Northern Territory Government

DEPARTMENT OF HEALTH

Inquiry into Foetal Alcohol Spectrum Disorder

Submission on behalf of the Child and Adolescent Mental Health Team.

Top End Mental Health Services

Darwin, Northern Territory.

June 2012.

It has only recently come to our attention that the National Inquiry into Foetal Alcohol Spectrum Disorder is occurring. It should be stated at the onset of this contribution that hearing of the Inquiry has prompted much discussion within our small team and this document is just a small part of what we hope will be a continuing discussion; one of quality improvement with regards to working to understand, address and manage this complex and unique disorder.

We as a team still have much to learn on this matter and whilst the problems associated with FASD are not new, through recent readings, discussion and through our practical experiences and observations we have come to realise that FASD has not been a widely discussed phenomenon within our work community; it has to an extent been a forgotten topic.

The team within which we work is the Child and Adolescent Mental Health Team and it is located in Darwin, Northern Territory (NT). It is a Tertiary Mental Health Service within which a small multi-disciplinary team work together to meet the mental health needs of children and adolescents from 0-18years of age. Our team is represented by a diverse range of skilled professionals, including a Psychiatrist, Psychiatric Registrar, Psychologists, Social Worker, Speech Pathologist, Family Therapist and Mental Health Nurse.

The work of the team is largely assessment and therapeutic in nature. We are involved in assessing and case-managing young children and adolescences, who present with a plethora of complex mental health issues. We largely receive referrals for diagnostic clarification and assistance for further comprehensive therapeutic interventions. We assess, treat and manage clinical syndromes such as:

- Disorders of Attention and Activity:
- Conduct Disorders of Childhood and Adolescence:
- Depressive Disorders:
- Anxiety Disorders:

- Suicidal behaviour and deliberate self-harm:
- Eating Disorders:
- Post-Traumatic Stress Disorder:
- Obsessive Compulsive Disorder:
- Tic Disorders:
- Autism Spectrum Disorders:
- Speech and Language Disorders:
- Reading and other specific learning disorders:
- Intellectual Disability:
- Gender identity Disorder:
- Behavioural problems of infancy and preschool children:
- Attachment disorders:
- Wetting and soiling:
- Sensory impairment:

The other facet of our work is a thorough assessment of influences on psychopathology.

We service remote communities across the top End of the Northern Territory. Our team currently provides specialist mental health services to: Tiwi Islands, Groote Eylandt, Batchelor, Nhulunbuy, Maningrida, Gunbalanya, Jabiru, Katherine, Pine Creek, Nauiyu, Wadeye, Darwin and Palmerston regions.

We have found in our practice that each and every community has different needs and requires a unique approach. Thus, in acknowledging that we liaise and work with the aforementioned communities we wish to advise that we cannot speak on behalf of each community we work with. However, we do as a team share the following information, in the hope that it will be of use to the Inquiry when considering the unique shared needs of the regions that are part of the Top End of the Northern Territory; when developing a national strategy to address the needs of individuals, their families and communities experiencing adverse consequences of FASDs.

We service a complex community in the Top End of the Northern Territory with children and adolescences from a variety of diverse culturally and linguistically differing backgrounds. We are a young, often transient population and we want to stress the need to the inquiry that in the NT we require a management plan/response to FASD that considers and reflects the complex needs of our

diverse population, and acknowledges that FASD's transcends ethnicity, economic and educational status and age.

We acknowledge that according to the literature there remains no uniformly accepted criterion for diagnosing FASD and that there are very real "Challenges in determining accurate prevalence, despite the considerable progress made over the past several decades to accurately establish and monitor the prevalence of FASDs. The full magnitude of the problem is still not known." (Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis, 2004). In practical terms, learning about the lifelong struggles of families managing individuals with FASD, it can be seen that the emphasis on any intervention targeting future generations should be to PREVENT the presentation to begin with. With this in mind, it is our view that management strategies need to be:

Relevant,
Concise,
Evidence-Based and
Culturally Appropriate.

It is very much a whole of community problem requiring a whole of community response. However, studies do indicate that women in particular require information that is accurate, honest, non-judgemental, culturally appropriate and caring. Women use alcohol for a wide range of reasons, the harsh reality is that some use alcohol to cope with abuse, trauma, stress and despair. Women in lower socio-economic households may also use alcohol as a way to cope with associated stress (Alcohol and Pregnancy and Fetal Alcohol Spectrum Disorder: a Resource for Health Professionals, 2009).

The management of FASD is a journey impacting upon the quality of life of the individuals affected by FASD, their families and their communities. The reality is that the resources currently available in terms of community awareness are scarce. FASD is not a popular topic of interest and this is of concern given the complex and challenging life experiences families living with a FASD have across the world. The book "Educating Children and Young People with Fetal Alcohol Spectrum Disorders" (2012) provides a wealth of information in understanding many of the contemporary issues affecting individuals and their families, citing many references that depict the complex nature of detection, management and treatment options. It has been invaluable in guiding us towards understanding the many complexities surrounding FASD and inspired thought on how we might best respond to FASD.

We are also mindful that the difficulties associated with FASD do not subside, this is evident in the many studies to date that indicate that the implications are far reaching.

There is a wealth of knowledge on the many difficulties associated with FASD's including wide-ranging problems and sometimes co-morbid presentations. Documented difficulties experienced are physical and intellectual disabilities, hearing impairments, vision impairments, growth deficiencies, facial differences, damage to the central nervous system resulting in developmental disabilities including learning difficulties, challenges and delays with communication, behavioural difficulties, emotional and sensory challenges and so forth. Teasing these apart is problematic for all concerned, requiring significant time, energy, love, compassion and resourcing to manage. Whilst there is an acknowledgement that it is a complex phenomenon, there is also a consensus that it can be prevented. This is the message we would like to see spread around Australia, FASD can be prevented and we do have the power to make the change.

As the tertiary Mental Health government service provider for the Northern Territory, servicing Top End townships and communities, the Child and Adolescent Mental Health Service, needs to be aware of the need to consider the influence of FASD's regarding the manifestation of psychopathology, diagnosis and management. Whilst as a team we inquire about maternal substance use we should acknowledge that we do not currently complete an extensive follow up or investigate with regards to the timing, frequency, quantity or reasons for substance use. Whilst there is considerable information available informing us of the adverse consequences for infants/babies whose mothers drink alcohol whist pregnant- in practical terms, it can be challenging to obtain accurate information at a case-by-case level or intervention.

Prevention strategies:

The reality is that whilst a National Approach is being developed, every community within the Top End of the NT has varied needs and each deserves input to begin the process of articulating their view on the most effective way to integrate discussions and awareness of FASD into the fabric of their community. It is critical the views of the communities can be heard when developing future resources and management strategies in this field. This needs to be done in such a way as to acknowledge the reality that each community may have different needs, attitudes and ideas as to how to best manage FASD. More consultation is required on the topic at all levels from grass roots to government.

- We request that any national and or local campaign/s stress what FASD is and the reality that FASD can be prevented. There is hope for communities and individuals to change!
- We ask that when education campaigns and products such as warning labels raise awareness by presenting factual information that addresses the real life complexities affecting individuals with FASDs and their families and reiterates the message that FASDs is preventable. For example; as we witnessed with the TAC ads in Victoria, they were confronting but they got the message across that Speed Kills.
- We need for communities to understand how severe the implications can be for families when mothers consume alcohol whilst pregnant. Informing the community of the potential ramifications/ outcomes of pre-natal alcohol exposure to an un-born child is integral considering the far-reaching consequences.
- Women must be informed, safe and supported to make educated decisions for their un-born child health and wellbeing.
- We request that wherever possible relevant stakeholders are consulted when developing resources to address the needs of the population.
- We request that local resources are used: For example using local radio to get community discussions happening in remote areas that have their own radio channels in addition to the national campaign messages- local mediums should be employed to instigate further discussion in interested communities. Another possible solution would to have educated health professionals interviewed and available to answer questions, going into schools and conducting educational presentations.
- We are of the belief that including a real picture (in campaigns) of the complex nature of FASD's and the many possible outcomes would be of benefit to empowering women to make more informed decisions with regards to their self-care when pregnant. The other benefit would be the increase in public awareness of these conditions which one would hope may possibly lead to a better understanding of this topic within our communities.

- Keeping mindful of the fact that no two individuals with FASDs are alike as each and every presentation is different. So health authority warnings should follow similar vein as the Quit Smoking campaigns so that communities are more informed about the very real adverse consequences and potential risks to consuming alcohol whilst pregnant.

Intervention needs

As stated previously, when looking into FASD's it can clearly be seen across all the most recent literature that emphasis should be on Prevention measures- that it is a complex phenomenon that is not easy to manage and can be easily avoided if women/young females of abstain from consuming alcohol whilst pregnant. Our team is of the belief that any intervention should stress this point and that Educators, Health Professionals, and relevant stakeholders should receive training to support communities to develop clear management guidelines to ensure that FASD's are understood, supported and that communities are engaged in the discussion about how best to intervene. Staff working within the field need to feel confident in their skills.

Considering the current information available that:

"Many health professionals do not routinely ask pregnant women about their alcohol use, and many do not feel prepared to advise on the consequences of alcohol use in pregnancy. Health professionals have important role in ASKING women before and during pregnancy about alcohol use. ASSESSING the risk of alcohol use, ADVISING about the consequences, ASSISTING women to stop or reduce their alcohol consumption and avoid intoxication, and ARRANGING further support as appropriate." (Alcohol and Pregnancy and Fetal Alcohol Spectrum Disorder: a Resource for Health Professionals, 2009).

It can be clearly seen that awareness of the vast implications and the necessity to put an end to the Phenomenon should be stressed in any intervention/s. Ensuring women have their holistic needs met, that they do have access to relevant information and do receive the care that is needed to make informed and educated lifestyle choices to support the unborn child is imperative to effectively managing and working towards prevention of FASDs.

- Blackburn et al (2012) acknowledges that when managing the educational requirements of Complex Young People (CYP) with FASDs there must be honesty with regards to the fact that such cases present educators with new profiles of learning needs that educators may not know how to best address with current systems and curriculum frameworks. This unique group can have complex learning profiles requiring significant support to address their complex needs. Intervention strategies need to acknowledge this and work within the

relevant legislation to ensure the rights of a person with FASDs to an education are in fact being met.

- As The Journal of Pediatrics cited/acknowledged "Diagnosing FASD among children and adults historically has presented physicians with a challenge. "Cases of even full-blown FAS often go undetected at birth and later in life."(Pediatrics, 2005). This keeps children with FASDs vulnerable across many domains in their lives. Emphasis should therefore be made to develop an awareness and appreciation of the complex nature of FASDs. Intervention and Management strategies should be inclusive of many varied presentations that can be apparent in FASDs.
- Acknowledging its complex presentation and the reality that there can be co-morbid presentations (ie with disorders such as ADHD and ASD). Before effective interventions can be instigated there needs to be a consensus regarding the diagnostic criterion. To treat FASDs effectively we need to understand its complex presentation and the many difficulties that can arise in direct response to damage caused from having FASDs.
- We as a team respect that "Diagnosis is never an end point for any individual with a developmental disability and his or her family..." (Fetal Alcohol Syndrome: Guidelines For Referral and Diagnosis, (2004). Knowing this we request that intervention strategies stress the need for on-going care of people with FASDs and their complex needs across the lifespan.
- Intervention methods need to stress the fact that there can be mental health problems and lifelong health difficulties as a result of FASD, even though FASD's is not currently in itself a clinical diagnosis.
- We acknowledge that as the contemporary literature states, the term is so broadly defined that some authors argue that it is in fact too broad to be of clinical value (FADS Diagnostic and Prevention Network, (2004): 1). With FASD's being so ambiguous it has become understood as an 'umbrella term' and this in itself has implications in developing effective intervention and management plans. Each and every presentation is different and each management plan/intervention needs to work respectfully to address the rights of both the mother and the un-born child.

Management issues:

It is apparent that women can accidentally expose their child to alcohol by drinking alcohol before they come to learn that they are pregnant. Considering this, education with regard to planning pregnancies and or managing un-planned pregnancies should be integrated into any national campaigns and management plans within communities.

There are varied rates of alcohol use by pregnant women. In 2006 a survey conducted on 1103 women of childbearing age found that 24% of women would continue to drink alcohol should they become pregnant, and around 34% had continued to consume alcohol during their previous pregnancy. (Alcohol and Pregnancy and Fetal Alcohol Spectrum Disorder: a Resource for Health Professionals: (2009) Considering the fact that it still remains unclear the amount of alcohol that is safe for the foetus any management should reflect the need for pregnancy women to abstain from consuming alcohol. Knowing what we now know, our team also requests that the following be considered when discussing the implications on management across the nation:

- We recommend a multi-disciplinary approach to ensure that our breadth of knowledge and skills within the approach is balanced. To ensure that assessment, diagnosis and treatment and management are well planned and supported.
- We recommend a Longitudinal research approach to gather pertinent information about the presentation of FASD's to collect and compile symptom profiles so that we can develop appropriate diagnostic and management guidelines.
- Education- not only of at-risk individuals but also the professionals involved in providing a service to individuals, their families and the community as Frances Bacon once said "Knowledge is Power" we would like to see National Management of FASD that does share the information with those whom most need it.
- Servicing the needs of families in remote localities needs to be a priority, there are so few support services/agencies in remote localities and the education of this population needs to be prioritised in any management plans.
- Whilst a National Inquiry may begin the conversation and may well introduce the topic to modern Australia- Sustainable programs that cater to community needs and resourcing that are appropriate to each region will ultimately be required to begin to address the many and varied needs of each communities management of FASD in the Top End of the NT..

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