CatholicCare NT

Action to Prevent

Foetal Alcohol Spectrum Disorder

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CatholicCare NT Profile and Interest in FASD

CatholicCare NT operates as a Catholic Diocesan based independent not for profit service agency, accountable to the Catholic Bishop of Darwin, Bishop Eugene Hurley. CatholicCare NT has operated in the Northern Territory for 21 years, with some of our services including AOD services operating under various Catholic entities for many years prior to that. In many of the communities that we service there has been a Catholic presence for over 100 years. The heart of our commitment is to make a difference in people's lives; we seek to do this through a range of programs including drug and alcohol services in urban and remote areas, a broad range of counselling and family support programs, employment programs, specialist children's programs, men's programs, mental health services, and financial capability services. We operate programs and have staff permanently located in the following areas; in the APY lands, Titjikala, Santa Teresa, Alice Springs, Tennant Creek, Lajamanu, Katherine, Daly River, Wadeye, Palmerston, Darwin and in Wurrumiyanga and Milikapiti. Our outreach beyond these areas is significant.

The issue of drug and alcohol use in our urban and remote regions is complex and challenging. Alcohol misuse is seldom a standalone issue, often contributing to significant harm to the individual, family members and the broader community. Alcohol and other drug practitioners based in the community respond to affected family members, respond to court mandated clients, work with AMPs, provide case work to young people misusing alcohol and other drugs, provide education, work in prisons with pre-release prisoners, work with men whose employment is being impacted on by drug and alcohol use, the list goes on. It was in 2011 that as an organisation we started to recognise that pregnant women as drinkers were not visible in our services and a brief survey with AOD staff inquiring about their confidence and capacity to work with FASD demonstrated that although conscious of the issue, many lacked the skills and were not resourced to work with pregnant drinkers. There were not clear referral pathways and preventative work was similarly limited.

In 2012 we received a small amount of funding through the Australian government to develop the skills and capacity of our staff in working in this area. For two years we had a dedicated project working with women in urban and a number of remote communities to develop practices and resources that would strengthen our capacity to work with the client group. This work has a significant and ongoing impact on our organisation. (See attached posters which were part of this work).

1. The Prevalence in the Northern Territory of FASD

The prevalence of FASD in the Northern Territory cannot be definitively answered and speculation around the numbers can be derived from what the research is able to tell us and matching this with what we know about the Northern Territory. FASD's are more prevalent in some populations, disadvantaged populations and populations who have experienced dispossession and colonisation.

Social disadvantage constrains good decision making during pregnancy as women are often impacted on by addiction, cultural norms or pressure, lack of education, poverty, family violence, poor nutrition and tobacco use when pregnant also compounds the effects of maternal drinking, further making the link between social disadvantage and FASD.

Colonisation and dispossession has contributed to high levels of trauma and alcohol is often used as a way of coping. Trauma which has been experienced over generations is central to understanding poor health outcomes and contributes to the prevalence of FASD in the NT.

With this information, it is not surprising that FASD in the Aboriginal population is 100 times the rate of non-Aboriginal people in Australia. (Gray 2014).

Another significant risk factor for women is their relationship with men. Research (Parkes etal 2008) emphasises that women's drinking is impacted on by their partners alcohol consumption or from having fathers who are heavy drinkers. From a CCNT experience, binge drinking and heavy alcohol consumption by men is often mirrored by women, who become part of a drinking culture. Whereas 15 years ago women were primarily non-drinkers we are seeing less of a gap with women often consuming similar levels of alcohol to men. Further, Parkes cites a report that showed that 95% of women who had babies with a FASD revealed histories of domestic violence or sexual assault. Observations from our AOD service would have us understand that experience would be similar to the experience of vulnerable women in the NT.

There are numerous reports that clearly indicate that women, particularly Aboriginal women in the Northern Territory are vulnerable. The relationship between social disadvantage, colonisation and dispossession and poor alcohol policy impacts substantially on the experience of many Aboriginal women and we could expect that FASD's are very prevalent in this population group.

Alcohol dependence, illicit drug use and smoking cigarettes are all closely associated with social and economic disadvantage. The high levels of harmful AOD use continue to contribute to the gap between Indigenous and non-Indigenous wellbeing in Australia. Research (e.g. Silburn etal 2011) places maternal drinking as a foundational issue contributing to a pathway of vulnerability and disadvantage for Aboriginal children. Likewise a healthy pregnancy that includes reduced or no maternal drinking is a foundational pathway to resilience for Aboriginal children. Thus strategies for reducing FASD requires both broader conceptualisation of the underlying causes which support maternal drinking and concreted targeted strategies to respond to maternal drinkers.

There are no specialist diagnostic FASD services in the NT, and only two in the whole of Australia so it is difficult to be specific about actual numbers in the NT. Our experience of working in the community would indicate that women largely learn to live and adapt to having children who may have FASD and that it is not recognised as a particular disability and the cognitive, behavioural and emotional disorders are normalised. The enduring impacts are however experienced through low educational attainment, high levels of incarceration and poor health outcomes. Even without formal diagnoses or acknowledgement of FASD the prevalence of FASD in the Northern Territory is significant and requires a considered and sensitive response.

2. The Nature of the Injuries and Effects of FASD on its Sufferers

Foetal Alcohol Spectrum Disorder (FASD) is the term used to describe adverse outcomes caused by maternal exposure to alcohol. The most commonly seen form of this is Foetal Alcohol Syndrome (FAS). FASD is the result of women drinking at harmful levels during pregnancy especially chronic drinkers and binge drinkers. The effects of FASD are profound and generally have no cure, impacts of drinking during pregnancy include:

- Growth retardation
- Prenatal growth deficiency (small for gestational age)
- Post natal growth deficiency (unable to catch up even when given a good diet)
- Low weight to height ratio
- Developmental delay
- Learning and behaviour difficulties, intellectual disability and other defects
- Social difficulties

Long term impacts include mental health issues, disrupted education, take up of harmful AOD use, inappropriate behaviours (including inappropriate sexual behaviours), contact with the justice system, homelessness, no financial capabilities and inability to maintain positive relationships and employment difficulties. FASD in adults is often hidden or undiagnosed and is not acknowledged as a contributing factor in the lifelong difficulties that they experience.

AOD misuse clearly is the cause of significant health problems, contributes to unemployment and incarceration in Aboriginal communities. AOD misuse physically impacts on children when maternal drinkers create future generations of young Indigenous people who will struggle with a preventable disability and the gap between Indigenous and non-Indigenous people will continue to grow.

Action that the Government can take to reduce FASD based on Evidence and Consultation

CCNT recognises that responding to the issue of FASD in our community is complex and will need to be addressed at a number of levels. At a higher level we support government initiatives that address the social determinants of health and take into account the impacts of colonisation and dispossession. Alcohol Policy also requires revisiting in the context of balancing a range of communities needs and understanding the particular issues affecting women. We also encourage investment in the NGO AOD sector to increase capacity of drug and alcohol services to provide effective and responsive services.

Any response to FASD needs to incorporate the broader question as to 'why do women choose to drink during pregnancy?'. Women do not drink because they are reckless and intend to do harm, but rather are trapped in addiction, are in an unsupportive relationship, may be experiencing violence or mental health issues, are surrounded by a drinking culture, lack secure accommodation, have low educational attainment; the list can go on. Aboriginal women can be seen as a high risk group as they are more likely than other Australians to experience systemic and intergenerational levels of disadvantage meaning that good decision making is constrained by their life situation. Broader efforts in terms of investing in the housing and homelessness sector, health and education will support efforts to reduce the prevalence of FASD in our community. Increasing community based AOD services is essential.

Colonisation and dispossession continue to be a key factor in understanding and addressing FASD. In particular service provision needs to consider how responses incorporate healing, culture, are violence and trauma informed, community based and are participant and family directed (FASD evaluation). It is important that consultation with local communities drives FASD service delivery.

Alcohol policy in the NT, which is usually well intended often has unintended outcomes that negatively impact on FASD. Alcohol restrictions can support binge drinking and secretive drinking patterns and take people away from community and family supports. It also encourages drinking away from people who may ordinarily assist in intervening in negative behaviour, such as community Elders and supportive family members. Alcohol restriction can often have adverse effects on its intended beneficiaries, and we would encourage the Government to consider the impacts of alcohol restriction on young women.

While the broader community and health sector will have important roles to play in taking action to alleviate FASD, the NGO AOD sector in particular has an important role in education, prevention and treatment.

There is a current lack of investment in early intervention, prevention and family based AOD support in the NT, and no specialist women's AOD programs. Investing in this area will build capacity, expertise and knowledge about what works in the NT. The argument for a gender specific AOD service revolves around the relationship women have with alcohol and their shame attached to the impact it may be having on their unborn child.

CatholicCare NT supports the development of community driven and tailored responses to FASD. These need to be supported by well functioning and resourced alcohol and drug services. CatholicCare NT would encourage the Northern Territory Government to look at the emerging evidence in regards to good practice that is primarily coming from Canada. There is also some good emerging practice within Australia.

Best practice in approaching FASD prevention and service delivery includes:

Community Education and Community Development

- There is growing international evidence about effective community education for FASD. Developing community specific information, increase the awareness of harm caused on unborn children through drinking. This information would target both men and women, be non-stigmatising and encourage families to seek support if needed.
- Increasing capacity for AOD services to deliver school based education programs: Early intervention focusing on healthy relationships which includes a focus and increased awareness among young people about the harms associated with prenatal drinking.

Engaging Young Women in Child Bearing Age, with a focus on at Risk Populations

- Ensure that community based AOD services have incorporated FASD prevention and support as a service deliverable and are resourced to incorporate this. This would include targeted information for at risk families, this includes families where there are high levels of family violence and family conflict and DV associated alcohol use. Research indicates that engaging the broader family in dealing with drinking during pregnancy is more successful than just working with the drinker.

Support to Pregnant Women with Alcohol Dependency to Manage Pregnancy

- We would support the development of some targeted programs that provide specialised and intensive support for pregnant women with alcohol problems; this would include ongoing support to prevent further FASD pregnancies.

Capacity Building Strategies for the NGO AOD Sector

- Increasing collaborations and referral systems between clinics and our AOD services to better identify and provide intervention. Aboriginal pregnant women with AOD problems are more likely to have risk pregnancies and are less likely to seek assistance in relation to their AOD use. Through developing referral pathways and collaborative case management practices women will be identified earlier and can receive support throughout the life of the pregnancy to better manage their AOD use. This involves working with women to address the range of issues which may be impacting on their AOD use such as family violence, lack of

support, housing etc. Referral pathways will assist in women accessing appropriate social and health supports.

- Funding for resource development and community development initiatives which directly target FASD prevention.
- Support for NGO AOD services to build staff capacity to respond to FASD through incorporating FASD prevention strategies into policies and procedures, and through professional development of staff.

References:

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2. Parkes, T., Poole, N., Salmon, A., Greaves, L., & Urquhart, C. (2008). Double Exposure: A Better Practices Review on Alcohol Interventions during Pregnancy. Vancouver, BC: British Columbia Centre of Excellence for Women's Health.
3. Silburn SR., Nutton G., Arney F., Moss B., (2011). The First 5 years starting Early. Topical paper commissioned for the public consultation on the NT Early Childhood Plan. Darwin: NTG.