20 May 2014

Secretary
Select Committee on action to prevent FASD
GPO Box 3721
Darwin 0801

SUBMISSION TO SELECT COMMITTEE ON FASD, LEGISLATIVE ASSEMBLY OF THE NORTHERN TERRITORY BY Anyinginyi Health Aboriginal Corporation (Anyinginyi)

This is in response to the Call for Submissions on Action to Prevent Foetal Alcohol Spectrum Disorder as recently advertised.

Background

Anyinginyi is an aboriginal community controlled provider of primary health services based in Tennant Creek providing services to the Barkly region of the Northern Territory.

Anyinginyi provides services to regional and remote communities within the Barkly Region, covering some 303,295 square kilometres with a resident population of approximately 6,682 (NT Government At a Glance 2014), of which 80% are Aboriginal. There are 15 Aboriginal language groups in Tennant Creek and the surrounding areas, demonstrating the wide-spread diversity of community groups within this Region.

The health status of residents of the Barkly ranks amongst the worst in Australia.

To combat this Anyinginyi takes both an innovative and holistic approach to address the needs of the community – FASD provides an example of this type of approach.

Anyinginyi works on the concept that issues related to key social inequalities in health lie in the circumstances in which Aboriginal people are born, grow, live, work and age and that the intrinsic issues relating to poverty, unemployment, low socioeconomic status and poor living conditions underpin their significant mental health and generational wellbeing.

Our "FASD journey" to date has been as follows: 2011 – at this time FASD was a term seldom heard or used.

However being aware of the high level of alcohol consumption in the area (see attached), the work done and findings in the Fitzroy Valley and overseas research it was clear that FASD was certain to be a real issue in our community.

As a result Anyinginyi embarked on a mission to make ourselves and our community aware of FASD, to develop and deliver tools/ teaching aids to prevent FASD, to lobby for the development of clinical pathways and best practice for the treatment of FASD, to lobby for effective treatment for those with FASD and their families and to lobby for funding for FASD.

The results to date include:

- Local high school students produced a hip-hop video on "no drink while pregnant" that has been a major success around Australia;
- Students are currently preparing a stage play on FASD;
- All liquor outlets in Tennant Creek have signs developed by Anyinginyi regarding the dangers of drinking while pregnant;
- Regular education sessions to schools and communities;
- Development of a broad range of education materials that has now been adopted by the NT Department of Education for use in schols throughout the NT;
- Television advertisements currently in English but soon to also be in 4 local aboriginal languages;
- On invitation Anyinginyi presented at an international FASD conference in Vancouver, Canada, in 2012;
- Anyinginyi had 2 speakers at Australia's first national conference on FASD in Brisbane in 2013.

While Anyinginyi appreciates the funding provided by governments the fact is there is no dedicated funding for FASD – the funding of our journey has come from a number of different "buckets" and from self-funding by Anyinginyi.

There is no government funding available after 30 June 2014.

In response to point 2 of the Terms of Reference the following is advised

Prevalence

- The data systems of government health services and aboriginal community controlled health services are not geared to provide accurate data on the prevalence of FASD.
- Further the federal government is yet to agree on a diagnostic tool in relation to FASD.
- Due to the above 2 points there is no accurate data on the prevalence of FASD in the Barkly region and the majority of other regions.
- Given the above and the lack of comprehensive screening/research in the Barkly, prevalence can only be suggested from comparison with the Fitzroy Valley study that indicates a strong correlation between rates of alcohol consumption in a given community and rates of FASD in that community. On this basis Tennant Creek and the Barkly clearly demonstrate possibly the highest rates of alcohol consumption in Australia, with the corresponding implication for rates of FASD;
- Other evidence for the B01arkly can only be cited as "anecdotal" due to lack of an accepted diagnostic tool
 and professional resources to properly diagnose;
- All we do know is feedback from schools, police and other care providers on the high incidence of people with developmental problems.

The Nature of Injuries and Effects of FASD

- FASD hurts babies, families and communities, it is a range of disabilities and birth defects;
- It is permanent and cannot be fixed;
- It can cause brain damage, damage to internal organs, poor growth, developmental delays, birth defects, low intelligence and social learning and behavioural problems – children born with FASD have difficult lives with lots of problems that does not set them up for healthy adulthood;
- What has to be emphasised is FASD is 100% preventable;
- It is not just an aboriginal problem however it does affect aboriginal communities in specific and visible ways because of the cultures involved and the social determinants also present that effect health status;

- FASD crosses all socioeconomic boundaries and effects every aspect of a community health, welfare, education, child protection, law etc.
- The financial costs are also high a study in the USA in 2007 estimated the lifetime cost of one person with FASD at \$2m.

Actions the Government can take to reduce FASD

- Adopt a suitable diagnostic tool;
- · Formulate clinical pathways /best practice;
- · Dedicated funding for FASD;
- Fund appropriate treatment particularly in the early years e.g. Early Intervention Programs, as the sooner children with FASD can be helped, the better they learn and grow;
- The treatment process must include the family and provide support, acceptance and inclusion;
- · Partner with existing providers that have successfully developed preventive programs;
- · Implement Territory wide prevention programs;
- Work with local organisations to customise prevention and treatment strategies to suit local communities
- Research and learn from overseas experience;
- Take measures to reduce the consumption of alcohol;

Should any further information be required please contact Trevor Sanders, General Manager on 0408 660 752.

Yours sincerely

Trevor Sanders
General Manager

Anyinginyi Health Aboriginal Corporation

Attachment: As detailed

