Foundation for Alcohol Research & Education

FARE's Submission to the Select Committee on Action to Prevent Foetal Alcohol Spectrum Disorder

Legislative Assembly of the Northern Territory

May 2014

About the Foundation for Alcohol Research and Education

The **Foundation for Alcohol Research and Education (FARE)** is an independent, not-for-profit organisation working to stop the harm caused by alcohol.

Alcohol harm in Australia is significant. More than 3,500 lives are lost every year and more than 100,000 people are hospitalised making alcohol one of our nation's greatest preventative health challenges.

For over a decade, FARE has been working with communities, governments, health professionals and police across the country to stop alcohol harms by **supporting world-leading research, raising public awareness** and **advocating for changes to alcohol policy**.

In that time FARE has helped more than 750 communities and organisations, and backed over 1,400 projects around Australia.

FARE is guided by the World Health Organization's *Global Strategy to Reduce the Harmful Use of Alcohol*[i] for stopping alcohol harms through population-based strategies, problem-directed policies, and direct interventions.

If you would like to contribute to FARE's important work, call us on (02) 6122 8600 or email fare@fare.org.au

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[i] World Health Organisation (2010). *Global strategy to reduce the harmful use of alcohol.* Geneva: World Health Organization.

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Summary

The Foundation for Alcohol Research and Education (FARE) welcomes the opportunity to provide a submission to the Legislative Assembly Northern Territory *Select Committee on Action to Prevent Foetal Alcohol Spectrum Disorder.*

Fetal Alcohol Spectrum Disorders (FASD) are the leading preventable cause of non-genetic, developmental disability in Australia.[1] Despite this, little or no action has been taken on the prevention of FASD, its diagnosis and in supporting people with FASD and their carers. Where strategies on FASD have been implemented, these activities have often been ad hoc and inconsistently implemented by Australian governments.

In 2013, the former Australian Government announced a commitment of $20 million towards the *Australian Government Action Plan to reduce the impact of FASD 2013-14 to 2016-17: A Commonwealth Action Plan* (Action Plan). However, the Action Plan was released prior to the Government going into caretaker for the election, and the status of the Action Plan under the new Government remains uncertain. The unknown fate of the Action Plan demonstrates that while policy discussions on FASD are occurring, nothing is changing for people affected by FASD, their families and their carers.

The Northern Territory Government has recently indicated that it is exploring the 'antenatal rights of the unborn child' including options such as 'prosecute or alternatively restrain [women who are drinking through pregnancy] from engaging in conduct which harms their unborn child'.[2] This proposal is concerning because it will further stigmatise women who are alcohol dependent and pregnant, and deter them from seeking assistance. This will have the perverse effect of creating even greater levels of harms. The criminalisation of vulnerable people does not acknowledge the underlying issues that are faced by women who are alcohol dependent, such as mental health issues, family violence and intergenerational alcohol abuse.

It is vital that the Northern Territory Government explores evidence-based strategies to prevent, diagnose and manage FASD. This action is particularly urgent for the Northern Territory because the risk and prevalence of FASD is likely to be higher than in other areas of Australia. This is because women in the Northern Territory are more likely than women in other parts of Australia to consume alcohol at risky levels.[3]

As primary providers in health, education and the criminal justice system, state and territory governments have a significant role to play in FASD prevention, diagnosis and management. FARE is proposing tangible and practical recommendations that will reduce the incidence of FASD and vastly improve the life outcomes of people affected by FASD and their carers. These solutions are based on FARE's *Australian Fetal Alcohol Spectrum Disorders Action Plan 2013-2016* (FASD Plan) and target FASD across the spectrum, from prevention and diagnosis through to management across the lifespan.

Recommendations

1. That the Committee recommends that the Northern Territory Government conducts a territory-wide ongoing public education campaign about the harms associated with consuming alcohol during pregnancy. The campaign should use a range of media including television, radio, print materials and social media.
2. That the Committee recommends that the Northern Territory Government provides training to educate health professionals on FASD and enable them to routinely ask and advise all women about the harms associated with alcohol consumption during pregnancy. This training should make use of the resources and training materials from FARE's *Women Want to Know* project.
3. That the Committee recommends that the Northern Territory Government provides specialist support services to women who are pregnant and have alcohol-use disorders. This involves:
   - providing funding to alcohol and drug treatment services across the Northern Territory to allow them to develop women-centred practices, with a particular focus on women who are pregnant; and
   - developing a Northern Territory Model of Care for women who have alcohol-use disorders with clearly defined referral pathways into treatment.
4. That the Committee recommends that the Northern Territory Government representative on the Legislative and Governance Forum on Food Regulation supports the introduction of mandatory pregnancy alcohol warning labels.
5. That the Committee recommends that the Northern Territory Government introduces evidence-based policies that address the pricing, promotion and availability of alcohol, as part of its strategy to prevent FASD.
6. That the Committee recommends that the Northern Territory Government trials and evaluates the Australian FASD diagnostic instrument.
7. That the Committee recommends that the Northern Territory Government establishes at least one dedicated FASD diagnostic clinic in the Northern Territory.
8. That the Committee recommends that the Northern Territory Government provides funding to create a FASD diagnostic team that specialises in remote areas. This should be based on the *Lililwan Project*. The diagnostic team should train local health professionals who work in the community on FASD diagnosis so that this can continue once the diagnostic team leaves the area.
9. That the Committee recommends that the Northern Territory Government ensures that all people diagnosed with FASD in the Northern Territory are provided with a treatment and management plan that is evidence-based and designed to meet individual needs.
10. That the Committee recommends that the Northern Territory Government provides funding to organisations that support people with FASD, their parents and their carers.
11. That the Committee recommends that the Department of Education develops resources and training for teachers and other education professionals on understanding FASD and teaching strategies for students with FASD.
12. That the Committee recommends that the Northern Territory Government pilots a training program for judges, magistrates and correctional officers to assist them in identifying and managing FASD in people who are in contact with the criminal justice system.

13. That the Committee recommends that the Northern Territory Department of Justice examines sentencing options for people identified as having FASD who come into contact with the criminal justice system, similar to options provided to other people who have cognitive functioning disabilities.
14. That the Committee recommends that the Northern Territory Government continues to support Aboriginal and Torres Strait Islander peoples to develop community-driven solutions to address alcohol misuse. This includes providing a longer-term funding solution for the Anyinginyi FASD project.
15. That the Committee recommends that the Northern Territory Government establishes a small grants scheme for Aboriginal and Torres Strait Islander communities to develop and embed a 'whole of community' response to FASD, including diagnosis.

FARE's response to the terms of reference

This submission addresses the Terms of Reference using the numbering system adopted by the Committee.

2a) The prevalence in the Northern Territory of Foetal Alcohol Spectrum Disorder (FASD)

The most current data available suggests that prevalence for Fetal Alcohol Syndrome (FAS), one of the conditions within the spectrum, is between 0.06 and 0.68 per 1,000 live births in the general Australian population and between 2.76 and 4.7 per 1,000 births among Aboriginal and Torres Strait Islander peoples. However, these figures are likely to be significant underestimates due in part to low diagnosis rates.[4] Anecdotal reports suggest that in some communities where alcohol consumption is high, the prevalence of FASD is likely to be much greater than evidenced by existing studies. For example, it has been suggested that more than half of children in the Fitzroy Valley in Western Australia are affected by FASD or early life trauma.[5]

Although the true prevalence of FASD is difficult to ascertain, it is likely to be particularly high in the Northern Territory because of the high levels of consumption among women. Women aged 14 or over in the Northern Territory have the highest levels of risky alcohol consumption in Australia. Almost half (41.5%) consume at least five standard drinks on a single occasion (significantly above the national average of 29.8%), placing them at risk of short-term injuries and illnesses. Furthermore, almost one in five (17.2%) consume at least three standard drinks per day (significantly above the national average of 11.3%), placing them at risk of long-term health harms.[6]

2b) The nature of the injuries and effects of FASD on its sufferers

FASD is a non-diagnostic term representing a range of conditions that result from prenatal alcohol exposure. These conditions include:

- Fetal Alcohol Syndrome (FAS): FAS is characterised by facial anomalies, growth deficits and central nervous system abnormalities.
- Partial Fetal Alcohol Syndrome (pFAS): People with pFAS have central nervous system abnormalities, some but not all of the facial anomalies present in people with FAS, and may or may not have growth deficits.
- Neurodevelopmental Disorders Alcohol-Exposed (ND-AE): Individuals with ND-AE have central nervous system abnormalities without the facial anomalies or growth deficits.[7]

FASD is a lifelong developmental disability that is caused by exposure to alcohol in utero. The primary disabilities of FASD are due to the underlying brain damage caused by prenatal alcohol exposure. This can result in a variety of conditions including poor memory, difficulties with speech and language, cognitive deficits, difficulty with judgement, reasoning, and behavioural problems as well as social and emotional delays.[8] FASD is also associated with facial anomalies, sight and hearing problems, sleeping difficulties, sensory stimulation, organ damage and global developmental delay.[9]

However when the primary disabilities of FASD are undiagnosed or misunderstood, this can result in a person with FASD developing secondary disabilities such as mental health issues, alcohol and drug problems, disrupted school experiences and inappropriate sexual behaviours. Additionally, people with FASD tend to have difficulties coping with day-to-day living such as managing money and sustaining regular employment. As a result, the majority of adults with FASD may not be able to live independently.[10]

Much of the outward behaviour of people with FASD may appear as delinquent and/or antisocial to other people.[11] As a result, erroneous judgements are being made regarding the nature and intentions of that person as well as criticism of their parents and carers. This tendency to blame FASD on poor maternal or parenting choices and the deliberate bad behaviour of the affected individuals serves as an impediment to any progress on FASD.[12]

The effects of FASD are not limited to people with the condition. Parents and caregivers of children with emotional and behavioural problems experience a variety of stressors as a result of their responsibilities, including financial hardships, disruption of family and social relationships, fatigue, sadness and guilt.[13] These stressors are exacerbated by the fact that they receive inadequate support from services and the government. A qualitative study by Breen and Burns, commissioned by FARE, shows that carers are often stigmatised as 'bad parents' by services that assume they are not trying hard enough. There is also often poor communication and coordination between the practitioners providing health services. The most common issue raised by carers is the insufficient knowledge among health professionals about FASD.[14]

Unfortunately in Australia, people with FASD, their families and their carers have difficulties accessing disability support services and funding. Many are precluded due to a lack of official diagnosis or because FASD is excluded from eligibility criteria. There is also currently no standardised diagnostic instrument for FASD and there is limited diagnostic capacity among health professionals in Australia.

2c) Actions the Government can take to reduce FASD based on evidence and consultation

Immediate action is needed at the Commonwealth, state and territory government levels to prevent and diagnose FASD and provide support for people with FASD and their families. In 2012, FARE released The Australian Fetal Alcohol Spectrum Disorders Action Plan 2013-2016 (FASD Plan). The FASD Plan was developed in consultation with 33 leading FASD experts, and has been endorsed by the Australian FASD Collaboration and the peak FASD consumer and carer organisation, National Organisation for Fetal Alcohol Spectrum Disorders (NOFASD Australia).

The FASD Plan provides a fully costed roadmap for action to address gaps in the prevention, intervention, diagnosis and management of FASD in Australia. The FASD Plan is intended as a guide for Australian Governments and forms the basis for the following recommendations.[15]

Increase community awareness of FASD and prevent prenatal exposure to alcohol

Fundamental to preventing new cases of FASD is the reduction of harmful consumption of alcohol by the general population, and in particular by women during pregnancy. Prevention activities need to target the whole population to raise awareness of the potential risks associated with alcohol consumption during pregnancy, and create a supportive environment for women who are pregnant or planning pregnancy to be alcohol-free during this time. Prevention initiatives must also take into account the broader cultural environment that contributes to risky alcohol consumption.

Conduct an ongoing public education campaign about the harms resulting from alcohol consumption during pregnancy

Public education outlining the risks associated with alcohol use during pregnancy is vital to prevention. A study conducted in 2006 showed that women are more likely to intend to consume alcohol during pregnancy if they lack knowledge of the negative consequences of doing so.[16] The National Health and Medical Research Council (NHMRC) *Australian Guidelines to Reduce Health Risks from Drinking Alcohol to Health Professionals* (Alcohol Guidelines) recommend: "For women who are pregnant or planning a pregnancy, not drinking is the safest option."[17] The Guidelines have been in place since 2009, however, the promotion of these Guidelines has been limited.

Media campaigns using a variety of sources should be conducted across the Northern Territory to promote the message that consuming alcohol during pregnancy is potentially harmful. The campaigns should be readily accessible to all members of the community, and use simple and direct messages. Resources tailored to Aboriginal and Torres Strait Islander communities should use simple, clear language devoid of jargon, make use of visual themes using Aboriginal and Torres Strait Islander imagery and art work, and apply a narrative, storytelling approach. Ideas and lessons learnt from previous campaigns should be taken into account in the development of campaign materials, and these can be found through clearinghouses such as the Australian Institute of Health and Welfare Closing the Gap Clearinghouse or Australian Indigenous Health*Info*Net Clearinghouse.

Educate health professionals on FASD and enable them to routinely ask and advise all women about their alcohol consumption

As well as whole-of-community education, it is important to target education activities to women who are pregnant or may be pregnant. Health professionals are considered by women to be the best source of information for pregnancy, and women are often willing to make changes to their lifestyle, diet and alcohol consumption if advised to do so.[18] Unfortunately, health professionals are often reluctant to discuss alcohol consumption with women due to fear of upsetting the woman, time constraints or their own discomfort.[19] It is vitally important that all health professionals are trained to ask women of childbearing age about their alcohol consumption, not only for the potential to prevent a new case of FASD, but also to provide a consistent message on the harms associated with alcohol consumption during pregnancy.[20]

In July 2014, FARE will launch the *Women Want To Know* (WWTK) project. The objective of the project is to encourage health professionals to routinely initiate discussions with women who are pregnant or planning pregnancy about alcohol consumption and to provide advice that is consistent with the Alcohol Guidelines. As part of the WWTK project, a suite of materials have been developed to support health professionals in discussing alcohol with pregnant women. These include accredited training courses and leaflets for women. The Northern Territory Department of Health can use the materials from the WWTK project to encourage health professionals in the Northern Territory to routinely ask and advise women about alcohol consumption during pregnancy. Further training options for health professionals should also be adopted to support these resources.

Provide specialist support services to pregnant women who have alcohol-related disorders

It is essential to further target prevention activities to women who are at high risk of an alcohol-exposed pregnancy. Women who have alcohol-use disorders or are alcohol-dependent are at high risk of having a child with FASD.[21] Efforts to support women to reduce or cease their alcohol consumption are crucial in preventing new cases of FASD. These prevention activities should be supportive, and mindful of the factors that influence alcohol use during pregnancy such as depression and other mental health problems, domestic violence and poverty. Support and treatment programs should be developed that meet the needs of women, and pregnant women in particular. Currently, because men account for the majority of alcohol and drug treatment episodes, most treatment programs in Australia have been designed with men in mind and therefore struggle to fully meet the needs of women.[22]

It is important that the women who are at high risk of an alcohol-exposed pregnancy are referred to appropriate services. The most effective way to do this is through the development of a model of care in the Northern Territory. A model of care outlines clear referral pathways to ensure that women who are at high-risk are referred to appropriate services and receive comprehensive care to minimise the risk of someone falling through the cracks. The Western Australian Government has developed a Model of Care,[23] and this can be used to guide the development of a Northern Territory Model of Care.

Implement mandatory health warning labels on all alcohol products available for sale in Australia

Food Standards Australia New Zealand (FSANZ) commissioned a study that found that the adoption of alcohol health warning labels in Australia would have the following potential impacts:

- The majority of women will have noticed the warnings within two to three years after introduction;
- The warnings may be noticed more by younger women and heavier drinkers;
- Of those who notice the labels, approximately half will recall the message;
- There will be an increase in the number of conversations about the risks of consuming alcohol while pregnant; and
- Behaviour change may occur if labels are complemented at point of sale and at other message sources.[24]

Following a review of food labelling in Australia and New Zealand, published as *Labelling Logic* in January 2011, the Legislative and Governance Forum on Food Regulation (FoFR) decided, in December 2011, to support a mandated pregnancy warning label on alcohol products within two years.[25] Despite this decision, more than two years after this meeting there is still no mandated pregnancy warning label for alcohol.

At present the alcohol industry has a voluntary consumer information labelling scheme. The labels include two pregnancy messages, which are either text stating 'it is safest not to drink while pregnant' or a pictorial silhouette of a woman consuming alcohol with a line through it.[26] These labels are grossly inadequate. An audit of the labels two years after their introduction found that only 37 per cent of alcohol products carried a consumer information message. A vast majority (86 per cent) of these labels took up less than five per cent of the alcohol label, with 92 per cent of them placed on the back, side or bottom of the product.[27] The messages are weak, ambiguous and do not sufficiently explain the harms associated with consuming alcohol.[28] This demonstrates the alcohol industry's unwillingness to adopt evidence-based labels.

An evidence-based alcohol warning label regime is needed in Australia. The labelling regime should be:

- Mandatory so the label appears on all alcohol products for sale in Australia;
- Applied consistently across all products so they are visible and recognisable;
- Developed by health behaviour and public health experts;
- Regulated and enforced by government; and
- Accompanied by a national public education campaign.[29]

Alcohol labelling falls under the statutory responsibility of FSANZ. However, the decisions made about labelling are governed by FoFR, of which the Northern Territory Government is a member. The Northern Territory Government should use this membership as an opportunity to support the introduction of mandatory pregnancy warning labels for alcohol.

Address the factors that contribute to the broader culture of harmful drinking

It is important to recognise that alcohol consumption among women who are pregnant is reflective of a broader culture of harmful drinking. The way that alcohol is sold, promoted and made available contribute to the way alcohol is consumed and the associated harms. Across Australia, alcohol is more affordable than it has been in over three decades, it is more available than it ever has been and it is more heavily promoted. The most effective way to reduce broad ranging alcohol harms is through population wide strategies aimed at regulating the price, promotion and availability of alcohol.

Increasing the price of alcohol is an effective way to reduce alcohol consumption and alcohol-related harms.[30] While the Commonwealth Government is responsible for setting alcohol taxes, there is a role for state and territory governments in ensuring that bottle-shops, pubs and clubs do not recklessly promote discounted products or carry out activities that encourage the excessive consumption of alcohol.

There is also a substantial body of international and Australian research evidence that supports the approach of regulating alcohol availability to reduce rates of alcohol-attributable harms. The availability of alcohol can be reduced through the stricter regulation of trading hours and reductions in the number and density of liquor outlets in a locality.[31] [32]

If the Northern Territory Government is serious about preventing FASD, then it must also introduce evidence-based policies to alter the broader drinking environment.

Recommendations

1. That the Committee recommends that the Northern Territory Government conducts a territory-wide ongoing public education campaign about the harms associated with consuming alcohol during pregnancy. The campaign should use a range of media including television, radio, print materials and social media.
2. That the Committee recommends that the Northern Territory Government provides training to educate health professionals on FASD and enable them to routinely ask and advise all women about the harms associated with alcohol consumption during pregnancy. This training should make use of the resources and training materials from FARE's *Women Want to Know* project.
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   - providing funding to alcohol and drug treatment services across the Northern Territory to allow them to develop women-centred practices, with a particular focus on women who are pregnant; and
   - developing a Northern Territory Model of Care for women who have alcohol-use disorders with clearly defined referral pathways into treatment.
4. That the Committee recommends that the Northern Territory Government representative on the Legislative and Governance Forum on Food Regulation supports the introduction of mandatory pregnancy alcohol warning labels.
5. That the Committee recommends that the Northern Territory Government introduces evidence-based policies that address the pricing, promotion and availability of alcohol, as part of its strategy to prevent FASD.

Improve diagnostic capacity for FASD in Australia

Obtaining a diagnosis of FASD can improve the quality of life of a person with FASD. A diagnosis allows an understanding of the specific deficits of people with FASD, which in turn facilitates opportunities to arrange appropriate interventions. However, in Australia there is no standardised diagnostic tool and there are no FASD diagnostic clinics in the Northern Territory.

Publish, implement and evaluate the Australian FASD diagnostic instrument

Diagnosis is the first step towards providing support for people affected by FASD and ensuring that the likelihood of developing secondary disabilities is reduced. Unfortunately, diagnostic capacity is limited in Australia. Currently, few health professionals are aware of the condition, and the majority do not feel equipped to make a diagnosis and manage people with FASD.[33] There is no standardised

diagnostic instrument in Australia and no standard education about FASD for health professionals. Health professionals must rely on a variety of overseas diagnostic instruments to diagnose FASD. Canada has nationally consistent diagnostic guidelines and these have facilitated consistent diagnostic practice across the country and allowed for comparable data on FASD to be collected and monitored over time.[34] [35]

In 2010, the Commonwealth Government provided funding to the Australian FASD Collaboration, led by Professor Elizabeth Elliott and Winthrop Research Professor Carol Bower, to develop a screening and diagnostic instrument for FASD. The FASD Collaboration submitted a final report to the then Department of Health and Ageing in May 2012. The diagnostic instrument now requires testing in a range of clinical environments across Australia prior to its implementation.[36] The Northern Territory has the opportunity to be the first jurisdiction in Australia to trial and evaluate the diagnostic instrument, after which it can be rolled out across the country.

Establish FASD diagnostic services

Assessment and diagnosis of FASD can occur through the establishment of a dedicated FASD diagnostic clinic in the Northern Territory. Currently, Australia has two dedicated FASD diagnostic clinics, one in Sydney and one on the Gold Coast. The clinic in Sydney, funded by FARE, opens fortnightly and is based at the Children's Development Unit, within The Children's Hospital at Westmead in Sydney.[37] In this model, children (aged up to 16 years) undergo a comprehensive assessment by a multidisciplinary team before a final diagnosis is recommended.

The Northern Territory Government should provide funding to establish a clinic in the Northern Territory. This clinic could also serve as a facility to test the diagnostic tool.

A complementary model for diagnosis is also required to target at-risk communities in rural and remote areas of the Northern Territory. The approach should be based on *Marulu: The Lililwan Project* in the Fitzroy Valley of Western Australia. As part of the *Lililwan Project*, all children between the ages of seven and eight were assessed by a specialist multi-disciplinary team that travelled to the community. Information was also collected on early life trauma from the *Australian Longitudinal Study of Indigenous Children 2008*.[38]

To improve diagnostic capacity within rural and remote communities, it would be ideal if the diagnostic team is able to train health professionals who are based in the community. This will allow diagnosis to continue to occur after the diagnostic team leaves the area.

Recommendations

6. That the Committee recommends that the Northern Territory Government trials and evaluates the Australian FASD diagnostic instrument.
7. That the Committee recommends that the Northern Territory Government establishes at least one dedicated FASD diagnostic clinic in the Northern Territory.
8. That the Committee recommends that the Northern Territory Government provides funding to create a FASD diagnostic team that specialises in remote areas. This should be based on the

Lililwan Project. The diagnostic team should train local health professionals who work in the community on FASD diagnosis so that this can continue once the diagnostic team leaves the area.

Enable people with FASD to achieve their full potential

People with FASD often face a range of health, social and educational difficulties. Unfortunately, FASD is not consistently identified as a disability. As a result, their ability to receive support that enables them to reach their full potential is limited.

Support of individuals with FASD, their parents and their carers

Access to services and early intervention programs can result in better outcomes for people with FASD throughout their lives. However, FASD is not currently recognised as a disability which means that people with FASD and their carers have difficulty accessing support services. FASD is not recognised in the Commonwealth Government's *Better Start for Children with Disability* initiative which provides funded access to early intervention and treatments, assistance for children living in rural and remote areas, and a treatment and management plan to be developed and covered through Medicare. Access to the *National Disability Insurance Scheme* does not require a formal diagnosis.[39] However, not all people in the Northern Territory will be eligible for the scheme until July 2019,[40] and the effectiveness of the scheme for people with FASD remains to be seen.[41]

People with FASD require treatment and management plans that are evidence-based and tailored to individual needs. According to an assessment of five intervention programs in the USA, successful programs had the following elements:

- A component of education or training for parents that was built into the program;
- Explicit instructions for the child when learning new skills, rather than relying on the child to learn through observation and information-processing alone; and
- Programs and techniques being integrated into existing community services, such as special education, therapy or counselling services that the child was already attending.[42]

Given that FASD diagnosis in Australia is in its infancy, FASD intervention programs should not be dependent on receiving a formal diagnosis first, otherwise the 'window of opportunity' for preventing secondary disabilities could be missed.[43]

Parents and carers of people with FASD also require access to support services as they are likely to be experiencing financial and emotional stress. Support is vital, especially since the caregiving is likely to be lifelong. Currently, support for people with FASD, their parents and carers in Australia is limited to two organisations: the Russell Family Fetal Alcohol Disorders Association (RFFADA) and NOFASD Australia. Further funding is needed for these and similar organisations to continue to provide support and expand their capacity to maximise the reach and effectiveness of their services.

Treat people with FASD in a socially inclusive manner in education and if in contact with the criminal justice system

Education

FASD can directly affect a child's performance at school as the underlying brain damage limits how well a child with FASD can process information and understand and meet the expectations set for them. For example, people with FASD may have difficulties concentrating in the classroom and transferring learning to apply from one situation to another.[44] Across North America, guidelines have been produced with information on how to understand and interpret the thought processes and behaviours of a child with FASD, and to determine the most appropriate teaching strategies for these students.[45] [46] A Churchill Fellowship undertaken by Kym Crawford (an education specialist) on the Canadian experience of addressing FASD concluded that:

- People working in education, including principals, teachers, education assistants and Aboriginal and Torres Strait Islander education officers, need professional development training on how to educate students with FASD;
- Current specialist support services should be expanded to provide assistance for students with FASD; and
- State government education departments need to work closely with diagnostic services (when these exist) to develop a support system immediately after diagnosis.[47]

Australia still lacks a longer-term, coordinated approach to supporting children with FASD in the education system. Recently, two FASD positions in the Northern Territory Government Department of Education have been appointed through the Commonwealth Government's Stronger Futures. The aim of this project is to improve the educational outcomes of children with FASD in schools across the Northern Territory. These positions are currently funded until 30 June 2015. The Northern Territory Government should consider expanding the FASD team in the Department of Education and continue their funding beyond the original agreement.

Criminal justice

People with FASD are at disproportionate risk of being involved in the criminal justice system. The various factors that contribute to this include difficulties in school and difficulties in maintaining employment. Additionally, people with FASD are often vulnerable to exploitation.[48] Once in a prison environment, a person with FASD may be victimised, used as a scapegoat and negatively influenced by peers.[49] The correctional and criminal justice sectors in Australia are generally not prepared to address the needs of people with FASD within the offender population.

In Australia, FARE funded the Queensland University and the Collaboration for Alcohol Related Developmental Disorders to ascertain levels of awareness of FASD among members of the Queensland Judiciary, and the impact of FASD on their practice. The study revealed that although 80 per cent of participants had heard of FASD and 75 per cent thought it was relevant to their work, 82 per cent had never sent a person for a FASD assessment because 'they did not know where to send the person'.[50]

Across Canada there is a growing body of information about appropriate management and sentencing options for people with FASD. In British Columbia, the John Howard Society of Central and South Okanagan has developed a Gateway Mentoring Program that provides one-to-one mentorship to people with FASD who are involved in or are likely to be involved in the criminal justice system.[51] In Manitoba the FASD Youth Justice Program, established in 2004, provides people accused of a crime with an opportunity to receive an assessment for FASD prior to sentencing. The program developed a checklist of 'red flags' that court and justice officials use to trigger a referral for diagnosis.[52]

The Northern Territory Government should ensure that FASD is a consideration in sentencing. This includes training judges, magistrates and correctional officers on FASD and its impacts on individuals.

Recommendations

9. That the Committee recommends that the Northern Territory Government ensures that all people diagnosed with FASD in the Northern Territory are provided with a treatment and management plan that is evidence-based and designed to meet individual needs.
10. That the Committee recommends that the Northern Territory Government provides funding to organisations that support people with FASD, their parents and their carers.
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13. That the Committee recommends that the Northern Territory Department of Justice examines sentencing options for people identified as having FASD who come into contact with the criminal justice system, similar to options provided to other people who have cognitive functioning disabilities.

Close the gap on the higher prevalence of FASD among Aboriginal and Torres Strait Islander peoples

Aboriginal and Torres Strait Islander peoples require culturally appropriate prevention, intervention and management strategies that are supported and controlled by local communities. An example of this is the Anyinginyi FASD project in Tennant Creek, run by the Anyinginyi Health Aboriginal Health Corporation. The focus of this project is to identify existing services and develop a suite of resources to be used within the community. The project includes the development of a "Pregnancy Pamper Pack" for health professionals to distribute to pregnant women containing information on alcohol, and the creation of a hip hop song called "Strong Baby, Strong Life!" in collaboration with the local young people.[53] The funding for this project ceased on 31 December 2013. The Northern Territory Government provided $100,000 for the project, but this is due to expire on 30 June 2014.[54]

A further example of a project that has been effective in supporting a community in addressing FASD is the *Marulu Strategy* in the Fitzroy Valley of Western Australia, which began in 2008. Part of the strategy was the *Lililwan Project*, which was established to conduct the first prevalence study of FASD

in Australia through a partnership of experts in local Aboriginal culture, Aboriginal and Torres Strait Islander health, paediatrics, research, epidemiology and human rights. In addition to surveillance, the project provided each child with FASD with a personalised management plan involving their families, doctors and teachers. The project also educated the Fitzroy Valley communities about the risks of consuming alcohol during pregnancy and about the challenges faced by children with FASD and their families. This Strategy has been recognised by Australia's Social Justice Commissioner, who described the *Marulu Strategy* and the *Lililwan Project* in particular as "an example of researchers reciprocating both the spirit and intent of the community by working to address the challenges of FASD in genuine partnership done where research is done with the community and not just about the community."[55]

Recommendations

14. That the Committee recommends that the Northern Territory Government continues to support Aboriginal and Torres Strait Islander peoples to develop community-driven solutions to address alcohol misuse. This includes providing a longer-term funding solution for the Anyinginyi FASD project.
15. That the Committee recommends that the Northern Territory Government establishes a small grants scheme for Aboriginal and Torres Strait Islander communities to develop and embed a 'whole of community' response to FASD, including diagnosis.

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[1] O'Leary, C. (2002). Foetal Alcohol Syndrome: A literature review. National Alcohol Strategy 2001 to 2003-04 Occasional Paper. Commonwealth Department of Health and Ageing, Canberra.

[2] Lateline ABC. (14 March, 2014). N.T. alcohol experts oppose criminalisation of pregnant drinkers. http://www.abc.net.au/lateline/content/2014/s3963901.htm

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