

20th April, 2012

Social Policy and Legal Affairs Committee
House of Representatives
PO Box 6021
Parliament House
Canberra ACT 2600

Dear Mr Graham Perrett MP,

Re: CYI Submission to Inquiry into Foetal Alcohol Spectrum Disorder.

Thank you for giving Cape York Institute the opportunity to provide this letter as a Submission to the Inquiry into Foetal Alcohol Spectrum Disorder.

The Cape York Institute would like to respond to the Inquiry by strongly advocating for firm and robust measures that specifically target preventing this irreversible condition that is dimming the potential for future generations of Cape York. It supports an integrative strategy that works with women, families and communities prior to pregnancy.

The Cape York Institute is an independent policy and leadership organisation. The Institute champions reform in Indigenous economic and social policy and supports the development of current and future Cape York leaders. The Institute's Director is Noel Pearson, an Aboriginal leader and activist from the community of Hope Vale. Our guiding framework is the CAPE YORK AGENDA which aims to ensure that Cape York people have the capabilities to choose a life that they have reason to value. Our work falls into four broad areas: policy and research, leadership, welfare reform and evaluation.

The Cape York reform agenda aims to work towards restoring social norms, with a primary focus on the wellbeing and rights of children. The Cape York Agenda identifies the breakdown of social norms as a reason for the social dysfunction affecting many remote Indigenous communities and is working towards restoring social norms in these communities. It focusses on enabling the individual and avoids creating or perpetuating dependency. Thus, each project puts in place structures which support people to build their own lives as they choose to live.

It is a challenge to restore social norms and build a vibrant, healthy and productive community when members are suffering from the effects of Foetal Alcohol Spectrum Disorder (FASD). A study in far north Queensland estimated a FASD prevalence of 1.5 per cent in the Aboriginal child population, with one Cape York community having a prevalence of 3.6 per cent (Rothstein, Heazlewood and Frazer, Health of Aboriginal and Torres Strait Islander children in remote Far North QLD: findings of the Paediatric Outreach Service, Med J Aust, 2007, 186:519-521). In general, specific, reliable and robust data is lacking and we are likely underestimating the extent of the problem in Cape York Indigenous communities.

The communities and families of Cape York that are continually feeling the clinical effects of FASD, affecting learning and behaviour of the young, and carrying on into adult life, are left collectively unable to achieve their full potential. Given that FASD is 100 per cent preventable but has lifelong ramifications, this is an urgent matter in the communities of Cape York that requires firm preventative measures to be introduced as soon as possible.

Given the irreversible and very serious nature of FASD, prevention must go beyond education campaigns and warnings to raise awareness of alcohol consumption during pregnancy. It is crucial that the community is consulted and engaged throughout the process, rather than being the recipients of another strategy or program. In this regard, we would advocate that FASD prevention, treatment and management should be

incorporated into overall health and wellbeing strategies in the communities, strategies that see individuals as part of their families and communities.

Recommendations:

There are a few measures that the Cape York Institute recommends for the Cape York region:

- **A family development strategy.** The task of welfare reform is to develop support and intervention strategies which result in family members taking up their responsibilities. Strategies that tackle FASD in Cape York communities need to tackle the breakdown of social norms around alcohol consumption that are experienced by the whole family. Therefore, although the pregnant woman needs to be supported, she is within a web of influence and behaviour that also must be addressed. Such a program can possibly be delivered through a family case management model that guides all engagement between service providers and women of child-bearing age, to ensure that the best support services are provided and integrated to at risk women. This will require advocating for increased and better services for women of childbearing age that can provide intense support both pre, during and post pregnancy in a culturally appropriate manner.
 - Pre-pregnancy care is important as often FASD occurs in the first trimester before the woman may know she is pregnant.
 - Tackling women in the 'pre-pregnancy' phase can be in the years before they fall pregnant.
 - Having care around the entire pregnancy is not only important for preventing FASD but multiple other conditions that are linked with a poor pregnancy and outcomes such as low birth weight.

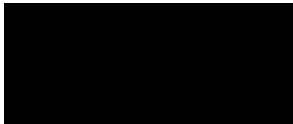
Furthermore, other risk factors in high prevalence in these communities, such as smoking and depression need to also be addressed. Awaiting presentation at a clinic by the individual will not detect many cases. An engagement of family members and the community is needed to help create accepted social patterns of behaviour around pregnant women, and indeed the entire family.

- **Integration with other strategies and services.** The Cape York Institute advocates a holistic development approach with employment, health, education and housing, for example, all affecting measures to tackle FASD. Given the complexities of alcohol addiction in indigenous communities, strategies to prevent FASD cannot be purely clinical or educational. Safe and stimulating home environments and employment are also important underlying factors.
- **Stronger prevention measures as needed.** Heavy daily drinking or binge drinking have the most risk in harming the foetus, but there is no lower limit that can be guaranteed to be completely safe, and thus guidelines recommend stopping drinking whilst pregnant (NHMRC current guidelines). The Cape York Institute advocates abstinence. Unfortunately, in some cases social norms have deteriorated so excessively that educational campaigns, social supports and integration with other services must be challenged as being completely inadequate as a reasonable response to the prevalence of this problem in these communities. Dire circumstances have necessitated that appropriate responses must now be designed and implemented. The children of these communities are born with a significant disadvantage to be able to choose the life they have reason to value. Cape York Institute advocates for the rights of children and would therefore recommend that strategies such as conditional income management linked with appropriate support services are

canvassed as options, as well as reviewing Alcohol Management plans to incorporate strategies to specifically prevent FASD.

With regard to management issues, there is a need to continually enhance drug and alcohol services in the communities. Access to appropriately trained staff, both medical and psychosocial is important, but so is the continuity of care – a challenge for remote communities. The management also demands sufficient drug and alcohol services for the affected mother and an integration of these services with family planning and child and maternal child health services. In communities that can have already have multiple siloed service providers, the answer may not be to roll out another program, but to see how current services can be enhanced, supported and expanded to provide holistic care that can tackle FASD in combination with the multiple comorbidities often present. All services must have an inherent component for the building of family and individual capacity and capability, that aims to build community capacity and ownership. It is critical that responses avoid seeing people as a bundle of needs at which various programs are reactively thrown at rather than taking greater care to understand FASD and design a response that is proactive and builds family and community capacity. Integrating any future FASD response with current processes of capacity building, such as the Cape York Welfare Reform project, is therefore important.

Yours sincerely



Gummi Fridriksson
Chief Executive Officer
Cape York Institute for Policy & Leadership