

**STATEMENT TO THE HOUSE OF REPRESENTATIVES STANDING
COMMITTEE ON SOCIAL POLICY AND LEGAL AFFAIRS**

INQUIRY INTO FOETAL ALCOHOL SPECTRUM DISORDER



NATIONAL CONGRESS
OF AUSTRALIA'S FIRST PEOPLES

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Statement by the National Congress of Australia First Peoples to the House of Representatives Standing Committee on Social Policy and Legal Affairs

Inquiry into Foetal Alcohol Spectrum Disorder

Introduction

1. The National Congress of Australia's First Peoples (Congress) is a national representative body for Aboriginal and Torres Strait Islander Australians. Congress is an independent national voice that advocates for the rights of Australia's First Peoples and for securing their economic, social, cultural, political and environmental development. Congress membership is spread across all States and Territories. Congress has 4,400 individual members and 140 organisational members who collectively represent approximately 50,000 Aboriginal and Torres Strait Islander peoples across Australia.
2. Congress welcomes the Standing Committee on Social Policy and Legal Affairs' inquiry into Foetal Alcohol Spectrum Disorder (FASD) and supports the Australian Government's initiative in referring this matter for investigation and development of policy responses.
3. Congress notes and supports the submissions that have been provided to the Committee by Aboriginal and Torres Strait Islander organisations, many of whom are Congress members. In considering the particular impact of FASD on Aboriginal and Torres Strait Islander communities, Congress encourages the committee to carefully consider and respond to the views that have been put forward on this issue by Aboriginal and Torres Strait Islander organisations and give weight to the evidence they have provided. For example, the Lililwan Collaboration provides a case study of how a local community-led initiative in the Fitzroy Valley of Western Australia has developed a multifaceted approach to the prevention, diagnosis and management of FASD.¹
4. Information on the educational, clinical and systemic issues related to FASD exists in the many comprehensive submissions that have been provided to the inquiry and will not be repeated in this paper. Instead Congress provides an overview of the issue and provides some key principles and recommendations.

Recommendations

5. In relation to FASD Congress makes the following recommendations:
 - a. Development and implementation of a comprehensive national strategy to reduce alcohol misuse that includes specific community-led measures for Aboriginal and Torres Strait Islander peoples.
 - b. Development of a coherent national plan to respond to FASD with a comprehensive approach and integrated strategies supported at the local level.
 - c. Community-wide education, information and social marketing campaigns that discourage tolerance of harmful drinking in the general population and raise awareness of the impact of alcohol in pregnancy. Campaigns need to be tailored for Aboriginal and Torres Strait Islander communities and presented in a way that does not stigmatise women or particular groups.
 - d. Mandatory labelling and health warnings for all alcohol about the risks associated with its use and misuse, including risks in pregnancy.
 - e. Include FASD in the definition of disability so people with FASD are able to access support and individuals and families affected by FASD are included in the National Disability Insurance Scheme.
 - f. Development of culturally specific tools and training required by health professionals to better detect, treat and manage FASD, including diagnosis and screening instruments, clinical guidelines and referral. These tools must be integrated within the existing Aboriginal and Torres Strait Islander health system and plans.
 - g. Education and training for government and non-government health professionals to equip them to deal with all aspects of FASD.
 - h. Education, training and policy responses by other sectors including education, criminal justice system, children's services and employment services to increase understanding and appropriate responses to address the needs of children and adults with FASD, and their families.
 - i. Implementation of strategies to improve data collection, research and evaluation of the prevalence of FASD and the effectiveness programs and services.
 - j. Expansion of services to support people with FASD, their families and professionals.

Defining the Problem

6. FASD has a significant impact on the lives of the individuals affected, their families and communities. This condition impacts upon local services and professionals in health care, criminal justice, social services, education and employment. While FASD has specific impacts on Aboriginal and Torres Strait Islander communities, Congress supports the position of the National Indigenous Drug and Alcohol Committee (NIDAC) that it is a national issue:

While NIDAC is particularly concerned about the impact of FASD on Indigenous Australians and communities, it does not see FASD as a uniquely Indigenous issue, nor does it view FASD as an issue only for pregnant women. Rather, NIDAC considers FASD to be an issue facing the country as a whole and one that needs to be addressed by the whole community.ⁱⁱ

7. The issue of FASD needs to be viewed in the context of alcohol use generally by the Australian population. At the national level, Australians are heavy consumers of alcohol. Drinking is associated with many aspects of social life and excessive alcohol use is linked to a wide range of serious health and social problems.
8. More Aboriginal Australians abstain from alcohol compared to other Australians but those Aboriginal and Torres Strait Islander people who do drink, do so at higher risk levels. The use of alcohol, tobacco and drugs is a factor in chronic disease that contributes significantly to illness and death and therefore it is a contributing factor to the gap in life expectancy between Aboriginal and Torres Strait Islander and other Australians. Congress recognises the serious and widespread problem of alcohol misuse, including during pregnancy, and strongly supports a holistic program of action to reduce alcohol-related harm.
9. FASD also needs to be considered in the context of the range of issues facing Aboriginal and Torres Strait Islander communities including historical factors. To quote NIDAC:

Patterns of alcohol, tobacco and other drug use among Indigenous Australians have been shaped by history. With the effects of dispossession, alienation, trauma and loss recognised as contributing factors to the lower health and socio-economic status that Indigenous Australians continue to experience today, the use of alcohol, tobacco and other drugs have consequently become the cause and effect of much suffering in Indigenous communities.ⁱⁱⁱ

FASD as a cause of disability

10. FASD is thought to be a major cause of disability but is known to be under-diagnosed and under-reported. This may particularly be the case among Aboriginal and Torres Strait Islander people, who are significantly over-represented among Australians with a disability. In its submission the First Peoples Disability Network states:

By any measure Aboriginal and Torres Strait Islander people with disabilities (including Aboriginal people with FASD) are amongst the most disadvantaged Australians. They often face multiple barriers to their meaningful participation within their own communities and the wider community. The vast majority of Aboriginal and Torres Strait Islander people with disabilities are at the periphery of all aspects of the disability services sector.^{iv}

11. Identification and referral for multidisciplinary diagnosis early in development is a protective factor and is essential for accurate assessment of the developmental needs of infants and children thought to be affected by FASD.
12. Early identification and intervention of children at risk is a critical and pivotal preventive measure since it can reduce the negative flow-on effects of secondary disabilities that individuals with FASD are at high risk of developing and increase knowledge and awareness in community services.
13. Significant benefits can be gained from the provision of developmental screening and follow-up diagnosis for the individual, for the family and for the community in general. However a lack of training for health professionals means that diagnosis of FASD will be unlikely or inaccurate and follow up service provision inadequate throughout life.
14. Families seeking medical advice and intervention for a child exposed prenatally to alcohol often encounter barriers to identifying FASD which can lead to further problems for the individual and their family. There are multiple reasons for this including not wishing to 'label' the problem, a belief that nothing can be done to fix any damage, lack of training and confidence in diagnosing FASD or the belief that the family will be stigmatised rather than helped by this diagnosis.
15. Diagnosis is a positive starting point. Ensuring the needs of individuals with FASD are appropriately managed will reduce the likelihood of secondary disabilities developing. However current disability and other policy does not take into account the range of functional deficits associated with organic brain disorders such as FASD and therefore denies services to the majority of affected families, increasing the risk of secondary disabilities.

16. Developing policy specific to FASD combined with sector training in identifying FASD and its effects will improve understanding and collaboration between sectors, help to keep any duplication of inappropriate and ineffective services to a minimum and improve support and outcomes for affected families.

Other Impacts

17. While the economic impact of FASD is not quantified, anecdotal evidence supports the view that this condition is related to significant costs in terms of the range of services required, forgone economic opportunities for people with FASD and their carers, and the association of FASD with other social impacts issues such as over-representation in the criminal justice system.
18. The relationship between the criminal justice system and Aboriginal and Torres Strait Islander people who have cognitive impairment has been described comprehensively by the Aboriginal Disability Justice Campaign (ADJC). Case studies collated by the ADJC illustrate the isolation and marginalisation of individuals with FASD, the difficulties they and their families experiencing access services, and the pathways that for some have ended in indefinite detention without a conviction.^v
19. FASD is a multi-faceted health and social problem that requires a comprehensive approach, a range of strategies and a collaborative effort from many parties.

Principles regarding policy development affecting Aboriginal and Torres Strait Islander Peoples

20. Congress draws the Committee's attention to important principles that should apply to all policy and service delivery in regard to Aboriginal and Torres Strait Islander communities.^{vi} In this regard, the UN Declaration on the Rights of Indigenous Peoples provides a foundation and guide. Relevant to the issue of FASD are the Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities.
21. Congress supports policies that enable local community control and self-determination and which empower our Members, their families and communities to develop their own institutions and responses. Congress emphasises the strengths of communities, and supports innovative solutions that are evidence-based and acknowledge the central role of culture and connection to Country.
22. Congress supports strategies that advance Aboriginal and Torres Strait Islander autonomy and sustain the capacity and development of Aboriginal and Torres Strait Islander people and their communities. Congress endorses the emerging body of evidence that shows it is investment in programs and services, developed in genuine collaboration with Aboriginal and Torres Strait Islander communities and properly funded, that is the key to building capacity and achieving sustained benefit.
23. Congress suggests the following principles be applied in any area of policy development affecting Aboriginal and Torres Strait Islander peoples:
 - Empowerment, self determination and self management by First Peoples.
 - Full and effective engagement of First Peoples in decisions that affect them including in the negotiation and formulation of legislation, policies and programs.
 - A spirit of cooperation, partnership and shared responsibility.
 - Recognition of the importance of long-term planning and investment.
 - An understanding that issues affecting First Peoples are complex and contextual and that flexibility and innovation are required.
 - Recognition of the need to develop legislation, policies and programs in a manner consistent with First Peoples' social obligations and cultural values of caring for the wellbeing of individuals, families, communities and Country.
 - An approach that respects the cultural diversity of First Nations and distinguishes between their differing goals and priorities.

- Clarity of responsibility for service delivery and increased effectiveness across Government leading to better policy and program outcomes.
- Accountability and high performance standards and effective monitoring by all parties.
- Respect for the existing leadership and governance arrangements of First Peoples while taking action where necessary to strengthen leadership, governance and capacity.

Principles regarding FASD

24. In addition to the general principles stated above, Congress suggests specific principles be adopted in relation to the issue of FASD.
25. Key factors for success in Aboriginal and Torres Strait Islander based alcohol and drug programs have been identified as being strong leadership, strong community engagement, appropriate infrastructure and use of a paid workforce to ensure long term sustainability. In addition adequate resourcing and planning of interventions is important. To be effective evidence suggests interventions should:
- have the support and be controlled by local communities
 - be designed specifically for the needs of particular communities and sub groups within them
 - be culturally sensitive
 - have adequate resourcing and support
 - be resourced to cater for clients with complex needs
 - provide ongoing care
 - achieve an appropriate balance between broad-based and substance specific services
 - be part of a planned, integrated set of interventions^{vii}.
26. Research has also found that where communities lack capacity, partnering with non-Aboriginal and Torres Strait Islander organisations can be successful if there are agreements for the local community to take full control within an agreed timeframe.
27. In the area of awareness raising, education and health promotion about the risks of alcohol in pregnancy, women cannot be considered in isolation from their families and communities. Programs that challenge the cultural place and misuse of alcohol

across the entire community are more likely to have long lasting success in addressing the cause of FASD than those that target only the behaviour of women of reproductive age. It is important that campaigns are positive, build strength and do not stigmatise women and people affected by FASD, as this would be counterproductive.

28. In relation to supporting individuals who have FASD, these individuals, their families and communities must be involved in shaping policy responses and services if they are to be effective.

29. A key challenge in managing FASD among Aboriginal and Torres Strait Islander peoples is that approximately 9 per cent of Aboriginal and Torres Strait Islander people live in remote areas and 15 per cent in very remote areas.^{viii} Aboriginal and Torres Strait Islander communities that are in rural or remote locations face particular challenges that include geographical isolation, a lack of services, language differences and complex socio-economic conditions. These factors need to be taken into account in developing policy responses to FASD. Aboriginal and Torres Strait Islander peoples require culturally appropriate diagnostic and treatment services to assist them in preventing new cases of FASD and to support those who are currently affected.

References

ⁱ Lililwan Collaboration: Inquiry into Fetal Alcohol Spectrum Disorders, submission, 2012

ⁱⁱ National Indigenous Drug and Alcohol Committee, Addressing Fetal Alcohol Spectrum Disorder in Australia (2012)

ⁱⁱⁱ NIDAC website,
http://www.nidac.org.au/index.php?option=com_content&view=article&id=197%3Anidac-strategic-plan-2012-2014-background-and-further-information&catid=34%3Aabout-nidac&Itemid=60

^{iv} Submission to Parliamentary FASD Inquiry, First Peoples Disability Network, 25 May 2012

^v Submission to FASD Inquiry, Aboriginal Disability Justice Campaign, 16 January, 2012

^{vi} See Congress's Statement of Principles <http://nationalcongress.com.au/wp-content/uploads/2012/02/CongressPrinciples1.pdf>

^{vii} Closing the Gap Clearinghouse, What works to overcome indigenous disadvantage, 2011

^{viii} Productivity Commission, Overcoming Indigenous Disadvantage Key Indicators 2011