Central Australian Aboriginal Congress

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Submission to the

Senate Community Affairs References Committee

Inquiry into effective approaches to prevention and diagnosis of FASD and strategies for optimising life outcomes for people with FASD

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Table of Contents

Executive Summary

The context for FASD in Aboriginal Australia

The high prevalence of alcohol related harm (including FASD) in Aboriginal communities is strongly linked to the processes of colonisation which have undermined the capacity of some families to care for their children. Any approach to addressing FASD in Aboriginal communities must therefore be founded on the rights of our peoples as established under international agreements to which Australia is a signatory.

Poverty and inequality are both strongly correlated with increased rates of addiction, including to alcohol. Government must address the widening income gap and falling incomes of Aboriginal people particularly in remote Australia.

Culture and spirituality are important in addressing intergenerational trauma through supporting resilience, positive social and emotional wellbeing, and living a life free of addiction to alcohol and drugs. Programs for preventing, diagnosing or treating FASD where there are significant numbers of Aboriginal people must incorporate positive attitudes to Aboriginal culture and ways of being, and resourced to be trauma-informed and healing-focused.

Provision of culturally appropriate advice on alcohol and pregnancy (term of reference c.)

Aboriginal community controlled health services (ACCHSs) have structural advantages in delivering services to Aboriginal women and families, and hence improved outcomes compared to non-Indigenous services.

In recognition of their greater effectiveness, higher acceptance by Aboriginal people, and better delivery of culturally-responsive services, programs for the prevention, diagnosis and treatment of FASD in Aboriginal communities should be preferentially provided through ACCHSs and/or negotiated with them.

Best practice in preventing, diagnosing and managing FASD (term of reference f.)

Efforts to prevent FASD must be located within a broader strategy to reduce alcohol related harms of all kinds. The key approaches, supported by substantial international evidence, are:

- *population-level alcohol supply reduction* to reduce overall alcohol consumption levels especially amongst women of child-bearing age and their partners, with the recent Northern Territory Government Alcohol Reforms providing world-leading evidence of the effectiveness of such approaches;
- *early childhood development programs* to break the inter-generational cycle of disadvantage and alcohol abuse and offset the developmental

effects of alcohol consumption on children in the family, whether incurred before or after birth; and

- *individual approaches to reducing alcohol use and preventing FASD*, delivered through alcohol treatment programs, primary health care services (ACCHSs) and through accesses to culturally appropriate family planning.

Awareness of and support for FASD in schools (term of reference g.)

Schools need to be adequately resourced to identify and support those with FASD or other developmental issues. Effective partnerships between ACCHSs and education providers are necessary to ensure that services work cohesively for Aboriginal families, there are no duplications or gaps, and that limited resources are used efficiently.

FASD in vulnerable populations (term of reference h.)

The true prevalence of FASD in Aboriginal Australia is unknown, however it has been estimated to be at least 3 and 7 times as common in the Aboriginal as it is in the non-Aboriginal population, and in some places much higher.

In response to the prevalence of developmentally vulnerable Aboriginal children in the communities we serve, Congress initiated a Child and Youth Assessment and Treatment Service (CYATS) in 2018.

CYATS provides a best-practice service for the early detection of neurodevelopmental conditions such as FASD, ADHD and Autism Spectrum Disorder (ASD), providing a multidisciplinary approach to diagnostic assessment, early intervention, and support for families to access the NDIS. This service, the first of its kind in the Northern Territory, is founded on a strong partnership with Alice Springs Hospital paediatrics and other health and education agencies, and is integrated with other child, youth and parenting programs within Congress. An important part of CYATS is the level of engagement by the team with the families.

Despite its successes and its growing reputation future funding is uncertain with the Australian Government component ceasing at the end of 2019.

FASD in the criminal justice system (term of reference i.)

Rates of FASD are very high for young people in the justice system, which has a high Aboriginal population with one study showing that over a third (36%) of young people in detention had FASD in a detention population that was three-quarters (74%) Aboriginal.

FASD and the NDIS (term of reference k.)

Populations bearing the burden of multiple, complex overlapping social and health challenges are those least able to navigate the complex bureaucracy of personalised systems such as the NDIS. These barriers are multiplied

significantly in cross cultural situations. This points towards the need for culturally secure, Aboriginal community-controlled providers of NDIS services including for diagnosing and treating FASD. Congress' CYATS (see above) is a prime example of such service delivery addressing the needs of developmentally vulnerable Aboriginal children and young people in a remote area.

Given the limitations on the operations of the NDIS in remote areas, Congress has developed a funds-pooling model for children aged 0 to 6 in Central Australia and is currently negotiating the implementation of this model with the National Disability Insurance Agency (NDIA). This model would see universal access to evidence-informed early childhood programs adapted to local social and cultural contexts for all children aged 0 to 6.

Recommendations of *FASD: The Hidden Harm* (term of reference m.)

The 2012 House of Representatives Standing Committee on Social Policy and Legal Affairs report recommended mandatory health warning labels on alcoholic beverages that advises women not to drink when pregnant or when planning a pregnancy. Unfortunately, largely due to the direct and indirect influence of the alcohol lobby, debate on the implementation of such labels continues.

Recommendations

Recommendation 1. That any approach to addressing the high prevalence of FASD in Aboriginal communities must be based upon the rights to self-determination of Aboriginal peoples as established under international agreements to which Australia is a signatory, including theUnited Nations Declaration on the Rights of Indigenous Peoples.

Recommendation 2. That the Australian Government commits to reducing poverty and inequality as a key way to prevent the addiction to alcohol which, in many Aboriginal families, underlies the poor developmental outcomes of children, including through FASD. This commitment should include an increase in the Newstart and similar citizenship entitlements by $75 per week for all participants, and an additional loading on such payments for those in remote or very remote areas to address significantly higher costs of living.

Recommendation 3. That all programs for preventing, diagnosing or treating FASD where there are significant numbers of Aboriginal people in the community be founded on a positive attitude to Aboriginal culture and ways of being, and resourced to be trauma-informed and healing-focused.

Recommendation 4. That, as a key primary prevention measure for FASD, the Australian Government provides leadership for the national adoption of objectively evidenced policy approaches to reducing alcohol-related harm

at a whole-of-population level, which include action on price and availability similar to those contained in the successful and world-leading Northern Territory Alcohol Policies and Legislation Reforms.

Recommendation 5. Provision of access to evidence-informed early childhood development programs for children aged 0 to 4 in at risk families is a key strategy for the primary prevention of alcohol-related harms in the future and for breaking the intergenerational cycle of the harmful use of alcohol. Sustained investment in such programs should be a foundation for addressing alcohol related harm including FASD.

Recommendation 6. That Australian Governments work together to support and extend services which are effective in reducing alcohol consumption amongst individuals. They include well-resourced interventions in the primary health care based on Congress model of 'three streams of care' (medical treatment, psychological therapy, and social and cultural support; culturally appropriate family planning for women and/or their partners who consume alcohol and where the woman does not wish to become pregnant; and appropriately resourced, culturally-safe residential and community-based alcohol treatment programs.

Recommendation 7. Government should avoid investment in approaches for which there is no reasonable prospect of effectiveness or which discriminate against or further marginalise disadvantaged groups. These include criminal sanctions against women who drink while pregnant; mandatory treatment linked to criminal sanctions; non-targeted education and persuasion strategies, including most school-based education and media campaigns; any program or policy founded upon discrimination on the basis of race.

Recommendation 8. That the Australian Government seeks to ensure that State and Territory Education Departments are providing adequate resources for the provision of psychological and other support services for students diagnosed with FASD or with other developmental conditions, and that these services are provided in collaboration with Aboriginal Community Controlled Health Services for Aboriginal and Torres Strait Islander children.

Recommendation 9. More information is needed about the prevalence of FASD and other alcohol-related cognitive and emotional impairment in Aboriginal Australia. Research should be supported which aims to identify patterns of prevalence and incidence of these harms, whether caused in pregnancy through FASD, through lack of responsive parenting and neglect in early childhood, directly through the health effects of alcohol consumption, or otherwise indirectly through violence, accidents and injury.

Recommendation 10. That the Australian Government recognise the Central Australian Aboriginal Congress Child and Youth Assessment and Treatment Service (CYATS) as an exemplar of innovative Aboriginal community-led FASD assessment and treatment services, and build on the success of this

service by establishing demonstration sites in other Aboriginal Community Controlled Health Services in a range of settings (urban, rural and remote). Demonstration sites should include a common formal evaluation and research component to measure incidence / prevalence; to maximise service delivery effectiveness including through culturally responsive, trauma informed care; and to translate this knowledge to other settings. Demonstration sites should be provided with 5 year block-funding to allow proper monitoring and evaluation and service refinement over time.

Recommendation 11. Given the rates of FASD and other neurodevelopmental conditions in the youth justice system, all young Aboriginal people going through the criminal justice system should have access to a neurodevelopmental assessment, which may have an impact on sentencing and receiving the right care.

Recommendation 12. That the National Disability Insurance Agency (NDIA) implement population-level funds-pooling for Aboriginal children aged 0 to 6 in remote and regional areas, to provide sustainable, universally accessible, evidence-informed, culturally adapted, early childhood programs. To maintain access to additional specialist services under the NDIS to those children who are diagnosed with a specific disability such as FASD while aged 0 to 6, a proportion of the total funds – rather than the whole amount – could be pooled.

Recommendation 13. That the NDIA commit to ongoing funding for central coordination and logistical support for the effective delivery of visiting NDIS-funded services to remote and regional Aboriginal communities, in recognition of the failure of market-driven approaches in these areas of Australia

Recommendation 14. That, as recommended by the House of Representatives Standing Committee on Social Policy and Legal Affairs report, FASD: The Hidden Harm (2012) and by numerous other agencies, Food Standards Australia New Zealand (FSANZ) mandate a health advisory label advising women not to drink when pregnant or when planning a pregnancy to be included on all alcohol products of greater than 100ml, to be implemented within one year

Background

About us

1. Central Australian Aboriginal Congress (Congress) is a large Aboriginal Community Controlled Health Service (ACCHS) based in Alice Springs. We are one of the most experienced organisations in the country in Aboriginal health, a national leader in primary health care, and a strong advocate for the health of our people. Since the 1970s, we have developed a comprehensive model of primary health care that includes: multidisciplinary clinical care; health promotion and disease prevention programs; and action on the social, cultural, economic and political determinants of health and wellbeing.

2. Congress delivers services to more than 16,000 Aboriginal people living in Alice Springs and remote communities across Central Australia including Ltyentye Apurte (Santa Teresa), Ntaria (Hermannsburg), Wallace Rockhole, Utju (Areyonga), Mutitjulu and Amoonguna.

3. In recent years, the community-elected Congress Board of Directors has focused on improving the developmental outcomes of Aboriginal children. This has led to the creation of an innovative model for the delivery of child and family services, based on the belief that the best way to "close the gap" is to make sure it is not created in the first place.

The context for FASD in Aboriginal Australia

The effects of colonisation and the right to self-determination

4. The nurture and care of children is at the heart of Aboriginal culture. For tens of thousands of years, our diverse peoples raised healthy, resilient and creative children. Today, many of our families still do.

5. However, contemporary Aboriginal families have been deeply affected by the processes of colonisation including dispossession and impoverishment; the forcible removal of children and its intergenerational effects; the suppression of culture and language; and the experience of racism and discrimination. Aboriginal families continue to live with these effects of colonisation which challenge their capacity to care for their children.

6. It is in this context that the high levels of alcohol use in contemporary Aboriginal communities should be seen. Numerous inquiries and reports, such as the *Royal Commission Into Aboriginal Deaths In Custody* in 1991 [1], and the report of the Board of Inquiry into the Protection of Aboriginal Children from Sexual Abuse, *Little Children are Sacred* in 2007 [2] have noted the highly adverse role that alcohol has on Aboriginal children and families. Despite the evidence accumulating over decades, governments have failed to respond adequately to the needs of Aboriginal children and families.

7. Any approach to addressing the high prevalence of FASD in Aboriginal communities must recognise this underlying process of colonisation and its effects. It should therefore be founded on the rights of Aboriginal peoples as established under international agreements to which Australia is a signatory, including the *United Nations Declaration on the Rights of Indigenous Peoples* [3], which states:

   Article 22: Particular attention shall be paid to the rights and special needs of … persons with disabilities in the implementation of this Declaration.

   Article 23: Indigenous peoples ... have the right to be actively involved in developing and determining health, housing and other economic and social programmes affecting them and, as far as possible, to administer such programmes through their own institutions.

Poverty and inequality

8. Absolute deprivation (poverty) and relative deprivation (inequality) are both strongly correlated with increased rates of addiction including to alcohol [4, 5]. In relation to this fact:

   a) in remote areas across Australia both poverty and inequality are worsening for Aboriginal people, with Aboriginal incomes falling and the income gap to non-Indigenous people widening [6];

   b) Aboriginal people are disproportionately dependent on citizenship entitlements such as the Newstart Allowance, the Parenting Payment and the Youth Allowance [7]. These are inadequate to meet the needs of families and their children, especially in remote areas where the cost of living is much higher, especially for food [8].

Intergenerational trauma and culture

9. The historical and ongoing experience of colonisation for Aboriginal people is now recognised as resulting in 'intergenerational trauma' whereby traumatic experiences

   … can be transferred from the first generation of survivors that have experienced (or witnessed) it directly in the past to the second and further generations of descendants of the survivors … this intergenerational trauma … is passed from adults to children in cyclic processes as 'cumulative emotional and psychological wounding' [9]

10. Culture and spirituality are important in addressing intergenerational trauma through supporting resilience, positive social and emotional wellbeing, and living a life free of addiction to alcohol and drugs [10]. In addition, services provided to populations carrying a large burden of trauma need to have the skills and resources to recognise the different ways that unresolved trauma can manifest (for example, in mental health issues including suicide,

addiction, or violence) and be able to address presenting issues in a way that promotes healing [9].

Recommendation 1. **That any approach to addressing the high prevalence of FASD in Aboriginal communities must be based upon the rights to self-determination of Aboriginal peoples as established under international agreements to which Australia is a signatory, including the *United Nations Declaration on the Rights of Indigenous Peoples*.**

Recommendation 2. **That the Australian Government commits to reducing poverty and inequality as a key way to prevent the addiction to alcohol which, in many Aboriginal families, underlies the poor developmental outcomes of children, including through FASD. This commitment should include an increase in the Newstart and similar citizenship entitlements by $75 per week for all participants, and an additional loading on such payments for those in remote or very remote areas to address significantly higher costs of living.**

Recommendation 3. **That all programs for preventing, diagnosing or treating FASD where there are significant numbers of Aboriginal people in the community be founded on a positive attitude to Aboriginal culture and ways of being, and resourced to be trauma-informed and healing-focused.**

Addressing the Terms of Reference

11. Congress is unable to provide a response to all 16 of the Inquiry's terms of reference. However, in the following sections we address some of the key issues, based upon the evidence-informed service models we have developed to meet the needs of the Aboriginal communities of Central Australia.

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

12. Aboriginal community controlled health services (ACCHSs, sometimes referred to as Aboriginal Medical Services) are the most important service delivery system for evidence-based, culturally appropriate services to address FASD in Aboriginal communities. There are 140 ACCHSs around Australia, delivering almost 3 million episodes of care annually through over 300 clinics, and employing over 6,000 staff whom, most of whom are Aboriginal and Torres Strait Islander Australians [11].

13. ACCHSs have a range of inter-linked structural advantages in delivering services and hence improved outcomes compared to non-Indigenous services (government or private). These structural advantages include:

    a) *a holistic approach to service delivery*, including through addressing the social determinants of child and family wellbeing, based on a lived understanding of the Aboriginal conception of health;

b) *culturally responsive services*: Aboriginal community-controlled organisations are able to provide their care within a culturally responsive setting, based on local knowledge, an Aboriginal governance structure and workforce, and strong relationships with the communities that they serve;

c) *better access, based on community engagement and trust*: a strong practice of community engagement founded on strong relationships with the community, in turn based on a sense of ownership and history. Aboriginal people consistently prefer to use Aboriginal organisations such as ACCHSs over mainstream services giving them a strong advantage in addressing access issues, particularly when dealing with culturally sensitive issues relating to sexuality, pregnancy, childbirth and addiction;

d) *Aboriginal governance*: individuals and communities are encouraged and enabled to participate in decisions on service delivery, including though formal governing Boards;

e) *an Aboriginal workforce*: community-controlled services are significantly better at attracting, training and retaining Aboriginal staff leading to greater cultural appropriateness of services as well as benefits through providing employment and capacity building in the Aboriginal community;

f) *high levels of accountability*: Aboriginal community-controlled services are highly accountable to their funders for the services they provide through robust data collection and a reporting regime which is above the requirements of mainstream health and wellbeing services.

14. Such advantages were recognised by a recent Senate Inquiry which recommended that [12]:

> *… future selection criteria and funding guidelines should give weighting to the contribution and effectiveness of Aboriginal and Torres Strait Islander organisations to provide to their community beyond the service they are directly contracted to provide.*

15. Congress has documented the substantial evidence about the increased effectiveness of ACCHSs in delivering a holistic and comprehensive range of primary health care services, including those focused on the needs of Aboriginal women and children. A copy of the paper containing this evidence accompanies this submission.

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

Prevention

16. Efforts to prevent FASD must be located within a broader strategy to reduce alcohol related harms of all kinds. The key approaches, supported by substantial international evidence, are:

a) *Population-level alcohol supply reduction* to reduce overall alcohol consumption levels especially amongst women of child-bearing age and their partners;

b) *Early childhood development programs* to break the inter-generational cycle of disadvantage and alcohol abuse and offset the developmental effects of alcohol consumption on children in the family, whether incurred before or after birth; and

c) *Individual approaches to reducing alcohol use and preventing FASD,* delivered through alcohol treatment programs, primary health care settings and through accesses to culturally appropriate family planning.

Population-level alcohol supply reduction

17. Reducing the consumption of alcohol amongst all women of child-bearing age and their partners is the key primary prevention approach to reducing developmental vulnerabilities caused by alcohol consumption. This is because:

    a) the developing child is most vulnerable to exposure to alcohol in the first three to six weeks after conception, which is often before many women are aware that they are pregnant [13];

    b) the relatively high proportion of women who continue to drink at risky levels during pregnancy – in Australia, it is estimated that over a third of women who report drinking at risky levels (including 'binge drinking') continue to do so into pregnancy with only a small likelihood that they will abstain from alcohol entirely during pregnancy [14];

    c) the risk factors for having a child with FASD includes a woman having a male partner who drinks [15]. There is also emerging evidence that fathers' alcohol consumption can affect the development of the unborn child [16], adding to the likely exposure of the effects of alcohol consumption before either parent is aware of the pregnancy;

    d) there are significant developmental harms done to children in the years after their birth into families where alcohol misuse is frequent. Parental alcohol misuse is frequently associated with domestic violence and neglect of children during their critical early years. This lack of responsive parental care and nurture can have similarly profound effects on brain chemistry, causing delays and blockages in development which many children carry into their school years and beyond [17].

18. For these reasons, and in line with key studies [18], reducing the prevalence of FASD must include broad-based public health measures to reduce alcohol consumption amongst the whole population, including women of child-bearing age. There is a very strong international evidence-base that indicates that*:*

a) increasing the price of alcohol, and particularly that of cheap alcohol, is a 'best buy' for reducing consumption and hence alcohol related harm at a population level; it is also a highly cost effective intervention [19]; and

b) physical availability is the next most important determinant of alcohol harm, in particular through reducing trading hours and license density [19, 20].

19. In October 2019 the Northern Territory Government introduced a package of reforms to deal with the jurisdiction's long-standing issue with high levels of alcohol-related harm. The reforms included [21]:

    a) a floor price to prevent the sale of cheap alcohol;

    b) a Banned Drinkers Register (BDR) to reduce the access to take-away alcohol by problem drinkers;

    c) Point of Sale Interventions at all bottle shops in three regional centres;

    d) a new Liquor Act that includes risk-based licencing and greater monitoring of on-licence drinking; and

    e) a commitment to high quality, ongoing independent evaluation.

20. These reforms are informed by the best available evidence from around the world on what works to reduce alcohol related harm. Without yet a full year effect, they have already demonstrated very significant reductions in alcohol-related harm across the Northern Territory including:

    a) a reduction by almost a third (31%) in alcohol-related Emergency Department presentations;

    b) a reduction by a quarter (25%) in alcohol-related assaults;

    c) a reduction by one-fifth (21%) in alcohol-related domestic violence assaults; and

    d) major reductions in substantiated child neglect and hospital admissions for maltreatment

21. These results provide objective evidence for population-level reductions in harmful drinking as a result of the reforms. They can be expected to lead to significant reductions in the prevalence of FASD and other developmental conditions related to adverse childhood experiences such as trauma from exposure to domestic violence in the Northern Territory. See Attachment for details.

Recommendation 4. **That, as a key primary prevention measure for FASD, the Australian Government provides leadership for the national adoption of objectively evidenced policy approaches to reducing alcohol-related harm at a whole-of-population level, which include action on price and availability similar to those contained in the successful and world-leading Northern Territory Alcohol Policies and Legislation Reforms.**

Evidence-informed early childhood development programs

22. Another key primary prevention approach to reducing the incidence of FASD is through supporting healthy development in early childhood. Parental alcohol use is frequently associated with lack of responsive care and under-stimulation and neglect of children during their early years. Even where FASD is not present, this is strongly linked to vulnerabilities in development which children carry into their school years and beyond, leading to heightened risks of addiction (including to alcohol) in later life [22, 23].

23. However, sustained investment in evidence-informed early childhood programs can offset early childhood disadvantage and are a 'best buy' in terms of addressing health and social inequity and breaking the cycle of harmful alcohol use in the long-term. They are thus an essential part of the effort to reducing alcohol-related harm through addressing developmental vulnerabilities in children, whatever their starting point, that is, whether originating with exposure to alcohol before birth (FASD) or with family dysfunction related to alcohol consumption after birth.

24. Examples of such preventative programs include the Nurse Family Partnership (NFP) Program Home Visitation and the Abecedarian model of Day care focused on play based learning, conversational reading and enriched care giving. These programs work with children to access the stimulation, quality relationship and access to services to optimise healthy development. While NFP uses an outreach based model with emphasis on home visits and contact with mothers, the Abecedarian day care model has a focus on daily contact with the child at a centre where children experience enriched care. Such early childhood programs can reduce the use of alcohol and other substances by young adults [24] including reducing the number of young women who start drinking before the age of 17 [25].

Individual approaches to reducing alcohol use and preventing FASD

25. Many women drinkers may need access to treatment to assist them to reduce or quit drinking, particularly if they are, or are considering becoming pregnant. The role of male partners is also important – not only because of the emerging evidence about the association of their alcohol consumption with foetal abnormalities, but also because their support is likely to be crucial for women to abstain from alcohol during preconception, pregnancy and in the early years of their child's life [18].

26. The international literature demonstrates that treatment can be effective [26]. However, 'effectiveness' should not just be measured by the number of clients who abstain completely from alcohol after treatment: reduced alcohol consumption and improved social functioning (including within families) are also important measures of success. Culturally appropriate, well-resourced and evidence-informed alcohol treatment services therefore form an important part of preventing FASD by assisting women to reduce their alcohol consumption or abstain altogether.

27. Interventions from the primary health care setting are known to be effective in reducing alcohol use [19]. Well-structured interventions – such as the Congress 'three streams of care' model should provide medical care (including the use of pharmacotherapies), psychological care (including structured therapies) and social and cultural support (to help the client change the social context which is part of the reason that addiction occurs and is maintained).

28. Assisting women and/or their partners who drink and are not planning to become pregnant to avoid conception is an important avenue for preventing FASD [27]. Readily available family planning and contraception supported by culturally appropriate sex education therefore remains an important strategy for implantation in primary health care settings.

29. residential and community-based treatment programs which include social and cultural support for clients during and after treatment and adequate investment in infrastructure and training and transitional accommodation

Approaches with little evidence of success

30. There are a number of approaches which are sometimes suggested which have little or no evidence to support them in reducing alcohol consumption and/or preventing FASD, as follows.

31. There is no evidence to support criminalising women who drink during pregnancy. While drinking during pregnancy poses a threat to the health of the unborn child, criminal sanctions may have negative consequences, for example through deterring women from seeking antenatal care or assistance with their drinking. Instead, the evidence suggests that approaches that concentrate on reducing alcohol consumption before pregnancy, and which are non-stigmatising and broad-based (focusing on wellbeing, nutrition, and enhancing the woman's living status) are most effective [14].

32. Mandatory treatment linked to criminal sanctions has very little evidence of success in reducing alcohol consumption for high-risk drinkers. It appears to work least well for young people, can add to the disadvantage experienced by marginalised groups, and may displace voluntary clients from limited treatment spaces [28].

33. In general, education and persuasion strategies, including school-based education and media campaigns, have at best a minimal, short-term effect in

raising awareness and reducing alcohol consumption, and as a substantial review of the international literature notes, 'cannot be relied upon as an effective approach' [19]. With particular reference to FASD, evaluation of public awareness campaigns and supporting resources elsewhere showed that health messages failed to reach high risk groups [29].

34. Approaches which discriminate on the basis of race are likely to be counter-productive. The experience of racism is associated with increased alcohol consumption. Indigenous Australians commonly experience high levels of racism, from relatively minor incidents such as being called racist names, through verbal abuse, to serious assault [30]. There is a strong association between racism and poor mental health and alcohol misuse [31]. As well as addressing racism directly, this also points strongly to the need for interventions to tackle alcohol in Aboriginal communities to be non-racially discriminatory.

Recommendation 5. **Provision of access to evidence-informed early childhood development programs for children aged 0 to 4 in at risk families is a key strategy for the primary prevention of alcohol-related harms in the future and for breaking the intergenerational cycle of the harmful use of alcohol. Sustained investment in such programs should be a foundation for addressing alcohol related harm including FASD.**

Recommendation 6. **That Australian Governments work together to support and extend services which are effective in reducing alcohol consumption amongst individuals. They include well-resourced interventions in the primary health care based on Congress model of 'three streams of care' (medical treatment, psychological therapy, and social and cultural support; culturally appropriate family planning for women and/or their partners who consume alcohol and where the woman does not wish to become pregnant; and appropriately resourced, culturally-safe residential and community-based alcohol treatment programs.**

Recommendation 7. **Government should avoid investment in approaches for which there is no reasonable prospect of effectiveness or which discriminate against or further marginalise disadvantaged groups. These include criminal sanctions against women who drink while pregnant; mandatory treatment linked to criminal sanctions; non-targeted education and persuasion strategies, including most school-based education and media campaigns; any program or policy founded upon discrimination on the basis of race.**

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

35. Congress understands that there is an awareness of FASD in Central Australian schools. The NT Department of Education has a responsibility to support the identification and management of neurodevelopmental conditions such as FASD and to provide psychological and student support services in

partnership with Aboriginal health services. Effective partnerships between ACCHSs and education providers are necessary to ensure that services work cohesively for families, there are no duplications or gaps, and that limited resources are used efficiently.

Recommendation 8. **That the Australian Government seeks to ensure that State and Territory Education Departments are providing adequate resources for the provision of psychological and other support services for students diagnosed with FASD or with other developmental conditions, and that these services are provided in collaboration with Aboriginal Community Controlled Health Services for Aboriginal and Torres Strait Islander children.**

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

Prevalence of FASD in Aboriginal communities

36. The true prevalence of FASD in Aboriginal Australia is unknown, however it has been estimated to be between 3 and 7 times as common in the Aboriginal as it is in the non-Aboriginal population [32]. In Western Australia, one study concluded that 15.6% of avoidable intellectual disability in Aboriginal children is attributable to maternal alcohol use – twelve times the rate for non-Aboriginal children [33]; another found almost 1 in 5 children in remote Aboriginal communities to be diagnosable with the disorder [34]. In the same state, almost half (47%) of young Aboriginal people in criminal detention were found to be diagnosable with FASD [35].

37. In Central Australia, the Australian Early Developmental Index suggests a very high number of developmentally vulnerable Aboriginal children, with 60% considered vulnerable in at least one of five developmental domains and 43% on two or more of five developmental domains [36]. While not all such children would have FASD, alcohol consumption either pre- or post-birth would contribute a high proportion of these developmental vulnerabilities.

Recommendation 9. **More information is needed about the prevalence of FASD and other alcohol-related cognitive and emotional impairment in Aboriginal Australia. Research should be supported which aims to identify patterns of prevalence and incidence of these harms, whether caused in pregnancy through FASD, through lack of responsive parenting and neglect in early childhood, directly through the health effects of alcohol consumption, or otherwise indirectly through violence, accidents and injury.**

A multifaceted approach to addressing developmental delay and disability in Alice Springs

38. In response to the prevalence of developmentally vulnerable Aboriginal children in the communities we serve, Congress initiated the Child and Youth

Assessment and Treatment Service (CYATS) in 2018 through seed funding from the Commonwealth Department of Health, facilitated by the FASD National Consortium (Telethon Kids and PATCHES paediatrics). The establishment of CYATS was given further impulse by the roll-out of the National Disability Insurance Scheme (NDIS) and the fact that there was a very low level of diagnostic and treatment services for children with developmental delay in Central Australia.

39. CYATS provides a best-practice service for the early detection of neurodevelopmental conditions such as FASD, ADHD and Autism Spectrum Disorder (ASD), providing a multidisciplinary approach to diagnostic assessment, early intervention, and support for families to access the NDIS. This service, the first of its kind in the Northern Territory, is founded on a strong partnership with Alice Springs Hospital paediatrics and other health and education agencies, and is integrated with other child, youth and parenting programs within Congress as children may have comorbidities including recurring ear infections and hearing loss, vision impairment etc.

40. Building on the seed funding which was able to pay part of the salary of a neuropsychologist as a key component for a FASD diagnosis, Congress successfully applied for funding from several different sources including NT Government departments and the National Disability Insurance Agency to establish a multidisciplinary team consisting of a Team Leader; an Aboriginal Family Support Worker; two Speech Pathologists; Occupational Therapist; and two neuropsychologists.

41. The team conducts discipline specific assessments (e.g. speech pathology assessment for speech delay only) and multidisciplinary neurodevelopmental assessments for suspected neurodevelopmental disorders in children and young people aged 0-18 years, including child-protection ordered assessments and court-ordered/lawyer initiated assessments for youth in detention. The team also provides interventions including direct individual therapy and blocks of group speech and occupational therapy in non-clinical settings (home/school); community support; educational support; family support. Embedded within the broader suite of culturally-responsive child and family services, CYATS always seeks to operate in collaboration with and guided by families.

42. An important part of CYATS is the level of engagement by the team with the families. Often families are disengaged and require enormous support to participate in assessments. Families often experience severe social and personal turmoil and face language and cultural barriers to accessing specialist services. Cultural expertise is provided by CYATS Aboriginal Family Support Worker and where families require higher levels of support, CYATS will refer to and work alongside Congress' Family Support Services team.

43. While it is too early to gain a full picture of the occurrence of FASD in Central Australia, in 12 months of operation CYATS made 15 diagnoses of FASD, along with 2 for Attention Deficit Hyperactivity Disorder (ADHD), 6 for Autism Spectrum Disorder (ASD), and 7 other developmental diagnoses.

44. There is a high demand for the service with a long waiting list for neurodevelopmental assessment. Final diagnostic reporting takes on average 6-8 weeks to complete with information gathering of clinically relevant background information from schools, Territory Families, and health services (e.g. on maternal alcohol use) occurring in the pre-assessment phase, and a battery of 8-10 assessments informing diagnosis by the multidisciplinary team.

45. CYATS is tightly monitored within a Continuous Quality Improvement framework to ensure the service is meeting its targets and community expectations and is adjusted as needed.

46. However, despite its successes and its growing reputation as the only such service in Central Australia, future funding is uncertain with the Australian Government component ceasing at the end of 2019.

Recommendation 10. **That the Australian Government recognise the Central Australian Aboriginal Congress Child and Youth Assessment and Treatment Service (CYATS) as an exemplar of innovative Aboriginal community-led FASD assessment and treatment services, and build on the success of this service by establishing demonstration sites in other Aboriginal Community Controlled Health Services in a range of settings (urban, rural and remote). Demonstration sites should include a common formal evaluation and research component to measure incidence / prevalence; to maximise service delivery effectiveness including through culturally responsive, trauma informed care; and to translate this knowledge to other settings. Demonstration sites should be provided with 5 year block-funding to allow proper monitoring and evaluation and service refinement over time.**

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

47. Rates of FASD are very high for young people in the justice system, which has a high Aboriginal population. A pivotal study in Western Australia showed that 89 per cent of young people in a juvenile detention centre were found to have a severe neurodevelopmental condition. Thirty-six per cent of the young people had FASD. Seventy-four per cent of this prison population were Aboriginal. This also shows the common trajectory for children who do not receive early diagnosis and intervention [35].

48. In Alice Springs there is a level of awareness within the criminal justice system of FASD. Congress has made arrangements with the Courts for CYATS to undertake assessments on some young people appearing before the Courts.

Additionally, while not specifically funded to provide this service, Congress' CYATS team has provided education sessions to the legal officers and the police on FASD and related behaviours.

49. Engaging young people in assessments and treatments outside of detention centres is challenging and requires specific resourcing for Aboriginal support workers to ensure effective engagement.

Recommendation 11. **Given the rates of FASD and other neurodevelopmental conditions in the youth justice system, all young Aboriginal people going through the criminal justice system should have access to a neurodevelopmental assessment, which may have an impact on sentencing and receiving the right care.**

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

Limitations on NDIS in remote Aboriginal communities

50. The fundamental tenet of the NDIS and similar personalisation schemes that seek to give individuals choice and control over the services they receive, is well intended. There is a strong relationship between disempowerment and poor health and wellbeing [37, 38].

51. However, promoting personal choice for people in contexts where they are not able to meaningfully exercise that choice is likely to cause stress and undermine social and emotional wellbeing. In particular, personalisation schemes such as the NDIS do not work unless there are sufficient service providers to meet demand and provide choice [39]. This basic requirement is not met in many regional and remote areas where populations are dispersed and the costs of delivering services are high. Central Australia is one such area, particularly regarding diagnosis and support for children with developmental issues.

52. In addition, populations bearing the burden of multiple, complex overlapping social and health challenges are those least able to navigate the complex bureaucracy of personalised systems such as the NDIS [39]. These barriers are multiplied significantly in cross cultural situations such as apply for Aboriginal people in Central Australia where large sections of the population speak English as a second language and where the experience of mainstream services may lead Aboriginal people to be suspicious of them and to avoid engagement.

53. The recent trial of NDIS in the remote Barkly region of the Northern Territory demonstrates the limitations of the personalised model of care in such a context. The evaluation of the trial concluding that outcomes for NDIS participants were poorest for those living in remote Aboriginal communities,

and worked best for those already advantaged by good English literacy and/or computer skills [40].

54. This points towards the need for culturally secure, Aboriginal community-controlled providers of NDIS services including for diagnosing and treating FASD. Congress' CYATS (see above) is a prime example of such service delivery addressing the needs of developmentally vulnerable Aboriginal children and young people in a remote area.

Funds-pooling for Aboriginal children aged 0 to 6

55. Given the limitations on the operations of the NDIS in remote areas, Congress has developed a funds-pooling model for children aged 0 to 6 in Central Australia and is currently negotiating the implementation of this model with the National Disability Insurance Agency (NDIA).

56. Despite the high level of developmental vulnerability in the early years Aboriginal children are unlikely to be diagnosed with a neurodevelopmental disorder such as FASD until around aged 7 when these conditions are much more apparent and easier to assess.

57. For children aged 0 to 6, the focus should therefore be on universal access to evidence-informed early childhood programs adapted to local social and cultural contexts. If these primary prevention programs have not averted a disability, once a child reached 7 years old, a definitive diagnosis is able to be made and an individual pathway and plan made as per the usual NDIS procedures.

58. Therefore, for Aboriginal children aged 0 to 6, an estimate of the population-level of vulnerability should be used to pool NDIS funds, from what would have been individual packages, to provide sustainable, universally accessible, evidence-informed, culturally adapted, early childhood programs. This is a 'market deepening' strategy that will achieve economies of scale; enhance the purchasing power of remote and rural participants; attract and sustain the necessary services; and increase the efficiency of service delivery.

59. Congress estimates that the funds pool for Central Australian Aboriginal children aged 0 to 6 will be conservatively $21 million per year. To maintain access to additional specialist services under the NDIS to those children who are diagnosed with a specific disability while aged 0 to 6, a proportion of the total funds – rather than the whole amount – could be pooled.

Recommendation 12. **That the National Disability Insurance Agency (NDIA) implement population-level funds-pooling for Aboriginal children aged 0 to 6 in remote and regional areas, to provide sustainable, universally accessible, evidence-informed, culturally adapted, early childhood programs. To maintain access to additional specialist services under the NDIS to those children who are diagnosed with a specific disability such as FASD while aged 0 to 6, a proportion of the total funds – rather than the whole amount – could be pooled.**

Recommendation 13. **That the NDIA commit to ongoing funding for central coordination and logistical support for the effective delivery of visiting NDIS-funded services to remote and regional Aboriginal communities, in recognition of the failure of market-driven approaches in these areas of Australia**

(m) progress on outstanding recommendations of the House of Representatives Standing Committee on Social Policy and Legal Affairs report, FASD: The Hidden Harm, tabled on 29 November 2012;

60. As far as we are aware, many of the recommendations of *the House of Representatives Standing Committee on Social Policy and Legal Affairs report, FASD: The Hidden Harm* have not been implemented, even though they are generally limited in their ambition.

61. One of the more significant recommendations was for the inclusion of health warning labels on alcoholic beverages that advises women not to drink when pregnant or when planning a pregnancy (Recommendations 10 and 11). These mandatory labels were to be implemented by 1 January 2014. Unfortunately, largely due to the direct and indirect influence of the alcohol lobby, debate on the implementation of such labels continues, almost six years later.

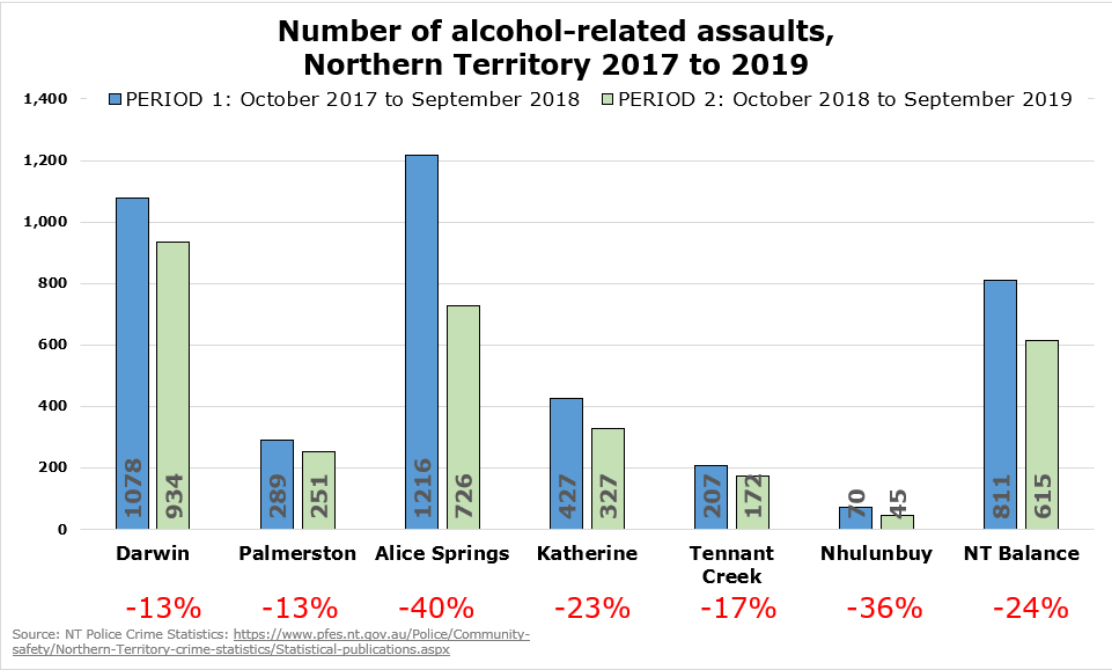
Recommendation 14. **That, as recommended by the House of Representatives Standing Committee on Social Policy and Legal Affairs report, *FASD: The Hidden Harm* (2012) and by numerous other agencies, Food Standards Australia New Zealand (FSANZ) mandate a health advisory label advising women not to drink when pregnant or when planning a pregnancy to be included on all alcohol products of greater than 100ml, to be implemented within one year.**

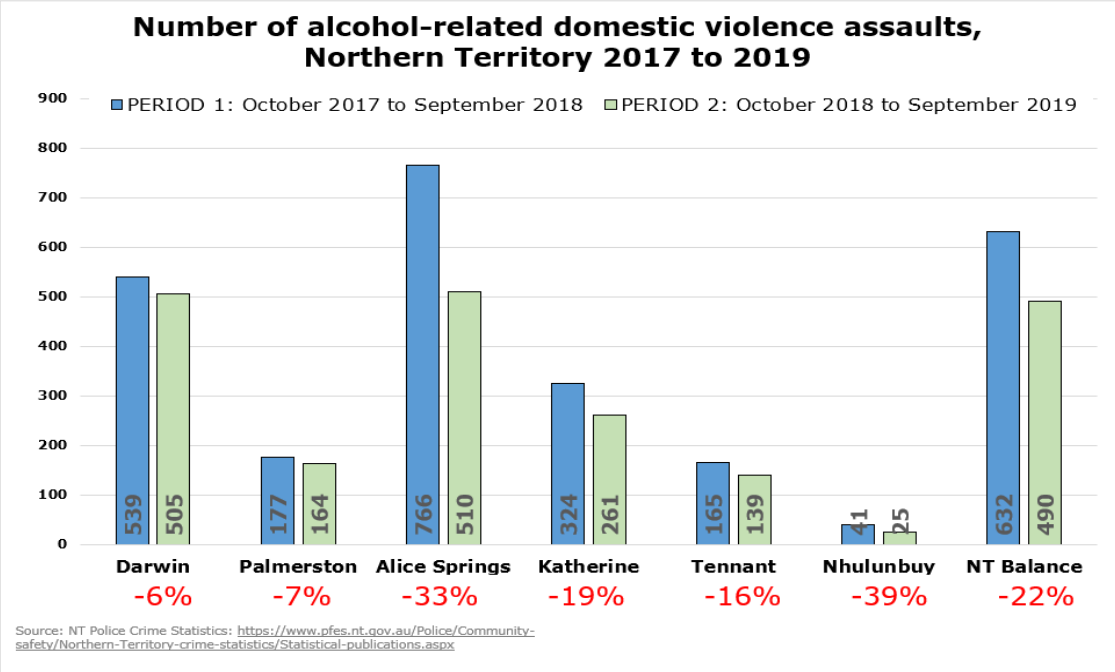
Attachment: Effect of Northern Territory Government alcohol reforms

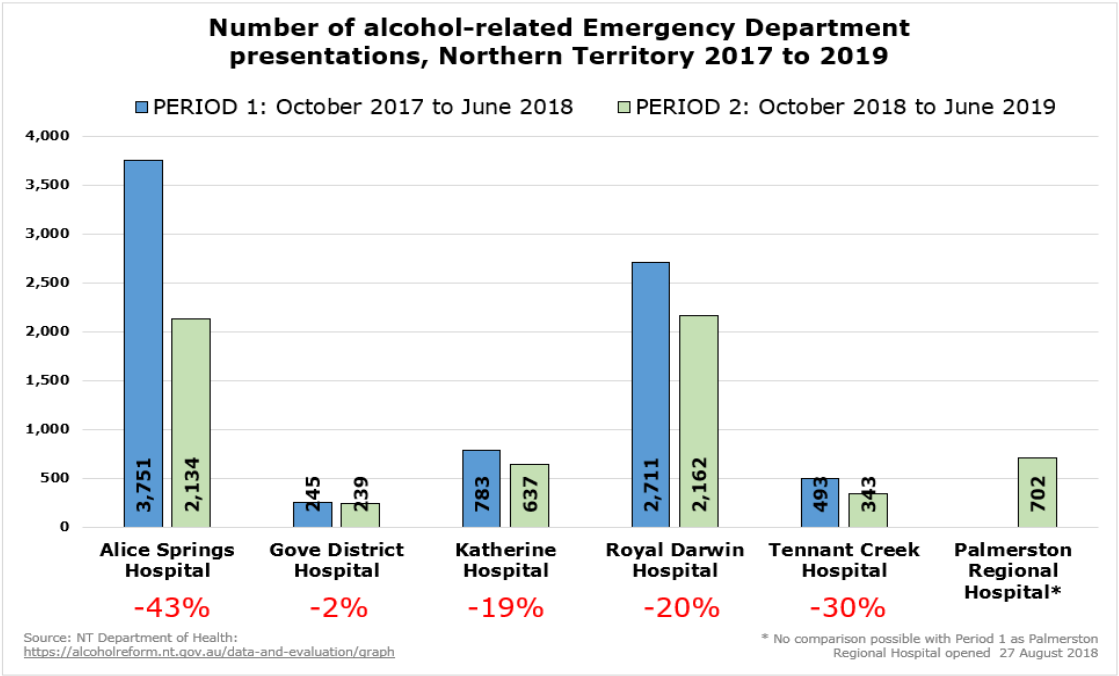
The following graphs show the effects of the Northern Territory Government alcohol reforms introduced on 1 October 2018 on key measures of alcohol-related harm. Each graph compares the levels of harm in the year before the introduction of the reforms (Period 1) with those in the year following the introduction of the reforms (Period 2).

These official figures form the Northern Territory Department of Health and the Northern Territory Police show that in the first full year of operation of the NT alcohol reforms:

- there has been a reduction of over 1,000 alcohol-related assaults across the Northern Territory (down 25% from 4,098 to 3,074);
- there has been a reduction of 550 domestic violence assaults where alcohol was involved (down 21% from 2,644 to 2,094);
- all areas of the Northern Territory have benefited, with Alice Springs and Nhulunbuy seeing the biggest falls in alcohol-related assaults (down 40% in Alice, and 36% in Nhulunbuy) although Darwin and Palmerston also saw significant reductions in alcohol-related violence (down 13% in both places); and
- although not yet available for the full year, there have been similarly large falls in the number of alcohol-related Emergency Department presentations (down 31% across the Northern Territory).




Number of alcohol-related domestic violence assaults, Northern Territory 2017 to 2019
PERIOD 1: October 2017 to September 2018
PERIOD 2: October 2018 to September 2019
900
800
700
600
500
400
300
200
100
0
539
505
177
164
766
510
324
261
165
139
41
25
632
490
Darwin
Palmerston
Alice Springs
Katherine
Tennant
Nhulunbuy
NT Balance
-6%
-7%
-33%
-19%
-16%
-39%
-22%
Source: NT Police Crime Statistics: https://www.pfes.nt.gov.au/Police/Community-safety/Northern-Territory-crime-statistics/Statistical-publications.aspx


Number of alcohol-related Emergency Department presentations, Northern Territory 2017 to 2019
PERIOD 1: October 2017 to June 2018
PERIOD 2: October 2018 to June 2019
4,000
3,500
3,000
2,500
2,000
1,500
1,000
500
0
3,751
2,134
245
239
783
637
2,711
2,162
493
343
702
Alice Springs Hospital
Gove District Hospital
Katherine Hospital
Royal Darwin Hospital
Tennant Creek Hospital
Palmerston Regional Hospital*
-43%
-2%
-19%
-20%
-30%
Source: NT Department of Health: https://alcoholreform.nt.gov.au/data-and-evaluation/graph
* No comparison possible with Period 1 as Palmerston Regional Hospital opened 27 August 2018

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