



Central Australian  
**Aboriginal Congress**  
ABORIGINAL CORPORATION | ICN 7823

## Submission to inform the Development of the National FASD Strategy 2018 – 2028

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*The Australian Government Department of Health undertook consultations to inform the development of the National FASD Strategy 2018 – 2028. The DoH released a discussion paper which formed the basis for the consultation and the questions in green, below. Congress' response is to these defined questions.*

*The discussion paper outlined the following key themes/priority areas for action that emerge from a rapid review of the available literature as well as the Roundtable discussion:*

- *Strategies to prevent FASD*
- *Evidence based screening and diagnosis*
- *Evidence based treatment and care for individuals affected by FASD and approaches that support individuals, families and carers across health, education, criminal justice and other settings*
- *Strategies to support professional education and training in FASD*
- *Strategies to improve research, monitoring and evaluation*

### **Do you agree with these priority areas for action in Australia?**

While the priority areas are broadly appropriate, they need to include the following.

#### **1. The strategy must include a specific focus on Aboriginal and Torres Strait Islander communities as a particular at-risk population.**

While FASD prevalence rates for both the non-Indigenous and Aboriginal and Torres Strait Islander populations are not known with accuracy, it is clear from both drinking patterns and from what limited diagnostic data is available that FASD rates are very significantly higher in Aboriginal and Torres Strait Islander communities (Closing the Gap Clearinghouse (AIHW & AIFS) 2014).

In relation to drinking patterns, in the Northern Territory two in five (39%) Aboriginal women in the 35 to 44 years age group consume alcohol at risky or high risk levels, two-and-a-half times higher than for non-Aboriginal women. In addition, one in eight Aboriginal women who were pregnant report consuming alcohol around the time of their first antenatal visit (Northern Territory Government 2010).

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The most recent estimates are that maternal alcohol use in Western Australia accounts for at least 3.8% of all cases of intellectual disability (O'Leary C, Leonard H et al. 2013). FASD is estimated to be between 3 and 7 times as common in the Aboriginal as it is in the non-Aboriginal population (Gray, Saggars et al. 2008) with the Western Australian study concluding that 15.6% of avoidable intellectual disability in Aboriginal children is attributable to maternal alcohol use – twelve times the rate for non-Aboriginal children. Similarly alarming figures have been found in other parts of Australia (Closing the Gap Clearinghouse (AIHW & AIFS) 2014).

High levels of alcohol consumption amongst women of child-bearing age, high levels of FASD prevalence amongst Aboriginal and Torres Strait Islander children, and the distinctive social and cultural service delivery needs of Aboriginal and Torres Strait Islander people (Australian Government 2013) demand a specific focus on and approach to the issue of FASD in Aboriginal and Torres Strait Islander Australia.

**2. The strategy must include a more strategic, evidence-based approach to preventing FASD.** This must be founded on the fact that FASD is one particular type of harm caused by alcohol that adds to all of the other harms, and therefore requires a whole of population response. We will provide more detail on this in the appropriate section below, but note that an evidence-based approach to prevention must take account of the following facts, particularly applicable to Aboriginal and Torres Strait Islander women:

- the high levels of drinking at harmful levels amongst women of child-bearing age and their partners;
- the likelihood that such women will drink at levels dangerous to their unborn child before becoming aware that they are pregnant;
- the relatively high proportion of women who may be expected to continue to drink at risky levels even after becoming aware of their pregnancy;
- that one of the risk factors for having a child with FASD is a male partner who drinks and the emerging evidence that pre-conception drinking by men may also lead to abnormal development of the unborn child;
- that harmful alcohol consumption can have life-long negative developmental effects on a child, irrespective of the presence of diagnosed FASD.

These facts point towards locating action to prevent FASD within a broader strategy to reduce consumption of alcohol amongst all women of child-bearing age and their partners. This means focusing on the most effective and efficient means of reducing alcohol consumption at a population level, namely

- **taking action on the price of alcohol** either through establishing a national floor-price or a volumetric tax, or some combination of the two; and
- **reducing the availability of alcohol**, through reduced trading hours, and restrictions on outlet density with a focus on the types of outlets associated with the highest levels of harm.

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## Are there other areas for action that should be prioritised?

See above.

## Strategies to Prevent FASD

*The DoH provided a number of examples of Australian and international efforts to prevent FASD, and to reduce stigma, to inform the discussion, then asked stakeholders to build on these ideas:*

### What are the success stories that can be built on?

The rollout of the National Disability Insurance Scheme (NDIS) and the Early Childhood Early Intervention (ECEI) approach provides a great opportunity to enhance the primary prevention of disabilities such as FASD, and to support their early detection and intervention to reduce their impact and cost over a life-time.

The need for a focus on early childhood development and disability in Aboriginal communities is particularly high – almost 2 in 5 (38%) of Aboriginal and Torres Strait Islander children are developmentally at risk or developmentally vulnerable, about double the rate for non-Indigenous children (Australian Department of Education and Training 2016). However, the assumptions behind the NDIS (individual based, in a service environment populated with multiple service providers) limits its appropriateness for these communities, especially in remote areas.

This has been shown in the Barkly Region of the Northern Territory (a demonstration site for the NDIS rollout) where there has been very little up take of the scheme, because there are not sufficient providers to provide the required services to the many eligible Aboriginal people.

Instead, a different approach is needed based on the pooling of funding for eligible clients to fund existing health service providers employ the required professional staff to provide the services. Under this model, the NDIS provides a unique opportunity to address issues of early childhood development and disability – including the prevention and treatment of FASD – in Aboriginal communities by:

1. Establishing centre-based early childhood programs at a population level for disadvantaged children. These programs should be delivered through appropriate existing organisations, , working should work in with individual NDIS-funded services for children with a diagnosed developmental delay or more specific disability such as FASD.
2. Embedding NDIS-funded services within centre-based early learning programs for all children from disadvantaged families so children who have been diagnosed with developmental delay not due to a reversible acute cause, and children with more specific disabilities, can be integrated with children within wider population-based services.
3. Preferentially recognising Aboriginal Community Controlled Health Services as the most appropriate providers and brokers of ECI services for Aboriginal families in remote areas.

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Australian Department of Education and Training (2016). Australian Early Development Census National Report 2015: A Snapshot of Early Childhood Development in Australia. Canberra, Commonwealth of Australia

## **What are the priority strategies to prevent FASD in the Australian context?**

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 evidence, are:

- 1. Population-level alcohol supply reduction** to reduce overall alcohol consumption levels especially amongst women of child-bearing age and their partners.
- 2. Programs specifically aimed at preventing FASD**, either by supporting women who want to or may become pregnant (and their partners) to avoid alcohol, and by helping those who are consuming alcohol to avoid becoming pregnant.
- 3. 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

### **1. POPULATION-LEVEL ALCOHOL SUPPLY REDUCTION**

Reducing the consumption of alcohol amongst all women of child-bearing age and their partners is centrally important to reducing the risk of developmental deficits caused by alcohol consumption. This is because:

- The developing child is most vulnerable to exposure to alcohol in the first three to six weeks after conception – often before many women are aware that they are pregnant (National Health and Medical Research Council 2009). One study of non-Indigenous West Australian pregnant women, for example, showed that one in seven women (14%) of child-bearing age consumed alcohol at a potentially dangerous levels during the three months prior to pregnancy, and that almost half of pregnancies were unplanned (National Indigenous Drug and Alcohol Committee 2012).
- The exposure of unborn babies to dangerous levels of alcohol before mothers are aware they are pregnant is exacerbated by the relatively high proportion of women

who continue to drink at risky levels into pregnancy – for 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 (Anderson A E, Hure A J et al. 2014)

- The risk factors for having a child with FASD includes a woman having a male partner who drinks (May P A, Tabachnick B G et al. 2013). There is also emerging evidence from the field of epigenetics that fathers' alcohol consumption can affect the development of the unborn child (Day J, Savani S et al. 2016). This too adds to the likely exposure of the effects of alcohol consumption before either parent is aware of the pregnancy.
- 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 anti-social behaviour and neglect of children during their critical early years. This lack of parental care and nurture can have similarly profound and permanent effects on brain chemistry and development, causing key deficits in development which many children carry into their school years and beyond (Mustard J F 2006).

For these reasons, and in line with key studies (National Indigenous Drug and Alcohol Committee 2012), reducing the prevalence of FASD should include broad-based public health measures to reduce alcohol consumption amongst the whole population, including especially women of child-bearing age. There is a very well-developed evidence-base that indicates that increasing the price and decreasing the availability of alcohol are the most effective approaches.

**Pricing of alcohol: a 'best buy' for reducing alcohol-related harm.** There is incontrovertible evidence that increasing the price of alcohol, and particularly that of cheap alcohol, reduces consumption and alcohol related harm; it is also a highly cost effective intervention (Babor T and Caetano R 2010). The three main policy approaches to supply reduction based on price are:

- a volumetric tax (taxing all or some alcohol products according to their alcohol content);
- a floor price (imposing a lower limit on price per unit of alcohol, preventing the sale and discounting of cheap alcohol); or
- local level agreements to remove cheap alcohol from sale.

**Reducing physical alcohol availability.** After price, the most important determinant of alcohol consumption is its physical availability, and in particular trading hours and license density (National Drug Research Institute 2007, Babor T and Caetano R 2010).

Reduced trading hours are a key strategy in the management of alcohol-related harm as extended trading hours (either take-away or on-premises) lead to an increase in consumption and a range of harms including to children (Laslett A M, Mugavin J et al. 2015). There is similar very well documented evidence that the density of liquor outlets (the number of active liquor licences in an area) is associated with higher levels of consumption (Livingston M 2011).

## **2. PROGRAMS SPECIFICALLY AIMED AT PREVENTING FASD**

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## Home-Visiting programs

The risk of a child being born with FASD can be addressed in two ways – by helping women who want to or may become pregnant to avoid alcohol, and by helping those who are consuming alcohol to avoid becoming pregnant.

There is international evidence of programs that assist women from disadvantaged backgrounds with both these strategies, thereby reducing the risk of a child being born with FASD. An important example is the Parent-Child Assistance Program in Washington State which involves home visiting (minimum 2 visits per month) to women at risk of giving birth to a child FASD, both during pregnancy and after birth (up to a total of three years) (Parent-Child Assistance Program 2012). Women on this program showed longer duration of abstinence from alcohol, along with greater completion of alcohol or drug treatment programs, more consistent use of contraception as well as other social and economic benefits (Grant, Ernst et al. 2005)

Conceptually the PCAP model is similar to the Australian Nurse-Family Partnership Program supported by Commonwealth Government and established in the Northern Territory (at Central Australian Aboriginal Congress) as part of a commitment to early childhood development (see section on early childhood development below). However, it differs by having a specific focus on reducing the risk of FASD by reducing alcohol and drug use, and recruiting women into the program either during pregnancy or (more significantly) upon the birth of an earlier child, ensuring a focus on reducing a women's alcohol consumption before she gets pregnant a second time. The NFP Program, focussing on child development, shows reduced risk of alcohol use for the child as it grows to maturity, but doesn't necessarily show evidence of maternal change in behavioural problems attributable to the use of alcohol or drugs (Olds D L, Kitzman H et al. 2004).

## Other Best practice treatments

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 (National Indigenous Drug and Alcohol Committee 2012).

The international literature demonstrates that treatment can be effective (Gray and Wilkes 2010). However, it is important to note that '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. It therefore forms an important part of preventing FASD by assisting women to reduce their alcohol consumption or abstain altogether.

*Interventions from the primary health care setting are known to be effective (Babor T and Caetano R 2010).* Well-structured interventions 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).

*Family planning.* 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 (Grant, Ernst et al. 2005). Readily available contraception supported by culturally appropriate sex education remains an important strategy.

*Residential and community-based treatment programs* are amongst the most common alcohol interventions, especially for Aboriginal communities. Few have been evaluated so it is therefore not known what percentage of clients who undergo treatment achieve either abstinence or reduced alcohol consumption after treatment, although mainstream literature suggests that in the best programs this figure should be around 20%. In all cases, social and cultural support for clients during and after treatment (such as assistance with accommodation, education, training and employment) is likely to increase effectiveness (Sarrazin M V and Hall J A 2004).

*Resourcing for assessment of cognitive impairment.* Those whose harmful alcohol use has left them disabled or cognitively impaired require specialised disability support. The alcohol treatment system is not appropriate for people whose cognitive impairment is such that they are unlikely to benefit. An important part of the treatment stream is therefore the ability to assess potential clients for cognitive impairment, and to determine if they require alcohol treatment or disability services, and/or assistance to find accommodation in a place where there is less ready access to alcohol. Such assessments involving family and carers are complex, time-consuming and require trained and skilled staff, with consequent cost implications for the treatment system.

### **3. EARLY CHILDHOOD PROGRAMS**

The key to long-term prevention of FASD and other alcohol-related harms is primary prevention through supporting healthy development in early childhood. The experience of the child, including in the months before birth, is critical for building a platform for a healthy life and deficits at this time are powerfully linked to disadvantage and ill health later in life including to an increased risk of unhealthy levels of alcohol consumption. Sustained investment in evidence-based 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.

In addition to FASD, there are critical periods in early brain development where if a child is not provided with appropriate care and parenting, then significant brain potential is permanently lost. Children who are not exposed to rich conversational language, read to daily, encouraged much more often than they are discouraged, who do not get sufficient regular sleep, and who come to expect and demand immediate gratification, are unlikely to develop brain potential in areas such as language and cognitive and emotional development.

Parental alcohol use is frequently associated with lack of responsive care, under stimulation and neglect of children during their early years, causing deficits in development which children carry into their school years and beyond. In particular, the link between poor development in the early years and the subsequent development of addictions and other life-long problems has been demonstrated by many studies, including a recent longitudinal study from Dunedin in New Zealand (Moffitt, Arseneault et al. 2011).

Once this pattern of development and behaviour is established, youth interventions, while necessary, are far more costly and less effective. There is ample evidence that it is much more effective – and efficient in terms of resources – to invest in early childhood development programs which aim to offset developmental deficits already incurred and to prevent the development of this pattern of behaviours.

Examples of such preventative programs include the Nurse Family Partnership (NFP) Program Home Visitation and the Abecedarian model of Educational Day care. 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 Educational day care 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 (Olds D L, Eckenrode J et al. 1997) including reducing the number of young women who start drinking before the age of 17 (Campbell, Conti et al. 2014).

Early childhood development programs are an essential contributor to raising children who are resilient and thus better equipped to avoid developing substance addictions and other problems in adolescence. They are thus an essential part of the answer to reducing alcohol-related harm through addressing developmental deficits 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.

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## How can the issue of stigma be addressed in prevention efforts?

It is particularly important to avoid any criminal justice sanctions against who be at risk of dangerous levels of drinking in pregnancy, although the careful evaluation of child protection approaches may be considered.

See response to question on 'criminal justice' and 'strategies/interventions that have established evidence or deserve trialling in the Australian context' below.

## 3. Evidence based screening and diagnosis

*The DoH requested information on the tool developed by Bower and Elliott in 2016, The Australian Guide to the Diagnosis of Fetal Alcohol Spectrum Disorder.*

## What are the remaining challenges to the uptake of the Guide into practice?

The critical factor is to ensure the uptake of the Guide – either in its current form, or appropriately modified – for use in the Aboriginal and Torres Strait Islander context given the particularly high risks of FASD experienced by this population.

The Aboriginal community controlled health services (Aboriginal Medical Services) are the most important service delivery system for evidence-based, culturally appropriate comprehensive primary health care. There are 140 of these services around Australia, in over 300 clinics delivering almost 3 million episodes of care that annually through around 6,000 staff whom, most of whom are Aboriginal and Torres Strait Islander Australians.

The practical and principled involvement of this sector is crucial for any effective approaches to address FASD in the Aboriginal and Torres Strait Islander community.

## What strategies should be employed to disseminate the Guide?

See above. This needs to be negotiated with the Aboriginal community controlled health sector, in the first instance its peak body, NACCHO (National Aboriginal Community Controlled Health Organisation) and its affiliates at the State and Territory level.

## **What strategies are necessary to translate the Guide into practice?**

Addressing the effects of alcohol consumption on childhood development and disability, and in particular FASD, requires both an understanding of how the cultural context, historical legacy and social determinants affect Aboriginal and Torres Strait Islander people, and the importance of working in partnership with communities and relevant organisations.

Working with and supporting existing processes such as the NACCHO-led 'FASD Prevention and Health Promotion Resources Package' – designed to equip Australian health professionals with the knowledge and skills needed to develop, implement and evaluate community-driven solutions to reduce alcohol consumption, tobacco smoking and substance misuse during pregnancy, and to cut down on the number of unplanned pregnancies in their communities – is key.

NACCHO, Menzies School of Health Research et al (2017) 'The FASD Prevention and Health Promotion Resources Package'. Available:  
[https://nacchocommunique.files.wordpress.com/2017/04/fasd\\_resources\\_package\\_summary.pdf](https://nacchocommunique.files.wordpress.com/2017/04/fasd_resources_package_summary.pdf)

## **Evidence based treatment and care and approaches that support individuals, families and carers**

### **What are the strategies/interventions that have established evidence or are showing promise and deserve trialling in the Australian context?**

#### **Parenting Under Pressure**

The Parenting Under Pressure (PUP) program combines all areas of life and how they influence a person's development, both parent and child, from the broadest influences (e.g. community, housing, income) to the more individual factors (nature of person, health, social connections). This includes parenting values and expectations, complemented by the parents developing an understanding of child development e.g. physical, behavioural, social, emotional, and cognitive development.

All interventions are based on Cognitive Behavioural Therapy and Motivational Interviewing with some mindfulness and acceptance, and interpersonal therapy. All therapies are recognised by Medicare as evidence-based psychological treatments and PUP provides these as a package.

The program can be implemented at any stage with any client/family of any age and is flexible to the families' needs. Interventions include parents:

- understanding themselves as parents (own attachment style and upbringing),

- managing own emotions (mindfulness)
- connecting with children (attachment)
- understanding child development and needs
- understanding how to manage their children.

The program also looks at the parent needs including:

- managing Alcohol and Other Drug issues,
- extending their own networks e.g. engaging in playgroups
- life skills e.g. finances, routines at home
- personal and intimate relationships including domestic violence.

#### REFERENCES:

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Parents Under Pressure (PuP) program website: <http://www.pupprogram.net.au/>

#### **Evaluation of 'Unborn child referrals' to child protection**

Unfortunately, there is a small proportion of women who may refuse to collaborate in voluntary support programs that potentially reduce their alcohol usage during pregnancy, such as home visiting programs as represented by the PCAP model overseas or the Nurse Family Partnership (NFP) Program Home Visitation scheme already established in Central Australia for Aboriginal women. For these women, additional measures may be needed to maximise the protection of their unborn child, stopping short of criminalisation (see question re criminal justice responses below).

For example, we understand that in Victoria, legislation allows for anyone in the community (including service providers) to contact child protection authorities *before* the birth of a child should they have concerns for the potential wellbeing of a child *after* their birth. Such referrals provide an opportunity for child protection services (in partnership with other service providers and as appropriate the woman's family) to support access to antenatal and other care, provide information on self-care during pregnancy, and plan for the unborn child's safety, stability and development upon birth (Department of Human Services 2007).

In many cases where women are drinking at dangerous levels, at least some of the risks of FASD may already have been incurred (i.e. in the early weeks of pregnancy). However, additional measures may prevent additional harm to the unborn child, provide an opportunity for intensive work to reduce such a woman's alcohol consumption during pregnancy, and also provide child protection services with an opportunity to act promptly following birth to protect the child using usual statutory processes.

As with all interventions in the area of alcohol use, care must be taken to minimise any discrimination against or further marginalisation of the women concerned. Individual human rights (such as the right to representation in any hearings) must be protected, and criminalisation of failures to comply avoided.

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### **What existing strategies/interventions or programs could be scaled up? What are the priority strategies that could be implemented in the school setting?**

Any evidence-based FASD prevention approach must be integrated as part of a population-level attempts to reduce alcohol consumption (see responses above re FASD prevention).

In general, education and persuasion strategies, including school-based education and media campaigns, have at best a minimal, short-term effect and as a substantial review of the international literature notes, 'cannot be relied upon as an effective approach' (Babor T and Caetano R 2010). With particular reference to FASD, evaluation of public awareness campaigns and supporting resources elsewhere showed that health messages failed to reach high risk groups (ANPHA 2012).

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### **What are the priority strategies that could be implemented in the criminal justice setting?**

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 (Anderson A E, Hure A J et al. 2014).

Mandatory treatment linked to criminal sanctions similarly has very little evidence of success. 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 (Pritchard E, Mugavin J et al. 2007). Note that this does not include short-term mandatory commitment for the purpose of assessment and care of people who may be at risk of harming themselves or others – such as non-criminalised short-term residential treatment orders for women under child protection orders during pregnancy (see above).

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## Strategies to improve research, monitoring and evaluation

### **What are the priority strategies to develop the data, indicators and milestones for this strategy?**

More information is needed about the prevalence of FASD and other alcohol-related cognitive impairment in Aboriginal and Torres Strait Islander Australia.

Research should be supported which aims to identify patterns of prevalence and incidence of these harms, whether caused in pregnancy through FASD, through poor parenting and neglect in early childhood, directly through the health effects of alcohol consumption, or otherwise indirectly through violence, accidents and injury.

### **What are the key strategies to address cultural appropriateness and safety of research and evaluation efforts?**

For the Aboriginal and Torres Strait Islander context, all such research and evaluation processes must take place with Aboriginal and Torres Strait Islander communities and organisation, not on them.

This means effective, long term negotiated relationships with Aboriginal and Torres Strait Islander service delivery organisations and peaks (for example, NACCHO and its State / Territory peaks), with a preference for carrying out research through Aboriginal and Torres Strait Islander research agencies (such as the Lowitja Institute).

Any research into FASD should be carried out in accordance with the relevant NH&MRC Guidelines regarding Aboriginal and Torres Strait Islander research (National Health and Medical Research Council 2003) and its associated guides.

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