Top End Women's Legal Service Inc.

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Mr Russell Keith
Committee Secretary
Select Committee on Action to Prevent Foetal Alcohol Spectrum Disorder
GPO Box 3721
DARWIN NT 0801

By email: russell.keith@nt.gov.au

Dear Mr Keith,

Re: Submission to the inquiry into Foetal Alcohol Spectrum Disorder ('FASD')

We thank the Committee for providing us with the opportunity to make submissions in relation to this Inquiry.

Who we are

TEWLS is a community legal centre funded by the Commonwealth Attorney-General's Department to provide referrals, legal advice and casework to women in the Top End of the Northern Territory. TEWLS is an active member of the National Association of Community Legal Centres and Women's Legal Services Australia. TEWLS provides assistance in a number of areas of law including domestic and family violence, sexual assault, family law, debts, discrimination and compensation for victims of crime. We provide outreach services for culturally and linguistically diverse women, Aboriginal women in the town communities surrounding Darwin and to women in prison.

Terms of Reference

Prevalence of FASD

We note that to date the most comprehensive study that has been undertaken to ascertain the prevalence of FASD in the Northern Territory indicates 0.68 per 1000 of non-indigenous newborns and 1.87 per 1000 indigenous newborns suffer from FASD (Harris and Bucens, 2003). A study undertaken in Western Australia in 2000 found that the rates of FASD were similarly higher in indigenous children than their non-indigenous counterparts (Department of Health, 2010). Other countries have similarly found increased rates of FASD in indigenous children. In 2008 the first national study was conducted by survey, with the Australian Paediatric Surveillance Unit estimating that the prevalence nation-wide was only 0.58 per 100,000 live births (Elliot, Payne,

Morris, Haan, Bower, 2008). In global terms, this is a mere one-tenth of the reported cases of FASD in non-indigenous communities worldwide, raising the concern of diagnosis (D.E.H., 2010). There is no nationally agreed upon diagnostic criteria, and diagnosis is often heavily influenced by facial feature association that does not take into account racial differences, which can potentially result in misclassification (Pyettfor, 2007). Further, overlap of symptoms with other conditions such as autism, epilepsy and Attention Deficit Hyperactivity Disorder (ADHD) can result in misdiagnosis, and thus influence findings.

Effects on its sufferers

The effects on FASD sufferers are immense and varied, including but not limited to: intellectual disability, cognitive impairment, impulse control problems, central nervous system problems, developmental delays and learning difficulties (Linder, 2005). The broader effects can include interaction with the Criminal Justice System, the prevalence of which is unknown in the Northern Territory. The Aboriginal Disability Justice Campaign estimates approximately 30 people a year are detained in W.A. jails alone 'because they are mentally impaired and unfit to plead' (Mills and Smale, ABC, 2014). Dr Sharman Stone conservatively estimates a minimum of 30 people with FASD are incarcerated annually in Australia (Hon. Dr Sharman Stone, 2014). This is painfully evident in the recent case of Rosie-Anne Fulton, a Territory woman by birth who is currently being detained in W.A., has not been convicted of an offence, is incapable of pleading due to cognitive impairment and has been refused release to return to her hometown Alice Springs (Hon. Dr Sharman Stone, 2014). We are certain that this is by no means an isolated incident. The Telethon Institute for Child Health Research is currently undertaking research into the prevalence of FASD in young offenders (Mills and Smale, ABC, 2014); however, no such study has been undertaken into the prevalence amongst adults in the Northern Territory. We similarly have a limited understanding of FASD sufferers who fall pregnant and the resultant social and cultural effects on the next generation.

What actions the government can take to reduce this disorder

To determine what action can be taken by the government to address this disorder, it is first necessary to understand why it happens. The social and economic determinants of alcohol use by women in the Northern Territory must therefore be explored.

It is a common experience of our clients to abuse alcohol (and drugs) to internalise and thus cope with their experiences of trauma. This is particularly evident in clients who have experienced ongoing domestic violence or have been the victims of sexual assault and have difficulty in accessing ongoing support services for depression, anxiety and Post Traumatic Stress Disorder, in addition to experiencing poverty. With additional barriers such as cultural, linguistic and geographical location, Indigenous women can struggle to escape the cycle of violence.

The affordability of housing and the long priority wait lists for Territory Housing and Yilli housing mean that victims of domestic violence often do not have the opportunity of leaving an abusive relationship and simultaneously finding stable housing that is conveniently located to schooling for their children. Cultural obligations are cited by women as reasons to stay in the relationship, regardless of men breaching cultural obligations by being perpetrators of domestic violence. Our clients often demonstrate stronger connections to their cultural obligations than their male counterparts and look to their family and community for moral support. These women are often faced with the impossible situation of leaving the only external support structures they have ever known and moving away with no support, limited employment opportunities and no access to childcare, while the perpetrator stays put.

Case Study (no real names used)

Kate grew up in a community just out of Darwin. She completed all her schooling as well as her higher education there with her brothers and sisters. Kate obtained full-time employment in her community and entered into a customary law marriage at the age of 18. Kate rarely left her community as she had everything she needed. Kate and her new husband Scott lived happily together for two years and shortly thereafter had their first child Jack. During this time Scott started to become verbally abusive and emotionally abusive and eventually physically abusive, often in front of Jack. Kate spoke with her mother who organised a culturally appropriate mediation to talk out the problems they had and stop the violence.

Scott didn't stop. He became angry that Kate had told others about their family business and began to beat her more as well as sexually abuse her. Kate became depressed and developed anxiety to the point that she couldn't sleep properly. Kate was overwhelmed with the idea of having to leave everything she had ever known simply to be safe, and with the prospect of no roof over her head, job or social support, she stayed put. Sometimes when the violence got bad she would stay with her mum, but whenever Scott came looking for her people would always tell him where she was. After all, she is his wife. Scott spent a lot of the family money on alcohol and Kate, feeling that she had no escape, took to drinking also.

Kate became pregnant once again. She continued to have difficulty sleeping. During her second trimester Scott beat her for 'being cheeky' and she miscarried the next day. Kate's depression grew and she couldn't work anymore. She tried to move in with her mother but her own son began to tell her she was 'worthless' and belonged to his father. He wanted to go home. Kate had a non-contact Domestic Violence Order (DVO) against Scott that he regularly breached, just to remind her who was in control of the relationship. Kate eventually went back to Scott and rarely leaves the house. There are no counselling services she can access at the community. She continues to drink as an escape from the violence that has become her reality.

Criminalising drinking at dangerous levels during pregnancy

We are deeply concerned with the NT Government's consideration of criminalising women who drink at dangerous levels during pregnancy and oppose the proposal for the following reasons:

1. Research into the area of FASD indicates that there is no correlation between deterrence and criminalisation. In fact, women who are suffering from substance abuse addiction are less likely to access health services they desperately need for both themselves and the foetus for fear of the consequences (Poole, 2014). This is particularly evident in Aboriginal women and girls who are already less likely to access health services. This would then have the disastrous consequence of placing both mother and their child's wellbeing at serious risk.
2. It is not a cost-effective measure to address the issue, as it will lead to greater rates of incarceration and have little to no effect on deterrence (Poole, 2014). The solution to this, is to introduce strategies at the outset such as community education and support.
3. Health professionals are reluctant to diagnose FASD due to the potential of over-lap with other conditions and the lack of a uniform diagnostic tool that incorporates racial differentiation in facial characteristics. There is further concern of the stigma attached to misdiagnosis and the lack of funding, specialist services and other resources to address the issue once diagnosed, resulting in professionals addressing symptoms as opposed to the condition. This reluctance will be further exacerbated if criminalisation were to occur (Dr Keith Edwards, 2014).
4. Given that most women are social drinkers, and many pregnancies are unplanned (it is estimated to be approximately 50% (Department of Health, 2010), women often have no idea that they are pregnant and continue to drink, particularly during their first trimester of pregnancy.
5. Health professionals acknowledge that there is no minimum quantity of alcohol that can be consumed to cause the condition- it is dependent on a variety of factors such as nutrition, age, epigenetics and maternal stress (ABC Health and Wellbeing, 2014). A lack of uniform recommendations from health professionals has caused confusion amongst women as to how much they can safely drink when pregnant.
6. The stigma attached to diagnosis will solely rest with the mother and will make it more difficult to access services. These women often drink to cope with difficult situations including domestic violence, poverty, overcrowding and isolation, and if struggling with addictions themselves, incarceration could have dire consequences on her wellbeing as well as any other family members she is responsible for.
7. The idea of criminalising pregnant women who engage in behaviour associated with their mental illnesses such as anorexia nervosa would be absurd to most community members, and bad public policy. Alcoholism is regarded as a mental illness and it should not be treated differently. Suffering from a mental health condition is difficult enough without the added issue of pregnancy. It is important to remember that

no law will reverse the damage already done to a foetus. Other conditions such as smoking, heavy exercise and obesity during pregnancy can cause a multitude of issues to the foetus as well as the mother. Will these be criminalised too? We are concerned that should this law be enacted, it would reflect a decline in acceptable legal intervention in a social and health problem, and create a minefield of potential issues, including 'where next' in an attempt to control alcohol consumption.

8. We have submitted recommendations to the Northern Territory Government in relation to reform of the *Medical Services Act* ('the Act') so women have access to the RU486 (abortion pill) as well as safe and accessible facilities to procure an abortion. We have had clients who have experienced sexual assault and/or domestic violence that has resulted in pregnancy. Some of these women suffer from conditions such as alcoholism and do not wish to undertake an invasive procedure to have an abortion. Access to these services may reduce the incidence of FASD.
9. Research conducted in the United States indicates that women from minority groups, are more likely to be subject to rigorous scanning in comparison to their Caucasian counterparts. This may, indicate that the implementation of laws to address the issue as well as diagnosis of FASD indicating a greater prevalence in minority groups is fraught with contention and confusion (Poole, 2014).
10. This issue cannot be addressed in isolation. It is everyone's responsibility to provide a supportive environment that is free from violence for pregnant women and children, particularly fathers-to-be. Research indicates greater difficulty in breaking addiction with partners and family members continuing their addiction (Poole, 2014). Men need to take responsibility for this issue as well. Further, research indicates that the stress of breaking an addiction by going 'cold turkey' can cause greater stress to the pregnant woman and consequently the foetus.
11. Enacting child protection legislation to protect the rights of the unborn child can have the undesired effect of isolating the mother from productive and meaningful interactions with her child. It can lead to feelings of 'maternal failure' and women may disengage from the process altogether (Poole, 2014).
12. Alcohol consumption is legal. Pregnant women being subject to different laws could be construed as discriminatory.
13. How will this be enforced? Will there be mandatory reporting, will women be subject to routine scans, including breathalyzer tests against their will and if these are inconclusive, involuntary blood tests? Will this not infringe on pregnant women's sovereignty over their own bodies, and cause added stress during what can also be a very stressful and difficult time for a woman. We note that mandatory drug testing was struck down by the Supreme Court of the United States and deemed unconstitutional (Linder, 2005).
14. In Wisconsin, women can be taken into protective custody pursuant to child welfare legislation (Linder, 2005). Wisconsin is clearly a conservative state and the reproductive rights of women have been

acknowledged as some of the worst in the United States. There are currently 2 abortion clinics open in this state as they recently imposed further restrictions on doctors performing this procedure including acquiring admitting privileges at hospitals and mandatory ultrasounds. Injunctive relief has even been sought to pause the admitting privileges (Basset, 2013). Why are we following the conservative jurisdictions, which support child protection legislation 'kicking in' from conception? This is a complicated area of law, which warrants consideration of third party action to harm fetuses and/or pregnant women, and associated civil and criminal liabilities.

15. American studies have indicated women from minority groups are more likely to be tested for alcohol misuse than white women and such legislation would affect women from low-income groups and minority groups more so than other socio-economic and racial groups (Poole, 2014).

    Alcohol related crime is undeniably prevalent across the nation, especially amongst the youth in the Northern Territory. This issue also requires a multi-faceted approach, which cannot be addressed in isolation including minors who have been the victims of rape.

Recommendations

1. That a portion of the Northern Territory Tackling Alcohol Abuse Community Fund be allocated to address this issue (Department of Social Services, 2014).
2. That programs, including volunteer programs be established through the Federal Government's 'work for welfare' scheme, to create awareness campaigns, education programs (including within schools) and mentoring systems.
3. Reconsideration of health policy guidelines in the Northern Territory to ensure a uniform approach is taken to addressing this issue by health professionals.
4. Outreach services, which provide holistic women's health support and can be accessed confidentially by women, including sustained engagement, home visits and follow-up (Poole, 2014).
5. An intensive three year mentoring program which women at risk can access (Poole, 2014).
6. Warning labels/ flyers are administered with alcohol to raise awareness including disclaimers to ensure consumers are aware and take ownership of the issue. It is not sufficient to make these standards optional, unlike the burden already placed upon the tobacco industry.
7. That culturally appropriate mediation techniques be utilised to create care plans for families dealing with a multitude of issues. We note there has been calls for customary disciplinary action to be taken, however we are unsure what this would entail (Stewart, Lateline, 2014).
8. A trial childcare centre be created based off the model of the Jean Tweed Centre in Canada, which has had positive outcomes in reducing the incidence of FASD in families at risk (Poole, 2014). This is a holistic approach that includes the whole family and

teaches parenting techniques, nutrition and incorporates play therapy and other techniques to create stronger families.

9. That a roll-out of programs such as the "Anyinginyi foetal alcohol spectrum disorder Tenant Creek" FASD program and programs such as the Ord Valley Aboriginal Health Service FASD prevention program should be given further consideration with a view to expansion of this project throughout Australia, particularly in the Northern Territory (Anyinginyi Health Aboriginal Corporation, 2012; Australian Indigenous Health Info Net 2014).

In sum the cost benefit of incorporating positive, evaluated methods, such as education, support and care at the outset to reduce the incidence of FASD as opposed to criminalisation is substantial. We acknowledge the importance of addressing this issue and commend the NT Government's initiative in instigating this inquiry. However, criminalising this behaviour is not the answer. The law cannot simply be expected to step in to address every issue that has long been left unchecked or there has been repeated systems or program, failures along the way.

We thank the Committee for the opportunity to provide input into this consultation and invite further opportunities to consult in relation to these important issues. Should you require further information please do not hesitate to contact Nicki Petrou or Aditi Srinivas.

Yours Sincerely,
TOP END WOMEN'S LEGAL SERVICE INC.

Nicki Petrou
Managing Solicitor

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