Aboriginal Peak Organisations Northern Territory

An alliance of the CLC, NLC, CAALAS, NAAJA and AMSANT

APO NT Submission to the

Northern Territory Select Committee

on Action to Prevent Foetal Alcohol Spectrum Disorders

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Contents

About Aboriginal Peak Organisations of the Northern Territory (APO NT)

Formed in 2010, APO NT is an alliance between the Northern Land Council (NLC), Central Land Council (CLC), and Aboriginal Medical Services Alliance of the Northern Territory (AMSANT), North Australian Aboriginal Justice Agency (NAAJA) and Central Australian Aboriginal Legal Aid Service (CAALAS). The alliance was created to provide a more effective response to key issues of joint interest and concern affecting Aboriginal people in the Northern Territory, including through advocating practical policy solutions to government. APO NT is committed to increasing Aboriginal involvement in policy development and implementation, and to expanding opportunities for Aboriginal community control. APO NT also seeks to strengthen networks between peak Aboriginal organisations and smaller regional Aboriginal organisations in the NT.

1. Introduction

APO NT welcomes the opportunity to make a submission to the Northern Territory Select Committee on the prevention of Foetal Alcohol Spectrum Disorders (hereafter referred to as FASD).

Alcohol consumption in pregnancy is linked with developmental issues in children including heart defects, low birth weight and FASD. FASD is an umbrella term for a range of neurodevelopmental disorders that are caused by in-utero exposure to alcohol. The heterogeneity of the effects of alcohol on the brain as well as the numerous other potential causes of neurodevelopmental problems in children makes accurate diagnosis of FASD difficult. Foetal Alcohol Syndrome (FAS) sits at the more severe end of the FASD spectrum and is a more easily recognised condition compared to other FASD conditions because FAS has characteristic physical characteristics. There is inadequate evidence about the prevalence of FASD in both Aboriginal communities and the Australian community as a whole. However, it seems clear that it is a substantial problem.

Alcohol misuse compromises childhood development. Childhood development can be compromised by a variety of health determinants often associated with the risk of alcohol misuse in general, including alcohol consumption during pregnancy, such as domestic violence, past and ongoing trauma and multiple sources of stress and disadvantage. Children of families where a number of these risk factors exist are at risk of ongoing difficulties in relation to physical, cognitive, behavioural and emotional development, including FASD. Without early intervention and support for these families, these children are likely to face

extreme educational and social difficulties, which can result in them becoming involved in child protection and justice systems. In adulthood there may well be difficulties sustaining employment and relationships and ongoing involvement with the justice system.

Recognition of the impacts of FASD, its implications for people's behaviours and its contribution to offending is integral. Current practices whereby FASD is largely ignored in the criminal justice system due to the dearth of intervention and management therapies only serves to further isolate and institutionalise individuals affected by FASD. It is critical that the justice system can take into account all significant disabilities that affect cognition and behaviour including FASD but also other causes of intellectual disability.

With better preventative policies, and improved diagnosis and early intervention services, the prevalence of FASD can be reduced and outcomes for sufferers improved.

Public health policies and clinical services aiming to impact on FASD must also be guided by the evidence base and integrated into broader policies that are working to overcome Aboriginal disadvantage and reduce alcohol and other drugs issues within Aboriginal communities.[1] This requires a holistic view of the factors underlying disadvantage, compromised health and wellbeing and developmental delay in Aboriginal children. This submission identifies ways in which the NT Government (NTG) can address disadvantage in an inclusive and culturally appropriate way using evidence based research.

Effective action to address disadvantage requires genuine partnership with Aboriginal people. The Closing the Gap Clearing House Report, '*What Works to Overcome Indigenous Disadvantage*'[2] found that what does work is community involvement and engagement; adequate resourcing and planned and comprehensive responses; respect for language and culture; development of social capital; recognising underlying social determinants; commitment to doing projects with, not for, Aboriginal people; creative collaboration; and understanding that issues are complex and contextual. It found that what doesn't work includes 'one size fits all' approaches and a lack of collaboration with communities.

[1] APO NT, 2014. Submission to the House of Representatives Standing Committee on Indigenous Affairs, Inquiry into the harmful use of alcohol in Aboriginal and Torres Strait communities.

[2] Closing the Gap Clearinghouse (AIHW, AIFS) 2011. *What works to overcome Indigenous disadvantage: key learning has and gaps in the evidence.* Produced for the Closing the Gap Clearinghouse. Canberra: Australian Institute of Health and Welfare & Melbourne: Australian Institute of Family Studies.

An essential aspect of addressing the social and structural determinants of health and wellbeing within Aboriginal communities is the need for concerted action on alcohol and drug misuse. In the NT, this requires evidence based alcohol policy reform, including supply reduction measures, harm reduction measures, demand reduction measures and support for community strategies to reduce overall alcohol consumption.

Measures to reduce the supply of alcohol are a critical 'circuit breaker' in reducing alcohol consumption at dangerous levels, particularly through sales restrictions and pricing mechanisms.[3] Action is also required to support building stronger community-based approaches to addressing alcohol related harm, including ensuring that Alcohol Management Plans are representative of the whole community and driven by the community.

This submission will address the prevalence of FASD on individuals, their families and communities and will offer sound evidence-based recommendations that the NT Government can take to reduce FASD. This includes policies and programs, which reduce alcohol related harm to Aboriginal families and communities; are based on best available evidence; have the informed consent of local communities and are based on the provision of sufficient information, evidence and expert advice.

[3] Op cit, n 1 and APO NT Central Australian Grog Summit Report, Alice Springs 2013.

2. Recommendations

BACKGROUND

Recommendation 1: Action on the prevention of FASD and mitigating adverse outcomes for people with FASD should occur in conjunction with a comprehensive policy approach to tackling the impacts of alcohol on our communities.

Recommendation 2: Responses to address compromised development resulting from FASD should be incorporated within a broader comprehensive approach to addressing childhood developmental vulnerability.

THE PREVALENCE OF FASD

Recommendation 3: Acknowledging the lack of research in this area, the NT Government should support targeted research on determining prevalence of FASD as well as on prevention and the provision of therapeutic services and interventions for those with FASD related issues.

SCREENING FOR FASD

Recommendation 4: All children should be screened through comprehensive child health surveillance systems for physical, emotional and cognitive problems.

Recommendation 5: Children who have features that may indicate a diagnosis of FASD should be referred to a paediatrician, as should any child who has significant physical, cognitive and/ or behaviour problems.

Recommendation 6: Paediatricians and other related experts in the NT should come to a consensus on how they should confirm a diagnosis of FASD or FAS.

Recommendation 7: The NTG should increase support for child health in Aboriginal PHC including provision of comprehensive child health surveillance**.**

Recommendation 8: Access to current, culturally appropriate information regarding substance abuse, addictions and associated risks and harms, as well as ongoing support and advice, should be broadly available

to all community members, including women before, during and following pregnancy.

PREVENTION OF FASD

Early childhood

Recommendation 9: Early childhood programs that are culturally appropriate evidence based and provided in sufficient intensity to make a difference to health and social outcomes should be funded as a priority. Urgent attention should be given to implementing the recommendations regarding early childhood and education in the Closing the Gap Clearinghouse report, *What works to overcome Indigenous disadvantage.*

Recommendation 10: The following services should be funded in Aboriginal PHC services across the NT:

- Social and emotional well being services that address both alcohol and mental health issues;
- The Australian Nurse-Family Partnerships Program should be provided to all primary health services with capacity;
- Case management of children with disability;
- Targeted family support to families referred to the child protection system who do not require urgent statutory intervention but who require ongoing support;
- The Abecedarian program should be funded as a trial in selected communities.

Recommendation 11: APO NT recommends the introduction of comprehensive, evidence-based policies by the NTG to reduce alcohol related harm, including FASD, through:

- reducing the supply of alcohol through a reduction in alcohol outlet density;
- removing cheap products (such as cheap cask wine and port) from sale;
- regulating the price of alcohol through a minimum or 'floor price' per standard drink or through a volumetric tax;
- enforcing restrictions on the right to drink through permits;
- reducing trading hours where alcohol is sold;

- reintroducing a system of photo ID at point of sale linked to a banned drinkers register;
- supporting community-based approaches to addressing related harm, including ensuring AMPs are truly representative of and controlled by the community; and
- investing in prevention rather than prisons; and
- avoiding any response based on the criminalisation of alcohol use, including by pregnant women, and ensuring that interventions are based on therapeutic principles and accompanied by stringent procedural safeguards

Health professionals:

Recommendation 12: Provide training (including on-line modules) to ensure health professionals are aware of the current NHMRC guidelines on drinking in pregnancy and improve training of health professionals in screening for alcohol related problems and providing brief interventions, support and referral, including in pregnant women. Fund health professionals to receive training about FAS and FASD including ensuring they know how to recognise FASD, refer appropriately and support families and children with FASD.

On criminalising pregnant women:

Recommendation 13: The NTG should not seek to prevent FASD through punitive measures, such as the criminalisation of women who drink while pregnant, and should ensure that any interventions are based on therapeutic principles and accompanied by stringent procedural safeguards.

THE PREVALENCE OF FASD IN THE JUSTICE SYSTEM

Recommendation 14: Young people in the juvenile justice system should be screened for cognitive and behavioural problems including FASD so that any deficits can be taken into account in sentencing.

Recommendation 15: APO NT endorses the recommendations made by NAAJA and CAALAS in their submission to the Inquiry in relation to FASD and the justice system.

4. Background

4.1 The harmful use of alcohol in the Northern Territory

Alcohol misuse is a national issue, which has been the subject of extensive public and academic debate. Unfortunately, excessive alcohol misuse disproportionately affects Aboriginal communities. APO NT and all of its members have, for many years, been advocating for coordinated action in relation to alcohol issues affecting our communities. Please refer to:

Attachment A: APO NT Submission on Alcohol Mandatory Treatment Bill

Attachment B: APO NT Central Australian Grog Summit Final Report

Attachment C: APO NT Media Communiqué – Outcomes of the Top End Grog Summit.

Alcohol abuse and misuse is devastating the lives of too many Aboriginal people and families in the Northern Territory. It is a central driver of community and family violence, ruins health, adversely effects parenting and impacts negatively on employment and education prospects. Indeed, Aboriginal people in the NT are three times more likely to die from an alcohol-related hospital admission than the Australian average. Sixty percent of assaults in the NT are alcohol-related, with the proportion of alcohol-related assaults even higher in some regional centres, like Alice Springs and Tennant Creek.[4] About eighty per cent of Aboriginal people in police custody in the NT have self-reported they had consumed alcohol within the last 48 hours prior to their arrest. The national rate is 63.8 per cent.[5]

It is important to recognise, however, that alcohol is not just an Aboriginal problem. The average consumption of alcohol for non-Aboriginal people in the NT was reported at almost 14 litres per person per year in 2007, compared with a national average of less than 10 litres, while the mean for Aboriginal people in the NT is 16 litres. In the NT, thirty-five per cent of the adult population drink either at a risky or high-risk rate in terms of long-term harm, or at a rate, which risks short term, harm on at least one occasion per month.[6]

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[4] Sharp, J. 'Mandatory Treatment in the NT: Is it really about health and wellbeing?' *Precedent* (Issue 118 September/ October 2013) and See: 'Get in the Know' http://thatsenough.com.au/get-in-the-know/

[5] NIDAC, 2013. Bridges and Barriers: Addressing Indigenous Incarceration and Health. National Indigenous Drug and Alcohol Committee. p 5.

[6] Op cit, above n 3.

With a thinly populated region occupying one sixth of the Australian landmass, the Northern Territory is one of the heaviest drinking regions in the world.[7]

It has been estimated that the cost of the harmful use of alcohol is $4,197 for every adult Territorian, almost four and a half times the national figure of $944 per adult. This estimate takes into account the costs incurred by health and medical emergency services, police, the courts and corrective services, and loss of workplace productivity.[8] Researchers on the Lililwan Project in Fitzroy Crossing suggest that the cost of FASD may be as high as US$22,000 per year, per individual, or a lifetime cost of US$2.5 million, taking into account service use and lost productivity. This estimate does not include welfare and justice costs, which would significantly increase the estimate.[9]

Thus, there is an overwhelming economic and social argument for investing in evidence-based policy aimed at preventing FASD and mitigating adverse outcomes for people with FASD in conjunction with a comprehensive policy approach to tackling the impacts of alcohol on our communities. Section 8.9 provides recommendations for effective action in tackling the alcohol related harm.

4.2 Early childhood developmental vulnerability in the NT

The Australian Education Development Index (AEDI) provides compelling evidence that the level of disadvantage in the early childhood Aboriginal population in the Northern Territory remains high.[10] Bruce Wilson, in his draft report into Indigenous Education, recently reported that Indigenous children are significantly behind their national counterparts on five different indicators: physical health and wellbeing; social competence; emotional maturity; language and cognitive skills and communication skills and general knowledge.[11]. The AEDI shows

[7] Op cit, above n 1.

[8] Ibid. Worthy of comment is the fact that this does not include the cost of family breakdown, unemployment (the figure assumes the individual has a job in the first place, and needs to take time off), child abuse and neglect, let alone the costs of FASD.

[9] Fitzpatrick JP., Elliot E.J., Latimer J., *et al*. (2012). 'The Lililwan Project: a study protocol for a population-based active case ascertainment study of the prevalence of fetal alcohol spectrum disorders (FASD) in remote Australian Aboriginal communities' *BMJ Open Access*, 2012 and Streissguth, A.P., Bookstein, F.L., Barr, H.M., Sampson, P.D, O'Malley, K., and Young, J.K., (2004), Risk factors for adverse life outcomes in fetal alcohol effects, *Journal of Developmental and Behavioural Paediatrics*, vol 25, pp.228-238.

[10] Wilson, B 'Review of Indigenous Education in the Northern Territory Draft Report, p.11-12 and 24-47.

[11] Ibid. This was also noted in APO NT's Submission to the Australian House of Representatives Standing Committee on Social Policy and Legal Affairs Inquiry into Foetal Alcohol Spectrum Disorder, December 2011, 15.

higher rates of vulnerability in every developmental area compared to both non-Aboriginal Territorian children and Aboriginal children nationally.[12]

There is a complex web of causative factors underlying the high rates of developmental vulnerability in Aboriginal children. These factors include anaemia, malnutrition, frequent infections, poor parenting skills and lack of access to quality childcare. Alcohol use by parents, both during and after pregnancy, is an important contributing factor childhood disadvantage and poor outcomes. Children whose mothers consume dangerous levels of alcohol during pregnancy, often continue to have their development compromised by ongoing alcohol and other drug issues within their family.

The compromised development of children whose parents have alcohol and other drug issues is also often related to poverty, socio-economic factors, low educational attainment of parents and caregivers, and the impacts of intergenerational trauma. Therefore, APO NT believes that a holistic view of the factors underlying disadvantage and developmental delay in Aboriginal children is required.

This also suggests that responses to compromised development caused by FASD should be incorporated within a broader comprehensive approach to childhood developmental vulnerability.

Recommendation 1: **Action on the prevention of FASD and mitigating adverse outcomes for people with FASD should occur in conjunction with a comprehensive policy approach to tackling the impacts of alcohol on our communities.**

Recommendation 2: **Responses to address compromised development resulting from FASD should be incorporated within a broader comprehensive approach to addressing childhood developmental vulnerability.**

5. The prevalence of FASD in the Northern Territory

5.1 Australian research findings

In Australia, the prevalence of FASD is largely unknown, however there have been studies to ascertain the rates of FAS and more limited work to assess rates of FASD. In Victoria the

[12] APO NT, Central Australian Grog Summit Report 2013, 19.

prevalence of FAS was calculated from birth records and was reported as 0.0- 0.03 cases per 1000 live births between 1995 and 2002.[13]

In Western Australia, the prevalence of FAS was reported as 0.18 cases per 1000 live births between 1980 and 1997.[14] In the Top End, from 1990-2000 the overall prevalence of FAS was recorded as 0.68 per 1000 children, with Aboriginal children recording a prevalence of 1.87.[15] FASD is likely to be much more common than FAS but there have been no peer reviewed Australian population surveys of FASD to date with the Fitzroy Valley survey not yet available.

In a national FAS survey, prevalence rates amongst the Aboriginal population were 14 times higher than for the non-Indigenous population in Australia.[16]

Ascertaining the rate of FASD is much more difficult due to the lack of a recognised screening instrument that is specific and sensitive, heterogeneity in the features of FASD (some of which will not be apparent in younger children) and the variable relationship between alcohol consumption and the effect on the foetus.[17]

The recent Commonwealth Inquiry into FASD[18] outlined the following research findings on FASD:

- The Foundation for Alcohol Research and Education (FARE) and the previous Departments of Health and Ageing (DOHA) and Families, Housing, Community Services and Indigenous Affairs (FAHCSIA) report that recent research estimates the prevalence of FASD to be between 0.06 and 0.68 per 1000 live births. Other experts consider this to be a significant underestimation.
- FARE reports that among Indigenous Australians, the incidence of FASD is estimated to be between 2.76 and 4.7 per 1000 births. Peadon, E., Fremantle, E., Bower, C. and Elliott, E. (2008). International Survey of Diagnostic Services for Children with Fetal

[13] Estimating the prevalence of fetal alcohol syndrome in Victoria using routinely collected administrative data. Allan K, Riley M, Goldfield S, and Halliday J. *Australian and New Zealand Journal of Public Health*. Volume 31, Issue 1, pages 62–66, February 2007).

[14] Fetal alcohol syndrome: a prospective national surveillance study,. Elliot E, Payne J, Morris A , Haan E, Bower C. *Arch Dis Child* 2008;93:732-737.

[15] Op cit, above n 10.

[16] Elliot EJ, Payne J, Morris A, et al, Fetal Alcohol Syndrome: a prospective national surveillance study. *Arch. Dis. Child* 2008, 93.

[17] Watkins, Rochelle, E, et al, 2012. A modified Delphi study of screening for fetal alcohol spectrum disorders in Australia. *BMC Paediatrics*.

[18] The Parliament of the Commonwealth of Australia. 2012. *FASD: The Hidden Harm. Inquiry into the prevention, diagnosis and management of Fetal Alcohol Spectrum Disorder.* Commonwealth of Australia.

Alcohol Spectrum Disorders, BMC Paediatrics, 8:12

- A study in far north Queensland estimated FASD prevalence of 1.5 per cent in the Aboriginal child population, with one Cape York community having a prevalence of 3.6 per cent.[19]

  A detailed incidence study of FASD in Fitzroy Crossing has yet to be published in the peer reviewed literature where it can be critically reviewed/

- A recent study estimated that up to 15% of cases of intellectual disability in Aboriginal children in WA were due to alcohol use in pregnancy. The rate of intellectual disability in Aboriginal children estimated to be due to alcohol use in pregnancy was 17.4/1000 live births. The equivalent rate in no Aboriginal children was 11.7/1000 live births. Most of the cases of intellectual disability were mild to moderate. It is important to note that not all children with FASD have an intellectual disability.[20]

The Lililwan Project researchers noted that alcohol consumption is common among women of childbearing age. Of all Australian women aged 18-24 years, 11% drink at risky/ high-risk levels on a weekly basis.[21] In one large national survey, 20% of Indigenous Australian women reported drinking in pregnancy although this does not infer that 20% of Aboriginal children will suffer from FASD.[22] The researchers also noted that:

> *"focus group work with Indigenous women suggest that the predominant reasons why they drink includes: lack of knowledge about harms to the fetus, unemployment, having a partner who drinks, domestic violence, loss of traditional land and culture and the legacy of the 'stolen generation' when children were forcibly removed from their mothers by government authorities between 1909 and 1969."*[23]

[19] Rothstein, Jonty, Richard Heazlewood and Marnie Fraser, 2007. Health of Aboriginal and Torres Strait Islander children in remote Far North Queensland: Findings of the Paediatric Outreach Service. *MJA* 2007; 186: 519–521.

[20] O'Leary C, Leonard H, et al. (2013). "Intellectual disability: population-based estimates of the proportion attributable to maternal alcohol use disorder during pregnancy." *Developmental Medicine & Child Neurology* 55(3): 271-277.

[21] Youth are the highest consumers of alcohol and their patterns of use are different from older people. Youth are also at a higher risk due to binge drinking. For more information on this see AIHW, Young Australians: Their health and wellbeing', *Cat. no. PHE 140 Canberra: AIHW. Australian Institute of Health and Welfare.* at http://www.aihw.gov.au/publication-detail/?id=10737419261

[22] Ibid, above n 10.

[23] Ibid.

5. 2 Determining prevalence

A population-based survey of a cohort of children might be useful to establish the prevalence of FASD in the Northern Territory, similar to that published by the Lililwan Project Researchers.[24] It would be prudent to wait till the results of this survey are published and can be reviewed critically as ascertainment of FASD is difficult given the multiple other causes of intellectual disability and behavioural problems including the common situation where no cause for intellectual disability can be determined. It would be useful to see if the methods used in the Liliwan project are robust before this project was replicated. However, implementing evidence based approaches to reducing FAS and FASD should not wait on prevalence studies. There are also wide gaps in our knowledge about FASD including how to best support families. Therefore, a broad approach to improving our knowledge base must be taken.

Recommendation 3: **Acknowledging the lack of research in this area, the NT Government should support targeted research on determining prevalence of FASD as well as on prevention and the provision of therapeutic services and interventions for those with FASD related issues.**

6. Screening for FASD

6.1 FASD Symptoms

FAS is a medical diagnosis involving four key features: alcohol exposure, growth deficiency, facial features and brain damage. FASD is an umbrella term that includes a wide spectrum of neurodevelopmental disorders caused by alcohol although the range of deficits that are encompassed by FASD can also have multiple other causes and in many cases of neurodevelopmental difficulties, the cause cannot be ascertained. Furthermore, damage can occur in the early years (0-3) if the child is exposed to poor parenting, neglect, violence, lack of stimulation – all of which are more common if parents have alcohol problems.[25]

[24] Fitzpatrick, et al: Development of a reliable questionnaire to assist in the diagnosis of fetal alcohol spectrum disorders (FASD). *BMC Paediatrics* 2013. 13:33.

[25] Mustard J F (2006). *Early Child Development and Experience-based Brain Development: The Scientific Underpinnings of the Importance of Early Child Development in a Globalized World.* The World Bank Symposium on Early Child Development.

This makes diagnosing FASD complex and it cannot always be ascertained whether an in-utero exposure to alcohol is the major or only cause of a child's disabilities.[26] A further implication is that intervention services need to encompass the full spectrum of neurodevelopmental disorders, not just those relating to FASD.

6.2 Universal Childhood Screening and Early Intervention within Primary Health Care (PHC)

Improving the diagnoses and treatment of FASD needs to be considered within the context of the broader issues of high rates of developmental vulnerability amongst Aboriginal children and the capacity of the health system to respond. As outlined earlier, the Australian Early Development Index (AEDI) survey has shown alarming rates of developmental and behavioural concerns in Aboriginal children at school entry. FASD is only one of a number of contributing factors to these high rates of vulnerability.

Comprehensive childhood surveillance up to the age of five years includes screening for developmental delays and behavioural problems and is a core service of Aboriginal primary health care (PHC).

The NT Aboriginal PHC system already includes a comprehensive child health surveillance system. Many services (including all NT government services) use the Healthy Under Five Kids screening program whereas some Aboriginal Community Controlled Health Services (ACCHSs) have adapted this program to the needs of their population or have developed their own system. Child health surveillance from 0-5 years facilitates the prevention, early detection, intervention and treatment of common conditions that cause morbidity and early mortality as well as prompting early referral for the management of more serious or chronic conditions, which may or may not include FAS or FASD.

Undertaking this surveillance requires both clinical child health skills and cultural competence. Upskilling both nurses and Aboriginal health practitioner in child health, including development screening, needs to be well resourced. Children with developmental delays require a review by a paediatrician and early intervention services, whatever the cause. Early intervention services should be provided as soon as possible with case management and family support provided within primary health services. Currently, early intervention services are often lacking which clearly limits the value of screening – and raises ethical issues about screening without intervention.

[26] Teaching students with FASD. Alberta Learning, Alberta Canada.

Early childhood programs that are evidence-based and comprehensive (such as the Australian Nurse-Family Partnerships Program and Abecedarian program) will improve outcomes for not only children with FASD but also children with other developmental delays and vulnerabilities.[27] This will be further explored below.

6.3 Arguments against universal FASD screening

Screening always has benefits and risks and screening programs should not be introduced without careful evaluation including ensuring that the screening program conforms to the WHO criteria for screening. Australian experts in 2012 concluded that there should not be universal screening for FASD even in high-risk populations (Watkins et al, 2012). Reasons included the complexity of the diagnosis lack of a suitable screening test with acceptable sensitivity and specificity and lack of adequate treatment services for children and families (Watkins et al, 2012).'[28]

Diagnosis of FASD has the potential to label and stigmatise the child and the mother. Workforce turnover in the NT is high and screening by staff without adequate training or support could lead to children being incorrectly labelled as having FASD. A child being incorrectly diagnosed as having FASD may potentially be damaging especially if the disabilities are mild but the child and family have reduced expectations for their future. Furthermore, many children will have multiple potential causes for their disability and focusing on one cause whilst neglecting other causal contributing factors may lead to suboptimal treatment. In particular, adverse factors in the early years (0-3) can have a major permanent effect on a child's physical, cognitive and emotional development. Intervening in this critical period to promote good parenting and reduce negative adverse effects (such as witnessing violence, or being neglected) is thus critical to improving long-term outcomes. If we wait until we can definitely diagnose FASD, we will have missed a critical window of intervention.

Primary health care professionals still need to be knowledgeable about FASD even if they are not specifically screening for it. Health service staff requires training, education and support, including understanding the impact of drinking during pregnancy, and a range of other risk factors (such as trauma, etc) on childhood development, so that appropriate support and intervention can be provided to affected families.

[27] Bartik, T.J (2011) *Investing in kids: Early Childhood Programs and Local Economic Development*, 95.
[28] Ibid.

Recommendation 4:	**All children should be screened through comprehensive child health surveillance systems for physical, emotional and cognitive problems.**
Recommendation 5:	**Children who have features that may indicate a diagnosis of FASD should be referred to a paediatrician, as should any child who has significant physical, cognitive and/ or behaviour problems.**
Recommendation 6:	**Paediatricians and other related experts in the NT should come to a consensus on how they should confirm a diagnosis of FASD or FAS.**
Recommendation 7.	**NTG should increase support for child health in Aboriginal PHC.**
Recommendation 8:	**Access to up to date information regarding substance abuse, addictions and associated risks and harms, as well as ongoing support and advice, should be broadly available to all community members, including women before, during and following pregnancy.**

7. The nature of the injuries and the effects of FASD on its sufferers

The nature of the injuries and the effects of FASD include brain damage, poor growth, developmental delay, difficulty remembering, short attention span, language and speech deficits, low IQ, problems with abstract thinking, poor judgement, social and behavioural problems, and difficulty forming and maintaining relationships. Individuals diagnosed with FASD frequently develop secondary disabilities associated with high rates of disrupted education (61%), including mental health problems (90%), trouble with the law (60%) and substance abuse (39%).[29] The above sections of this submission have provided further detail on the broader impacts and implications for sufferers and their families, including the risks associated with screening and diagnosis. APO NT also refers Committee members to the submissions provided by Danila Dilba, Anyinginyi, Congress, NAAJA, and CAALAS on the nature of the injuries and effects of FASD.

[29] Ibid, above n 10.

8. The prevention of FASD

8.1 Understanding why women drink when they are pregnant

The continued use of alcohol by women in pregnancy is strongly interconnected to other social, environmental, economic, and relational stressors.[30] Prevention is about understanding the relationship between alcohol and complex psycho-social issues including aspects of history and culture.[31]

Hayes (2012), in addressing why women still drink during pregnancy, noted that the *"historical and political background and the cultural aspects of drinking have been insufficiently considered"* and that:

> *"Programs aimed at changing individual risky behaviour failed to acknowledge the way in which the person is inextricably tied to the culture in which he or she exists.*
>
> *In many communities, alcohol use is a familiar and embedded practice that spans generations as well as individual lifetimes, from before birth to death. Its consequences are difficult to escape, whether a given person actually drinks or not.* ***For many Aboriginal women, alcohol, like pregnancy is a normal part of the life cycle.*** *"*[32]

Our understanding of how alcohol use in pregnancy has become normalised has been expanded by advances in environmental and genetic research, particularly that of epigenetics, that has shown how environmental factors, such as the experience of trauma, can be transmitted intergenerationally, leaving successive generations susceptible to physiological and behavioural expressions of trauma, including stress responses and a predisposition to maladaptive coping mechanisms such as alcohol misuse.[33]

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[30] Boyd, S.C and Marcellus L (Eds.) (2007) *With child: Substance use during pregnancy – A woman's centred approach.* Halifax: NS: Fernwood and Poole N and Greaves L (Eds.) (2007). Highs and Lows: Canadian perspectives on women and substance use. Toronto, ON: Centre for Addiction and Mental Health and Kvingne V.L., Bad Heart Bull, L., Welty, T.K., Leonardson, G.R., and Lacina, L. (1998). Relationship of prenatal alcohol use with maternal and prenatal factors in American Indian woman. *Social Biology,* 45, (3-4), 215-222. and Motz , M., Leslie, M., Pepler, D.J., Moore, T.E., and Freeman, P.A. 'Breaking the cycle: Measures of progress 1995-2005.' *Journal of FAS International: Special Supplement,* 2006 4, 22.

[31] Fetal Alcohol Spectrum Disorder Model of Care, Child and Youth Health Network, Government of Western Australia, Department of Health, p.71.

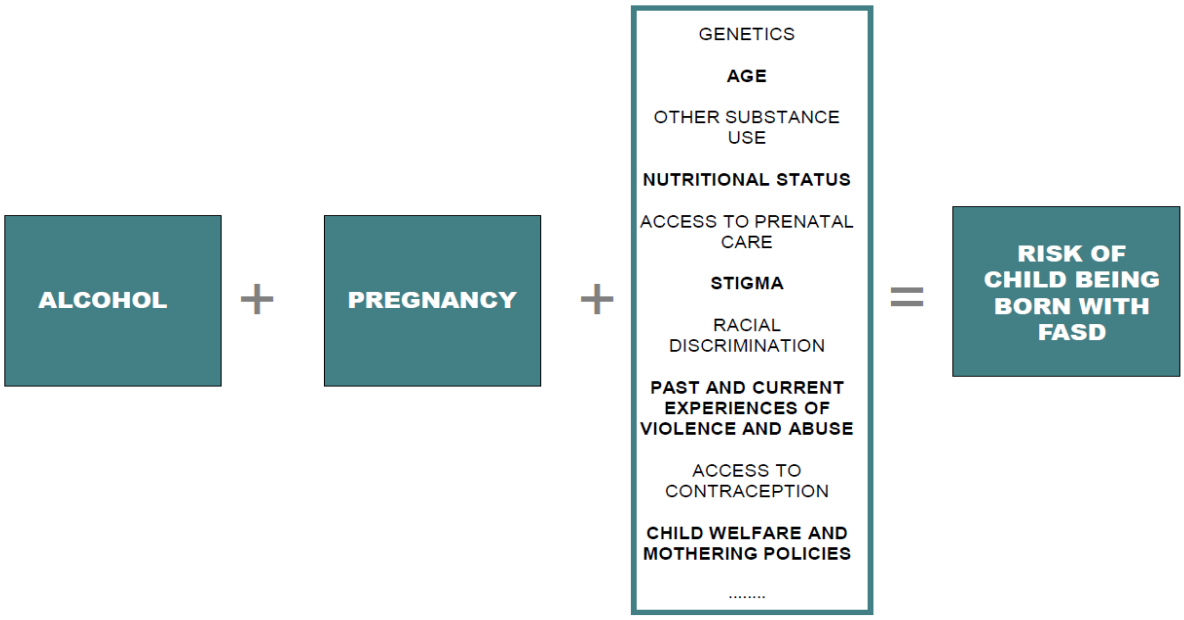
[32] Hayes L.G. 'Aboriginal women, alcohol and the road to fetal alcohol spectrum disorder', 197, *Medical Journal of Australia*, 1 (2012) 21-23. (emphasis added).

[33] Carey, Nessa, 2012. Beyond DNA: Epigenetics: Deciphering the link between nature and nurture. *Natural History*. Matthews, Stephen G and David I. W. Phillips, 2010. Minireview: Transgenerational Inheritance of the

Intergenerational and ongoing trauma is a significant underlying factor that can result in feelings of powerlessness or victimisation, and maladaptive coping strategies, such as alcohol and substance misuse to cope with psychological distress.

Nancy Poole, Director of the British Columbia Centre of Excellence for Women's Health in Canada, has charted how our understanding of the scope of FASD prevention has changed over time (the third column in Diagram 1 below).[34]

Diagram 1: Factors attributing to FASD



This research highlights that understanding the reasons and the broader determinants of why women drink alcohol during pregnancy is critical to developing prevention strategies.

8.2 Addressing the determinants of mental health and wellbeing

A number of these factors identified as impacting on women's use of alcohol during pregnancy require responses directed to the determinants of health and in particular the determinants of mental health and wellbeing as drivers of alcohol misuse.

The World Health Organisation (WHO) provides evidence that Indigenous health and wellbeing is profoundly affected by a range of interacting economic, social and cultural

Stress Response: A New Frontier in Stress Research. *Endocrinology*, January 2010, 151(1):7–1.

[34] Poole Nancy, 2014. 'Effective FASD Prevention: What do we know', Presentation delivered to the Menzies School of Public Health, May 2014, Darwin.

factors (social determinants of health) such as poverty, economic equality and social status.[35]

Reports by the WHO and the National Drug Research Institute (NDRI) found that social deprivation and associated factors such as income and education are clearly linked to the risk of dependence on alcohol.[36] Inadequate housing, infrastructure, job prospects and opportunities for recreation have been identified as areas in need of attention in order to help combat misuse.[37]

As stated in 'Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice':

> *"The co-morbidity of mental health and harmful substance use among Aboriginal people needs to be contextualized by the legacy of colonization, racism and marginalization from dominant social institutions. International and Australian research clearly demonstrates that health in general; mental health and substance misuse are affected by social and structural factors such as housing, education, employment, income, transport and access to supportive social networks. Until Aboriginal people are generally equal in terms of social indicators such as adequate housing, literacy levels, employment and income, the prevalence of harmful substance use and mental health problems among them is unlikely to decline."*[38]

Clearly, efforts to address FASD within Aboriginal communities must include evidence-based approaches to addressing these determinants of mental health and wellbeing. APO NT argues that stand-alone strategies to address the impacts of alcohol misuse will have limited effectiveness.

Psychosocial factors figure prominently amongst the determinants of mental health and wellbeing: the fundamental importance of control and empowerment; the debilitating impacts of social exclusion, racism and discrimination; and the protective role of culture, language and land.[39]

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[35] World Health Organisation. (2007) *The World Health Report 2007 – A Safer Future: Global Public Health Security in the 21st Century.*

[36] Wilkes E, Gray D, Saggers S, Casey W and Stearne A. *"Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice"* In: Purdie N, Dudgeon and Walker R. (Eds). 2010. Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice.

[37] Ibid.

[38] Wilkes, Gray, Saggers, Casey and Stearne, 2010, p.128

[39] APO NT, (2013) 'Not under the influence of evidence: A sober critique of the Alcohol Mandatory Treatment Bill, APO NT Submission on the NT Alcohol Mandatory Treatment Bill, May 2013. 'http://www.naccho.org.au/download/aboriginal-health/130531%20-

These factors highlight the importance of Aboriginal people regaining control of their own actions and services and the need to engage Aboriginal people in the planning and development of strategies to address the misuse of alcohol.

8.3 The components of FASD prevention

There is much evidence to draw on both internationally and locally. In Canada, the Network Action Team on FASD prevention argued that the following components need to guide prevention of FASD.[40] Policies aimed at preventing FASD should be:

- Respectful
- Relational
- Self-Determining and Women-centred
- Harm reduction oriented
- Trauma-informed
- Health-promoting
- Culturally safe
- Be supportive of mothering, and
- Use a disability lens.

A table of these components can be found in the Appendix of this submission: **Attachment D.**

APO NT also supports the recommendations on prevention in the Foundation for Alcohol Research and Education (FARE) Australian FASD Action Plan 2013-2016[41], which includes conducting a public education campaign; implementing mandatory health warning labels on alcohol products; providing specialist support services to pregnant women and educating health professionals.

Experience shows that the scope of FASD prevention must be broad and not just focused on alcohol. There are many contributing, underlying factors and the role of alcohol must be considered in a broader, community, holistic context.

%20APO%20NT%20Submission%20on%20Alcohol%20Mandatory%20Treatment%20Bill.pdf Retrieved 20 March 2014.

[40] Canada Northwest FASD Research Network, 2010 Fundamental components of FASD prevention from a women's health determinants perspective', February 2010. (See Appendix 1 for further details of the components).

[41] Foundation for Alcohol Research and Education (FARE) Australian FASD Action Plan 2013-2016

For these reasons, APO NT strongly opposes any approach based on the criminalisation of alcohol use during pregnancy. There is no evidence to support criminalisation as an effective or appropriate response. On the contrary, the evidence supports therapeutic and parental support approaches.

APO NT has previously provided two submissions to the NTG on mandatory treatment for alcohol problems. Both have stated that mandatory treatment legislation in the NT is seriously flawed and that the legislation should be changed in line with Victorian and NSW mandatory alcohol and other drugs legislation. APO NT believes that a short period of mandatory assessment and stabilisation can be justified when a person is at very high risk of harm from alcohol (including death or very serious health consequences) as long as there are no criminal consequences, including for absconding, and that stringent procedural safeguards are in place. We believe that this is sufficient and that mandatory treatment specifically for pregnant women does not need separate legislation. Indeed, targeted legislation is likely to deter women from accessing antenatal care and given that the majority of the damage to the foetal brain occurs very early, it will have minimal preventative effect.

Current best practice recognises the importance of four levels of prevention of FASD, grounded in supportive alcohol policy. These are:

1. Broad awareness building and health promotion efforts;
2. Discussion of alcohol use and related risks with all women of childbearing years and their support networks;
3. Specialised, holistic support for pregnant women with alcohol and other health/social problems; and
4. Post-partum support for new mothers and support for child assessment and development.[42]

8.4 FASD prevention within Aboriginal Primary Health Care

Health services have an important role. An effective way to reduce harm from alcohol consumption in pregnancy is through an integrated approach within comprehensive primary health care.

[42] Poole Nancy, 2014. 'Effective FASD Prevention: What do we know', Presentation delivered to the Menzies School of Public Health, May 2014, Darwin.

AMSANT's member health services, Central Australian Aboriginal Congress, Anyinginyi and Danila Dilba, have provided separate submissions to this inquiry and APO NT commends these to Committee members.

Aboriginal community controlled health services provide a range of clinical and non-clinical services that are relevant to the prevention, early detection and management of children with FASD. These include screening for hazardous drinking in health checks; high quality antenatal care; and universal childhood surveillance.

APO NT recommends that the NT Government provide additional positions in PHC to ensure that high quality comprehensive child health surveillance is undertaken, early intervention is provided, and families are supported through family support workers, and increased outreach capacity.

Screening for alcohol related harm and early intervention in PHC is modestly effective in reducing alcohol related harm although the effectiveness may be reduced in women compared to men.[43]

All pregnant women should be asked about alcohol and given advice to abstain as part of antenatal care as per the NHMRC guidelines. Clinicians will need training in how to have empowering conversations with women about alcohol, before they are pregnant, when they are pregnant and post partum. There is a need for a population-based approach to screening for alcohol related harm in PHC rather than just focusing on pregnant women, particularly as significant damage is done before pregnancy is diagnosed.[44] Furthermore, there is now early evidence that pre-conception heavy drinking in men may also be damaging.[45]

8.5 Ante- and post-natal support

The Australian Nurse Family Partnerships Program (ANFPP), based on the 'Olds model' of nurse home visitation and case management of children from vulnerable families provides structured support for pregnant women until the child is aged two. The program has been operating in the US for over 25 years and has been shown to: reduce alcohol and other drug use in mother and child; improve outcomes for educational attainment; and reduce rates of

[43] Kaner E, Dickinson H, Beyer F, Campbell F, Schlesinger C , Heather N, Saunders J, Burand B, Piennar P. 2007. Effectiveness of brief alcohol interventions in primary care populations.

[44] National Health and Medical Research Council (2009). *Australian guidelines to reduce health risks from drinking alcohol*. Canberra, Commonwealth of Australia.

[45] Taylor and Franics, 2014. "Fathers drinking. Also responsible for foetal disorders?" *Science Daily,* 14th February 2014.

child neglect and juvenile offending. The ANFPP has been piloted by selected ACCHS, and funding to expand the program to additional sites has been provided in the Federal Budget. The program should be funded for all willing ACCHSs.

8.6 Parent / family support

All children with high needs due to factors such as physical illness, disability, developmental delay and/or family dysfunction require case management within primary health care. Some ACCHS provide case management of children with high needs, however many are not funded to provide multidisciplinary care of children with high needs. We recommend that all ACCHS be funded to provide case management for high-risk children.

The NTG should support the ongoing delivery and expansion of community based programs, through Comprehensive Primary Health Care Services, such as nutritional, violence prevention, housing, alcohol and other drug programs that can be available to families and communities on an ongoing and voluntary basis. When appropriately resourced to deliver such programs, services such as community based health services, with which families voluntarily engage and can establish trusting relationships, have better and more cost-effective client outcomes than services where clients are mandated to attend.[46]

8.7 Early childhood services

The best practice principles emphasise the need for good early childhood services – for assessment of developmental difficulties and for appropriate family support, and interventions to support healthy development.[47]

However, there are risks in too narrowly targeting early childhood services to specific conditions. Better outcomes from investment would be achieved by building up services for children with functional deficits whatever their cause, particularly given the high rates of developmental vulnerability in remote communities. This would require targeted intervention for children at high risk of developmental delay as well as population based early childhood programs. There is already in place a comprehensive child health surveillance system in Aboriginal primary health care although this needs to be better supported.

[46] Rasmussen, C, et al, *The Effectiveness of FASD Programs on Outcomes of At-Risk Mothers, Families, and Parents with FASD,* Alberta Center for Child, Family & Community Research.
[47] REF

An example of an effective early childhood program is the 'Abecedarian program', which is an out of home care model, which demonstrates an enriched care approach for children at high risk of learning problems (including children with FASD). It has demonstrated long-term sustainable benefits including educational and social outcomes.[48]

8.8 Other PHC services.

Other relevant services in PHC include Social and Emotional Well being services, which can comprehensively address substance misuse and the underlying reasons behind the substance misuse. There is good evidence for the effectiveness of SEWB services located within comprehensive Aboriginal PHC services, yet many ACCHSs have only infrequent fragmented visiting services. SEWB services within ACCHSs need to be supported by residential AOD treatment, including facilities for families.[49]

Children and families with chronic illness/disabilities and/or complex needs require case management within Aboriginal PHC so that services provided to the family can be well targeted and integrated. This will include children with FASD and FAS. Families where children are at risk of neglect including families where parents are drinking should be provided with support through an intensive family support model as is already being provided at Central Australian Aboriginal Congress and other ACCHSs. Again, this will include children with FASD, particularly if the parents are still drinking or have poor parenting skills.

Women's health services including contraception can also assist women to delay pregnancies until their alcohol consumption has reduced.

Recommendation 9: **Early childhood programs that are culturally appropriate evidence based and provided in sufficient intensity to make a difference to health and social outcomes should be funded as a priority. Urgent attention should be given to implementing the recommendations regarding early childhood and education in the Closing the Gap Clearinghouse report, *What works to overcome Indigenous Disadvantage***

[48] Campbell, F. A., B. H. Wasik, et al. (2008). "Young adult outcomes of the Abecedarian and CARE early childhood educational interventions." *Early Childhood Research Quarterly* 23(4): 452-466.

[49] Gray D and Wilkes E (2010). *Reducing alcohol and other drug related harm*. Resource sheet no. 3 produced for the Closing the Gap Clearinghouse. Canberra, AIHW (Australian Institute of Health and Welfare) / Australian Institute of Family Studies. Babor et al. 2010 Babor T, Caetano R, et al. (2010). *Alcohol: no ordinary commodity*. Oxford, Oxford University Press.

Recommendation 10: **The following services should be funded in Aboriginal PHC services across the NT:**

- **Social and emotional wellbeing services that address both alcohol and mental health issues;**
- **The Nurse-Family Partnership program of nurse family visitation should be extended to all services with capacity;**
- **Case management of children with disability;**
- **Targeted family support to families referred to the child protection system who do not require urgent statutory intervention but who require ongoing support;**
- **The Abecedarian program should be funded as a trial in selected communities.**

8.9 The need to review Alcohol policy in the NT

FASD is part of a much bigger picture of alcohol misuse and abuse in our communities. Addressing the harmful use of alcohol generally will reduce the prevalence of FASD and the multitude of other adverse health, social and economic consequences of the harmful use of alcohol. Accordingly, APO NT supports evidence based alcohol policy reform, including supply reduction measures to support communities in reducing overall alcohol consumption, as well as harm reduction measures and demand reduction measures.

APO NT continues to lobby for regulatory measures to reduce supply including the reduction of liquor outlet density, introduction of take away sales restrictions, and adoption of price control measures such as a minimum floor price, as evidence-based strategies for effectively combating harm from alcohol, including FASD. Such supply reduction measures have been shown to be the most powerful interventions to reduce alcohol consumption and to greatly contribute to a reduction in associated child abuse and neglect.[50] APO NT believes that these are key measures that need to be prioritised as public health measures for addressing alcohol harm.

Measures to reduce the supply of alcohol are a critical 'circuit breaker' in the fight against alcohol misuse and its impacts through significantly reducing alcohol consumption at

[50] APO NT Submission to the Australian House of Representatives Standing Committee on Social Policy and Legal Affairs Inquiry into Foetal Alcohol Spectrum Disorder, 2011.

dangerous levels.[51] APO NT also supports the reintroduction of a system of photo ID at point of sale linked to a banned drinkers register as an effective mechanism to restrict access to those consuming alcohol at dangerous levels, and for stronger enforcement of licensing conditions.

APO NT also supports building stronger community-based approaches to addressing alcohol related harm. There is an urgent need to support local community responses; ensure Alcohol Management Plans (AMPs) are representative of the whole community and driven by the community; invest in prevention rather than prisons; and engage children and young people in education and solutions.

These measures are outlined in detail in our submission to the Commonwealth House of Representatives Standing Committee on Indigenous Affairs' Inquiry into the harmful use of alcohol in Aboriginal and Torres Strait Islander communities – please see **Attachment E.** We have also annexed copies of the final reports of the Central Australian Grog Summit, **Attachment B** and the Communiqué of the Top End Grog Summit, **Attachment C,** which identifies the outcomes. These summits brought together people from Aboriginal communities, organisations, and alcohol policy and research experts to discuss alcohol-related harm.

Recommendation 11: **APO NT recommends the introduction of comprehensive, evidence-based policies by the NTG to reduce alcohol related harm, including FASD, through:**

- **reducing the supply of alcohol through a reduction in alcohol outlet density;**
- **removing cheap products (such as cheap cask wine and port) from sale;**
- **regulating the price of alcohol through a minimum or 'floor price' per standard drink or through a volumetric tax;**
- **enforcing restrictions on the right to drink through permits;**
- **reducing trading hours where alcohol is sold;**
- **reintroducing a system of photo ID at point of sale linked to a banned drinkers register;**

[51] Ibid and APO NT Central Australian Grog Summit Report, Alice Springs 2013.

- **supporting community-based approaches to addressing related harm, including ensuring AMPs are truly representative of and controlled by the community;**
- **investing in prevention rather than prisons; and**
- **avoiding any response based on the criminalisation of alcohol use, including by pregnant women, and ensuring that interventions are based on therapeutic principles and accompanied by stringent procedural safeguards.**

8.10 Increasing public awareness

There remains significant room for improvement with respect to increasing public awareness of the antecedents of problematic pregnant substance use; reducing bias toward poor, minority women; building support for substance misuse programs; addressing policies that pit women against their unborn children; increasing knowledge of health providers regarding the issue; and attending to the scarce funding for prevention projects.[52]

[53] Please refer to the submissions made by Danila Dilba, Congress and Anyinginyi about raising awareness.

8.11 Health professionals

It is noted through the literature that most health care providers are challenged talking with pregnant women about their alcohol use. A 2002 survey of physicians and midwives in Canada suggested that the main reasons for not talking to women about their alcohol use during pregnancy were:

- Lack of time
- Lack of familiarity with screening instruments
- Lack of training in alcohol and pregnancy issues
- Lack of knowledge and skills to respond to pregnant women who drink
- Lack of knowledge about treatment and referral options and resources
- Providers feeling uncomfortable with asking women about their alcohol use
- Professionals encountering resistance from women themselves.[54]

[52] Mary, D. 'A social work perspective on policies to prevent alcohol consumption during pregnancy' 347-8 in Riley, E.P., Sterling C., Weinberg, J., Jonsson, E. (Eds) (2011) *Fetal Alcohol Spectrum Disorder: management and policy perspectives of FASD*, Germany: Wiley-Blackwell.

[53] Sayers, S and Boyle, J 'Indigenous perinatal and neonatal outcomes: A time for preventive strategies', 46 *Journal of Paediatrics and Child Health*, (2010) 475-478.

- Increased expectations about screening for a range of problems.

The House of Representatives Standing Committee expressed in their findings, like that of Canada, that there is some confusion amongst health professionals about guidelines on alcohol in pregnancy perhaps due to the recent changes in the guidelines.

Recommendation 12: **Provide training (including on-line modules) to ensure health professionals are aware of the current NHMRC guidelines on drinking in pregnancy and improve training of health professionals in screening for alcohol related problems and providing brief interventions, support and referral, including in pregnant women. Fund health professionals to receive training about FAS and FASD including ensuring they know how to recognise FASD, refer appropriately and support families and children with FASD.**

8.12 Alcohol Warning labels

APO NT supports warnings on alcoholic beverages. It is noted however, that such warnings may have limited effect on a population with relatively low English literacy, as is the case with Aboriginal and Torres Strait Islanders in the NT. Social marketing campaigns in remote communities may be effective but should be designed in partnership with communities to ensure that they are appropriate.

8.13 On Criminalising pregnant women

NT Minister Elferink recently stated that the NT Government was 'currently exploring the ante-natal rights of the unborn child', which 'could include prosecuting women who are drinking during pregnancy'. Although this was just a proposal, APO NT wishes to make it clear that we oppose criminalising women drinking in pregnancy. There is no evidence that criminalisation is an effective mechanism to prevent FASD. Researchers in Canada and the US have found that punitive responses drive women underground, with less likelihood of accessing the care they require. None of the punitive responses in the United States has resulted in enhanced access to prenatal care quality addictions treatment.[55]

[54] Parkes, T., Poole, N., Salmon, A., Greaves, L and Urquhart, C. (2008). *Double Exposure: A Better Practices Review on Alcohol Interventions During Pregnancy*. Vancouver, BC: British Columbia Centre of Excellence for Women's Health, pp. 13-14.

[55] Email from Nancy Poole to Brionee Noonan, 22nd April 2014.

CASE STUDY 2

Paltrow and Flavin: Forced interventions on pregnant US women

American researchers Lynn Paltrow and Jeanne Flavin reported on 413 cases from 1973-2005 in which a woman's pregnancy was a necessary factor leading to attempted and actual deprivations of a woman's physical liberty.[56] Of these cases, 10 involved the intake of alcohol. In one matter, a woman was incarcerated in the county jail, where she experienced dehydration, premature labour, developed urinary tract infections, sinus problems and lost 12 pounds. She spent more than a month in jail.[57]

In 112 cases, the American women told health staff about their substance abuse issues as requests for help, both with their addictions and for their babies. Instead, the health staff breached confidentiality and notified the department and subsequently, police were notified. In some cases, hospital medical staff collaborated with police and prosecutors to develop a coordinated system of searching pregnant women for evidence of illegal drug use, reporting women who tested positive to the police and helping the police carry out arrests of the hospitalised women.[58]

In *Ferguson v. City of Charleston*, the US Supreme Court held that such collaboration violated a patient's Fourth Amendment constitutional rights to privacy. Some of the findings of this research challenged the notion that arrests and detentions promote maternal, fetal and child health or provide a path to appropriate treatment. Detention in health and correctional facilities has not meant the pregnant women (and their foetuses) received prompt or appropriate prenatal care.

Both Patrow and Flavin stressed:

"In light of these continued efforts and our findings, we challenge health care workers, judges, and policy makers to examine the role they play in the arrests and detentions of and forced interventions on pregnant women. We call on these same people to develop and support only those policies that are grounded in empirical evidence, that in practice will actually advance the health, rights and dignity of pregnant women and their children, and that will not perpetuate or exacerbate America's long and continuing history of institutionalised racism."[59]

This research lends support to the medical and public health consensus that punitive approaches undermine maternal, fetal and child health by deterring women from care and from communicating openly with people who might be able to help them and challenges the

[56] Paltrow L.M and Flavin J. 'Arrests of and Forced Interventions on Pregnant Women in the United States, 1973-2005: Implications for Women's Legal Status and Public Health' *Journal of Health and Law Advance Publication*, January 15 2013, 299.
[57] Ibid, 319.
[58] Ibid, 326-327.
[59] Ibid, 335.

idea that arrests, detentions, and forced interventions of pregnant women are extremely rare and occur only in isolated, exceptional circumstances against a narrowly definable group of women.[60] In the NT, this group may include women that come under alcohol mandatory treatment measures.

Recommendation 13: **The NT Government should not seek to prevent FASD through punitive measures, such as the criminalization of women who drink.**

10. The prevalence of FASD in the Justice System

Research carried out in other jurisdictions suggests that the prevalence of FASD in the offender population is likely to be very high. Canadian studies of youths in the justice system suggest a rate of 20-40%.[61] Unfortunately, there are no Australian studies concerning the prevalence or incidence of FASD in the criminal justice system. Based on research carried out in other jurisdictions, preliminary research on the prevalence of FASD within the Northern Territory population generally, and the experiences of those working within the criminal justice system, we anticipate that the prevalence of FASD (and similar forms of cognitive impairment) within the offender population is high. Many of the behaviours, which bring a FASD-affected offender into contact with the criminal justice system, may be symptomatic of the FASD.[62] For example, FASD-affected individuals may have difficulty with impulse control, poor judgment, difficulty foreseeing and understanding the consequences of their behaviour, and may be particularly susceptible to peer pressure.[63] FASD may make it difficult for an offender to understand the relationship between offending behaviour and court processes and sentences, and may make it difficult for an offender to comply with court orders (particularly those with onerous conditions), without support. If a FASD-affected offender is sentenced to a term of prison, the aggressive social environment of a prison may place the FASD-affected offender at greater risk of exploitation or victimisation. The FASD-affected offender may also have trouble understanding the link between their offending and their time in prison. This means that many of the mainstream

[60] Ibid, 331-335.
[61] Svetlana Popova, Shannon Lange, Dennis Bekmuradov, Alanna Mihic, Jurgen Rehm, 'Fetal Alcohol Spectrum Disorder Prevalence Estimates in Correctional Systems: a Systematic Literature Review', *Canadian Journal of Public Health* vol. 102, no. 5, pp. 336-340.
[62] Commonwealth Inquiry into FASD, pp. 137 to 138.
[63] Ibid.

justice system processes and orders, including sentences of imprisonment, will be inappropriate and ineffective, and may fail to adequately recognise the special circumstances of a FASD-affected offender and their offending behaviour.

As NAAJA and CAALAS' joint submission to the Inquiry outlines in detail, processes need to be in place at all stages of the justice system to facilitate an improved response to offending behaviour by FASD-affected individuals, particularly youth. Despite the evidence discussed above indicating that the prevalence of FASD and other forms of cognitive impairment within the offender population is likely to be quite high, it is quite rare for a client to present with a formal diagnosis. We anticipate that FASD or other cognitive impairments often go unidentified in the criminal justice system. Even where defence, police, prosecution or a Magistrate or Judge suspect that a defendant may have FASD or other cognitive impairment, obtaining an assessment can be very difficult because of the dearth of assessment and support services and the lack of mechanisms and training within the justice system to facilitate an assessment efficiently and effectively.

If a FASD or other form of cognitive impairment is not identified, then processes and decisions made within the justice system, including bail and sentencing decisions, cannot be tailored to reflect the particular circumstances of the person with a FASD and their offending behaviour. Issues such as reduced culpability as a result of a FASD, or the need for carefully tailored conditions on a community-based sentence, are unlikely to be considered.[64] Indeed, the characteristics of FASD, if not attributed to FASD, may result in the court adopting a more punitive approach, as behaviours which may be symptomatic of FASD, such as difficulty complying with court orders, may be viewed as aggravating factors warranting a harsher penalty.

As NAAJA and CAALAS recommend, to address this, resources must be committed to:

- improving awareness and understanding of FASD and other forms of cognitive impairment amongst professionals working in the justice system;
- carrying out screening and increasing assessment capacity within the justice system, including through the appointment of specialist court-based clinicians;
- establishing and expanding non-custodial therapeutic options to the courts to ensure that the courts can divert FASD-affected offenders away from the prison system and

[64] Douglas, H, 'The sentencing response to defendants with foetal alcohol spectrum disorder' (2010) 34 *Criminal Law Journal* 221, 237.

into programs and services, which support FASD-affected offenders. Current options are extremely limited; and

- where a FASD-affected offender must receive a custodial sentence, ensuring that therapeutic secure care facilities are available as alternative to prison[65] and, if a FASD-affected offender is placed in a prison setting, ensuring that programs within prison and post-release are tailored to meet the needs of the offender.

Case study

A 22-year-old Aboriginal female who resided in Alice Springs had been diagnosed with Foetal Alcohol Syndrome. Despite this, the female has had repeated contact with the criminal justice system since 2008 and consequently experienced many periods of imprisonment. Magistrates in Alice Springs comment on the inappropriateness of imprisoning the woman but note the dearth of alternate options: *"The Northern Territory Government has chosen not to provide any services for people such as [X] .... The Northern Territory Government is well aware that there are people such as [X] in this community who need assistance, and they have chosen, at an executive level, to make a decision not to provide those services....I expect they're saying that the criminal justice system should be picking up and dealing with people who suffer as she suffers from an illness. In my opinion that's highly inappropriate....There are... few sentencing options available to this court....There is nothing to be gained from giving consideration to specific deterrence, there is very little gained in giving consideration to ... rehabilitation."*[66] The female was sentenced to a period of imprisonment.

Much can be learned from the extensive work carried out in other jurisdictions, including Canada and America, into effective responses to FASD-related offending. Canadian stakeholders have combined a high-level national framework for action with continuing legal professional education, availability of diagnostic tools, and a range of treatment options. This model also offers specialised community care, which puts in place a higher level of supervision and is an excellent option for low-risk FASD offenders. Indeed, several Canadian jurisdictions have developed intensive support programs for FASD-affected individuals involved with the criminal justice system.[67]

[65] See the dilemma presented in *R v Doolan* [2009] NTSC 60 at [17].
[66] Mr G Borchers SM, 2009, *Police v RF*, Northern Territory Court of Summary Jurisdiction Alice Springs.
[67] Douglas, H., Hammill, J., Russell, E. and Hall, W. 'Judicial views of foetal alcohol spectrum disorder in Queensland's criminal justice system' (2012) 21 *Journal of Judicial Administration* 178, 186.

In the Northern Territory, legislative changes must be made in addition to a commitment to increased resourcing. This is necessary to facilitate consideration of FASD and other forms of cognitive impairment at each stage of the justice system, and to ensure there is sufficient flexibility to meet the rehabilitation needs of a FASD-affected offender. This includes repealing mandatory sentencing or, at the very least, amending the 'exceptional circumstances' exemption to specifically designate the existence of a cognitive impairment as an 'exceptional circumstance'. The problem with mandatory sentencing and its application to people with cognitive impairments is discussed in detail in NAAJA and CAALAS' submission.

Unless urgent and significant action is taken to address the issue of FASD and the justice system, far too many offenders affected by FASD will cycle through the prison system unnecessarily. This is unacceptable and unsustainable in the current context of very high incarceration rates, and the massive overrepresentation of Aboriginal people in our prisons.

We note that many of the comments and recommendations we make in relation to FASD apply to other forms of developmental impairment, highlighting the need for screening, assessment and therapeutic responses to target all forms of cognitive impairment.

Recommendation 14: **Young people in the juvenile justice system should be screened for cognitive and behavioural problems including FASD so that any deficits can be taken into account in sentencing.**

Recommendation 15: **APO NT endorses the recommendations made by NAAJA and CAALAS in their submission to the Inquiry in relation to FASD and the justice system.**

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