely that there is a very high-prevalence of FASD among children in the youth justice system.<sup>32</sup>

Unfortunately, there is still no accurate published data about the prevalence of FASD among children in the care system, though anecdotally it is also expected to be high. This was recognised by the NT FASD Strategy,<sup>33</sup> which acknowledged the expected high prevalence of FASD among children in care:

*Another priority group is children in out of home care. Early assessment for neurodevelopmental impairment and linking these children with support services may prevent future contact with the juvenile justice system. The Territory Government will facilitate the assessment of all children in out of home care.*

The Royal Commission also discussed the issue of disability among children in care:

At 30 June 2016, there were 112 children with a disability in out of home care in the Northern Territory. Of these children, 44% had an intellectual or learning disability and 37% had a physical disability. In 2015–16, 72 children with disability who were in care were on a long-term order.<sup>34</sup>

As we pointed out in our submission to the Royal Commission,<sup>35</sup> timely assessments must be undertaken to diagnose disabilities when risks or vulnerabilities to young people emerge. Comprehensive holistic assessments can help to ensure that individualised support services are identified and provided to address the complex needs of these young people.

Despite the existence of several FASD assessment providers, we understand that there are still significant delays providing these assessments for children in the justice and child protection systems. These delays are due to the challenges outlined above, including in particular the difficulty staffing the multidisciplinary team required to undertake these assessments. Extensive delays can have unintended consequences for children in the justice system in particular, including causing young people to spend unnecessarily long periods on remand in detention.

## Access to NDIS

Access to NDIS for children in care and/or detention, is still intermittent and inconsistent. In particular, we have concerns that some National Disability Insurance Agency (**NDIA**) staff have continued to advise clients that support is not available in detention as Territory Families should be providing these supports. This is inconsistent with the *Principles to*

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<sup>31</sup> Carol Bower et al, 'Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia' *BJM Open* (19 February 2018) <http://bmjopen.bmj.com/content/8/2/e019605>.

<sup>32</sup> Final Report of the Royal Commission into the Protection and Detention of Children in the NT (2017), Chapter 15, 351.

<sup>33</sup> NT FASD Strategy p 23-25.

<sup>34</sup> Royal Commission Final Report, Chapter 33, p 440.

<sup>35</sup> Danila Dilba Health Service Submission to the Royal Commission into the Protection and Detention of Children in the NT (2017).

*Determine the Responsibilities of the NDIS and Other Service Systems as per COAG.*<sup>36</sup>

According to these principles, as it stands the role of the NDIS for children in child protection as per Reasonable and Necessary supports is for the following:

- Funding disability-specific family supports, which are required due to the impact of the person's impairment/s on their functional capacity, including for parents with disability;
- Disability-specific and carer parenting training programs both for when the child has a disability or the parent has a disability;
- Funding the reasonable and necessary disability support needs of children with disability in out-of-home care where these supports are required due to the impact of the child's impairments on their functional capacity, and are additional to the needs of children of similar ages, including:
  - Skills and capacity building for children with disability; supports to enable sustainable caring arrangements (such as additional respite and outside school hours care); home modifications (consistent with other applied principles);
  - therapeutic and behaviour support; and
  - equipment and transport needs (consistent with other applied principles).
- The coordination of NDIS supports with the systems providing child protection and family supports and other relevant service systems. This includes services which aim to support people experiencing or exiting family violence.

### *Support for Children in detention*

Children in detention with FASD require specialised services and supports. Until recently, no NDIS supports have been provided to children in detention, due to advice received from NDIA staff to the effect that people in detention, including children, do not typically receive supports until they are released. This position is clearly inconsistent with *NDIS (Supports for Participant) Rules 2013* and the guidelines above.

Our youth social support team (at Don Dale) have observed the lack of clarity regarding access to NDIS. Through our health justice partnership with NTLAC we have been able to make effective referrals for legal assistance to help children access NDIS. However, as the below case study demonstrates, these delays have already had devastating impacts. This case study is drawn from experiences of our Don Dale youth team, and our collaboration with NTLAC. A pseudonym is used for privacy reasons.

#### **Case Study**

Patrick\* is a young person who was detained at Don Dale Youth Detention Centre. Patrick had been diagnosed with Foetal Alcohol Spectrum Disorder and a history of trauma starting from abandonment

Mid-2018, an incident occurred and he was put in effective isolation, kept away from other young people to manage his behaviour and 'risk' to other staff and young people. Complaints were made to the Children's Commissioner on his behalf, but nothing was done

<sup>36</sup> See <https://www.coag.gov.au/sites/default/files/communique/NDIS-Principles-to-Determine-Responsibilities-NDIS-and-Other-Service.pdf>

and two weeks later was involved in a serious incident that resulted in further criminal charges and a further sentence of imprisonment.

It was not until after this incident that an assessment revealed Patrick has FASD with "very low" mental functioning, on top of his diagnoses for major depression and substance misuse disorder. Shortly after this, lawyers applied on Patrick's behalf to the NDIS for access to therapeutic supports in detention. However the application, which should be processed within 21 days, went unanswered for months. Patrick's lawyers applied for the case to be reviewed by the Administrative Appeals Tribunal and he was finally granted access, and recently (months later) he has begun receiving access to relevant support in detention.

As this case study demonstrates, there is a clear need for clear and consistently applied guidelines in relation to youth in detention. There is also a need for support for young people (and their carers, case workers or support people) to assist them in gaining access to necessary supports and to avoid unnecessary delays.

**Recommendation (8):** The Commonwealth Government should ensure that the National Disability Insurance Scheme (NDIS) is available to fund the provision of support for children in detention with FASD in a consistent way. In particular, the availability of providers of these therapeutic supports for children in detention should be reviewed to ensure that NDIS plans are actually implemented in detention.

### *Support for children in care*

Children with FASD who enter the child protection system are likely to require complex care. In light of this, there is a clear need for specialist support for these children to understand their FASD diagnosis and training and support for their carers.

The NDIS has responsibility for providing supports specific to the needs of children with disability, including for developmental delay. These supports would be in addition to the needs of children of similar ages in similar out of home care arrangements. The scheme fully recognises the diversity of out of home care arrangements and the level of reasonable and necessary supports are to reflect the circumstances of the individual child.

In light of this, the Royal Commission recommended standardised screening for these children for FASD when entering out of home care.<sup>37</sup> As far as we are aware, this is still not occurring. The Office of the Children's Commissioner (**OCC**) in a recent monitoring (2018-19) report found that:

*Territory Families' did not hold comprehensive, readily available information relating to the health and disability needs and related service provision, of young people in care.*<sup>38</sup>

Through the DDHS ABCD Clinic, we are in a good position to assist children and families to get access to the NDIS. Our capacity to do so has been increased through our health justice partnership with Northern Territory Legal Aid (**NLAC**). Earlier this year NLAC provided training to doctors at DDHS about the NDIS and how to make effective referrals so our clients can get the disability services they need.

We will continue to strengthen this multi-disciplinary collaboration to ensure that our clients get the support that they need.

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<sup>37</sup> Royal Commission Final Report, Recommendation 33.14.

<sup>38</sup> Office of the Children's Commissioner Monitoring Report (2018-2019), at p 42.



## Custodial workforce

It is well-known that children and young people with FASD often have difficulty understanding and following instructions, but to the untrained eye that may appear to be bad behaviour or wilful ignorance of instructions.<sup>39</sup>

As part of the Banksia Hill Study, the Telethon Kids Institute, examined the custodial workforce's response to FASD.<sup>40</sup> The study found that there were substantial gaps in knowledge, attitudes, experiences and practices related to FASD among the youth custodial workforce at the Banksia Hill Detention Centre, the only youth detention centre in WA.<sup>41</sup> In particular, the study demonstrated that:

- The custodial workforce were not adequately trained to understand FASD vulnerabilities and therefore staff often mistook behaviours associated with FASD as demonstrating noncompliance or wilful defiance;
- As staff are not aware of FASD vulnerabilities, they often react in ways which further escalate negative behaviours; and
- That there were not adequate information sharing systems in place when formal diagnosis exists.

The Royal Commission found that:

*The environment of youth detention in the Northern Territory on the whole did not provide the structured, regular, predictable and therapeutic environment required for children and young people with FASD.*<sup>42</sup>

It is the observation of the DDHS' youth social support team, who are based six-days a week at Don Dale, that this situation has not significantly improved since the Royal Commission. Our team have observed first-hand the continued difficulty youth detention staff and management face in trying to appropriately manage children with FASD, or undiagnosed neurodevelopmental impairments.

Our youth team have continued to raise concerns about the punitive use of separation, lock downs and other behaviour management techniques, in response to 'incidents' at Don Dale. In some cases, following incidents, access to programs has been denied, or severely reduced as a punishment for bad behaviour. This reflects a sentiment among staff that access to programs and activities, and time spent with other children is a reward or privilege, rather than a necessary part of these children's development.

The DDHS youth team has observed that this approach of restricting access and movements of children and their access to programs, has the effect of heightening tensions, and adding to unease within the centre. In particular, we have continued to raise concerns that a number of the children involved in significant incidents, those being placed in repeated separations, and those whose movements and association is most restricted have diagnosed disabilities (including FASD) or are currently being assessed for these conditions.

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<sup>39</sup> Royal Commission Final Report, Chapter 15, 351.

<sup>40</sup> Foetal Alcohol Spectrum Disorder (FASD): Knowledge, attitudes, experiences and practices of the Western Australian youth custodial workforce Hayley M. Passmore (Australia)

<sup>41</sup> Royal Commission Final Report, Findings.

<sup>42</sup> Royal Commission Final Report, Chapter 15, 351.



The high number of incidents at these times is reflective of the fact that this type of 'risk-oriented' behaviour management approach fails to address the complex underlying vulnerabilities of the children in detention. As a result, this approach fails to ease tensions or de-escalate the behaviours of the young people, often leading to further incidents or offending: a vicious cycle.

### *Training for Staff - Reframe*

Although management and staff at Don Dale are becoming increasingly aware of the prevalence of FASD and neuro-developmental impairment, there is still insufficient knowledge about how to work with and achieve good outcomes for the children and ensure good order in the detention centres. In light of this, we looked into evidence-based training programs that could be of benefit to the NT's custodial workforce.

We are drawn to the 'Reframe' training program being rolled out in Western Australia, with great outcomes. Following the conclusions drawn in the Banksia Hill Study, researchers at the Telethon Kids Institute developed this training program for custodial workforce, about how to work with children in detention with neuro-impairment.

As the Banksia Hill team noted:

*it is vitally important that frontline professionals engaging with vulnerable populations of children and young people are aware of neurodevelopment impairments and the resulting behaviours, as well as equipped with strategies to help work with affected young people. This is particularly relevant to professionals in the police, justice, child protection, education, health and community services sectors.<sup>43</sup>*

The evidence-based Reframe training about FASD and other neurodevelopmental impairments has been tailored specifically for the youth justice workforce. The training was trialled and evaluated with over 100 justice professionals in WA. It has been found to be a highly effective method of improving participants' understanding of FASD and its implications.

**Recommendation (9):** Evidence-based FASD training should be developed and delivered in the Northern Territory for all staff working with children in detention.

## Sentencing of children with FASD

Professionals in the justice system have continued to raise concerns about the increasing numbers of Aboriginal young people in the criminal justice system that are affected by FASD and other neuro-developmental impairments.

Research has continued to emphasise the need to divert Indigenous youth with FASD from contact with justice system.<sup>44</sup> As Professor Blagg noted in a recent paper, the Western Australian inspector of custodial services has recommended "community based alternatives to custody orders for people who are found unfit to stand trial but require some degree of supervision".<sup>45</sup> As Blagg notes:

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<sup>43</sup> Telethon Kids Institute, Reframe: Workforce training on the behavioural implications of Fetal Alcohol Spectrum Disorder (FASD) and other neurodevelopmental impairments (2019)

<sup>44</sup> See Blagg, Harry 'Indefinite Detention Meets Colonial Dispossession: Indigenous Youths With Foetal Alcohol Spectrum Disorders in a White Settler Justice System' (2017) *Social and Legal Studies International Journal* 26(3) at 337.

<sup>45</sup> Ibid at 343.

*An inadequate criminal justice response can increase the likelihood of people with FASD developing secondary impairments or disabilities, such as substance abuse, which in turn, increases their susceptibility to further contact with the criminal justice system.*

*Secondary disabilities are a cluster of social and psychological problems that develop as a result of FASD's primary effects being exacerbated by repeated negative contact with the criminal justice and related systems, inadequate support and misdiagnosis, existence on the fringes of society, racism and institutionalization<sup>46</sup>*

FASD is increasingly to be recognised as a symptom and legacy of colonisation. Judge Cozens, in the Territorial Court of Yukon, remarked in *R v. Quash*:

*The problematic consumption of alcohol that has resulted in children being born suffering from the permanent effects of FASD often finds its roots in the systemic discrimination of First Nations peoples, and resultant alienation they experience from their ancestry, culture and their families.<sup>47</sup>*

In particular, we are concerned that the NT currently has no therapeutic facilities for young people with high needs, including relating to their FASD or other diagnosed disabilities, and in many cases these children are left to languish in youth detention.

#### Case Study

Jimmy\*, was born prematurely, and diagnosed with failure to thrive. He has a history of developmental delay, learning problems and poor social skills. He has been in the care of Territory Families for several years, with a history of abuse, neglect, disrupted attachment, multiple care placements and parental substance dependence.

Jimmy was diagnosed with FASD with neurodevelopmental impairments, as well as Attention Deficit Hyperactivity Disorder (ADHD). Shortly after this, he was approved for access to the NDIS, but was remanded in detention for criminal offending before his plan was implemented. Despite the FASD and ADHD diagnoses, he was held on remand in detention for over a year, unable to access the therapeutic supports he needed.

As this case study demonstrates, there is a clear need for culturally appropriate, therapeutic secure facilities as an alternative sentencing option for children with complex needs that require intensive support and care. In particular, there are increasing numbers of children being found 'unfit to stand trial' due to mental impairment. As there are no suitable secure facilities, these children are likely to continue to be held indefinitely on remand in detention.

**Recommendation (10):** Commonwealth and Northern Territory Governments should coordinate to provide funding for the development and implementation of a therapeutic secure facilities for children with high needs relating to their disabilities, including children in the justice system. These should be developed in partnership with local Aboriginal Community Controlled Health Services.

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<sup>46</sup> Ibid.

<sup>47</sup> *R v. Quash* [2009] YKTC 54, para 62, cited in Blagg, Harry 'Indefinite Detention Meets Colonial Dispossession: Indigenous Youths With Foetal Alcohol Spectrum Disorders in a White Settler Justice System' (2017) *Social and Legal Studies International Journal* 26(3) at 340.