

Inquiry Into Alcohol Toll Reduction Bill
2007

Senate Enquiry 2008

Submission to the Senate

**King Edward Memorial Hospital for Women.
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Background

Pregnancy is a window of opportunity through which to address alcohol misuse. It is important to note that often alcohol misuse cannot in itself be recognised in isolation to other illicit substance misuse issues as often the attendees to the WANDAS service at King Edward Memorial Hospital are problematic poly substance misusing clients. Women who are pregnant or who may become pregnant are a high priority for intervention to reduce drug use (including alcohol use) (National Clinical Guidelines for the management of drug use during pregnancy, birth and the early development years of the newborn, 2006). Like most women, alcohol misusing women's primary concern is for the unborn children. Increasing numbers of women are seeking help for problematic substance misuse when pregnancy is confirmed. In addition to the problems associated with substance misuse there are also complex psychosocial problems, which need to be addressed.

The issue of alcohol misuse during pregnancy raises, dilemmas with respect to the way the problem is conceptualised and for policy development. The concept that the developing foetus and the subsequent child may be harmed by alcohol use during the pregnancy tends to lead to attitudes that sanction these women, marginalise them and bring them into both the criminal justice and the child protection system. As a result these women are stigmatised and have a fear of having their children removed from them. These are potent barriers to obtaining support services, treatment and essential health and obstetric care.

Within this context, it is important to emphasise the health impact on Indigenous women and their children as their numbers in the justice and child protection system is over-represented.

It is the view of the health practitioners in forwarding this submission that alcohol/substance misuse in pregnancy is a public health problem. It is our hope that a national consensus can be achieved to develop policies and practices that treat these women and their children in a fair and unbiased way.

This submission is also predicated on the assumption that a harm reduction model is the most appropriate way to manage the care of pregnant women who are misusing alcohol.

WOMEN AND NEWBORN DRUG AND ALCOHOL SERVICE (WANDAS)

In Western Australia tertiary level sub specialist multi disciplinary care for alcohol/substance misusing women is provided at a specialist ante-natal clinic at King Edward Memorial Hospital. The service was established in 1991 in response to women who were misusing alcohol/ illicit substances and not attending for ante-natal care. A specialist clinic was established consisting of an obstetrician and midwife, within 12 months this had expanded to a drug and alcohol worker and a social worker. Resources have always been

limited. In recent years key stakeholders have increased their involvement and KEMH now has a multi-disciplinary clinic once weekly consisting of:

Specialist Obstetrician

Clinical Midwife Consultant

2 midwives

Drug and alcohol worker (Next Step and Aboriginal Alcohol and Drug Service)

Psychiatrist Registrar

Dietician

Parent craft worker

Non Government Agencies

2 Social Workers

The number of referrals to the clinic has increase threefold since 2004. Resources are desperately needed to expand the service to meet the needs of pregnant women who are using alcohol/misusing illicit substances

Creating a robust service is of optimum importance to care effectively for alcohol misusing pregnant women in Western Australia. KEMH was involved in the development and publishing of the National Clinical Guidelines of the Management of Drug Use during Pregnancy, Birth and the Early Development Years of the newborn (commissioned by the ministerial council on drug strategy 2006). These guidelines are intended to support a range of HealthCare Workers caring for pregnant substance using women, and are based on the best currently available evidence. The guidelines support our ethos that Multi Disciplinary teams working collaboratively can achieve optimal pregnancy, birth and parenting outcomes, for each woman and her family. International and National best practise supports a multi disciplinary care team approach for all pregnant women with problematic alcohol use. Whilst this is available in metropolitan tertiary medical facilities it is lacking in rural and remote areas.

Statistics

Rossett and Weiner found that 5-10% of pregnant women drank at high levels enough to place their fetus at risk

Currently 14% of WANDAs attendees recognise alcohol their main problematic substance of choice

The financial, social and personal cost to families who have a member problematically misusing alcohol and other substances, including the impact of drug induced psychosis or other mental disorders.

Alcohol misuse during Pregnancy and the Infant

Adverse affects of fetal development from alcohol use during pregnancy is not an uncommon problem, but accurate information detailing the incidence and type of use in pregnancy and in parents following the birth of their babies is not available as this information must be voluntarily given.

Babies who come from alcohol and drug affected pregnancies may well be at risk of other adverse events such as increased rates of sudden infant death syndrome and long term neurodevelopment difficulties (Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorder). Milder forms of withdrawal may result in the baby being difficult to settle, difficult to feed and add to the stresses these often fragile families face. The babies from alcohol and drug affected pregnancies and with alcohol and drug affected parents remain at potential risk of neglect and other forms of child abuse. The ongoing care for these babies as they grow up is at present fragmented and many probably do not receive support services.

The babies and children are vulnerable and remain at potential risk for harm for as long as their parents take misuse alcohol. Ongoing advocacy for babies and children of alcohol and drug affected parents is needed to ensure they are not harmed from neglect or other forms of child abuse. Ideally this advocacy comes from a community based outlook as these children are part of our community. It may be more appropriate that this advocacy be performed by a separate organisation to the one that follows the parents to avoid conflicting parent and child interests. However, an argument can be made for a single unified support organisation that would help these families rather than the highly fragmented services that exist currently.

More research into the effects of drug use on children and families to help better direct services.

Alcohol/Substance use in Pregnancy and Mental Health

Existing services do not adequately manage mothers who have a dual diagnosis of mental illness and alcohol/substance misuse issues. Alcohol is recognised depressant and women attending the service with alcohol misuse issues will often have associated psychiatric problems such as depression related to their alcohol misuse.

These mothers are often separated from their infants and this seriously compromises the attachment process and the development of their children.

Services dealing with mental health and alcohol/substance misuse use often view the Mother primarily as their client and little, if any consideration is given to the welfare of the newborn child or the other children in the home, who will most likely experience adverse outcomes due to their parent's difficulties.

Evidence now suggests that alcohol and substance use among patients with mental disorders must be considered as usual rather than exceptional. People with co-morbidity problems present on a continuum of presenting problems.¹ Women attending the clinic with mental health issues constitute approximately 30 % of attendees to WANDAS Clinic. Mental illness is the leading cause for non- fatal burden of disease and injury in Australia. Women with Mental Health issues have difficulties accessing available treatment .In women with co-morbidity this poses further difficulties in accessing substance counselling. Both of these issues are compounded by services placing exclusion criteria on mental health illness or substance abuse use problems. Community mental health services often insist that these women address their substance use issues prior to accepting them into their service.

Correlating with the ‘gold standard’ approach to resolving these issues, Topp has highlighted themes which must be addressed to create a robust HealthCare system which meets the needs of this vulnerable client group, this includes:

- Promotion of prevention and early intervention
- Integrating and improving the health care system, in particular links between services.
- Participation in the community including out reach services.
- Appropriate inpatient facilities for mothers (and their infants) with psychosis and other serious mental health illness and their infants

Alcohol/Substance Use in Pregnancy and Medical Issues

Women who use misuse alcohol and illicit substances during pregnancy are also more likely to have complex medical problems. Often relating to health problems affecting liver function, vitamin deficiency and anaemia.

Optimising their health for the pregnancy and reduction of severe complications means that they need the expertise of a range of sub specialist physicians.

Periodontal disease has been shown to have a significant negative impact on health and may increase the risk of preterm birth. Poor dental health is a significant issue for a large numbers of drug dependent women particularly those on opiate substitution programs. Currently there is a critical lack of accessible dental services available to these women.

Pregnancies of mothers who continue to use alcohol are high risk pregnancies with an increased incidence of low birth weight, prematurity and FAS/FASD.

Note: These conditions are preventable

¹ Drug and Alcohol Office. Dual Diagnosis Resource Kit. 2006.

In order to optimise the pregnancy care of women who are misusing alcohol, it is important to ensure their medical care is provided as much as possible on a one stop basis. This also facilitates coordination of the care, reduces duplication, and allows for better prioritisation of need thus improving the efficiency of care and subsequently the cost.

Alcohol/Substance Use in Pregnancy and Social problems

In 2004/05 the Social Work Department was involved with approximately 300 women who had delivered infants at King Edward Memorial Hospital who were at high risk- 80% of those with substance use problems also had domestic violence. These psycho-social problems were assessed by the Social Work Department as a risk to their parenting. Nearly 90% of these women have the additional burden of poverty related factors such as chronic debt, unstable living conditions and chronic homelessness.

In 2005/06 the number of women requiring social work services had increased to 430 women. While alcohol/substance use problems trigger a chaotic lifestyle, difficulty in functioning, chronic homelessness and a strain on family support, domestic violence and mental health issues are more potent destabilising co-morbidities

Ways to strengthen families who are coping with a member (s) using illicit substances

Every year an increasing number of infants are drawn into the welfare net either through statutory action with babies placed in foster care or into their grandparents' and other relatives' care. However about two-thirds of women seen by Social Workers fall below the threshold of high risk requiring statutory intervention. Alcohol and Substance use is not always a clear indicator of a parents' lack of commitment to their child and the preserving of family is important where at all possible. Therefore in order to prevent deterioration in functioning and strengthen their capacity to parent, referral to external community agencies for their long-term needs is a common and essential component of good practice.

A quality improvement project was therefore designed and undertaken in the Social Work Department with the aims of:

1. Understanding the supports and barriers to effective inter-agency discharge planning for vulnerable parents of newborns.
2. Developing a model for effective continuum of care in collaboration with key agencies.
3. Building the capacity for inter-agency collaboration and engagement by key community agencies with KEMH clients.

46 patients were recruited over a 3 month period and data was obtained on 80% of those recruited. The findings at 3 months post-discharge of the patient and her newborn were:

- a) Only a quarter of all referrals remained active with community agencies and
- b) Seventy percent of clients were not receiving a service from any of the agencies to which they were referred.²

40% of the women who had been recruited had substance use problems, 65% had mental health issues and 58% had been identified as having a history of poor parenting of their existing children. These women were at the lower end of risk and their situation was considered not high risk enough to warrant a referral to the child welfare authorities. **However, the experience of the social workers in this Hospital is that when these women present for subsequent pregnancies they had accumulated more risk factors and their substance use comes to foreground.** Other associated sequelae such as their mental health problems and homelessness have also intensified and by this stage the intervention of child welfare authorities becomes necessary. A number of women in the above study who had received no services from the agency to which they were referred reported no change in the risk factors that precipitated the referral and some reported an increase in stress and additional risk factors within 3 months.

Factors Associated with successful community based support:

1. Agencies still providing a service at three months had particular service delivery models, namely an intensive, home-visiting service with weekly, face-to-face contact.
2. Clients identified a non-judgemental attitude on behalf of the community based worker as necessary to their acceptance of these services.
3. Clients indicated the 'hands-on' nature of these services had been helpful, as had their practical assistance and information.
4. Transport and financial restrictions were identified by all groups as being significant barriers to accessing services. These are very real barriers that can make keeping appointments virtually impossible. A lack of child-care and the very job of caring for a newborn were also barriers. All of these factors mean that linking to practical resources is important, but also that home-visiting and outreach services may be of more use to this client group.
5. The vast majority of clients have a regular connection both to their Child Health Nurse and their General Practitioner.
6. Clients also identified family as being a significant source of support therefore engagement of extended family and particularly the father of

² Stratton,K, Harrison,C.,Lloyd.L. Complex Continuity of Care-Community Consultation..2006.

the baby would need to be considered as part of any service development.

Alcohol misusing women's needs often straddle agencies.³ Services are funded to serve a particular category of need- 'single input' service and each have different entry criteria depending on the funding imperative. These services have the effect of fragmenting the needs of the woman, her child and family, risks duplication, and allow organisations to pass the buck. They are also very confusing for referring agencies. Therefore a woman may be told that in order to be able to keep the baby in her care she will need to agree to a contract that requires her to submit to urine testing, attend therapy for her addiction, attend parent skills training, attend relationships counselling and resolve her chronic debt and housing issue. There may be 6 different agencies that she will need to attend usually using public transport while also fitting in the care of her baby and the stresses that generally accompany her life-style. The findings of the audit described above receive support in the literature and in other inquiries^{4 5} and the principles underpinning the recommendations for support services that are described below are universally recognised.

Impact on Families: Grandparents:

Increasingly grandparents take on the responsibility of the care of those infants born to women who have a problem substance use. Currently the only government funded agency (Wanslea Family Care) report that there are 167 grandparents who are involved with their program. The services provided are advocacy, access to information and support. There is a Grandparent Liaison officer at Centrelink whose role is to assist grandparents to obtain appropriate income support. The age group of these grandparents is 42-83 and they are caring for children as young as 1 week of age till 22 years of age. The grandparents' most pressing need is emotional support in caring for children who have special needs and some of these children have been traumatised by their earlier experiences.

The Recommendations reflect the need for continuity of care across all care providers and maternity services, with effective partnerships and a cohesive framework of intergovernmental and inter-sectoral articulation of standards of service delivery. Currently services operate as single projects rather than integrated as a state-wide system.

Ways to strengthen families who are coping with a member using illicit drugs

Recommendations

³ Scott, D... & Campbell, L (1994) Family centred practice in the interface between child welfare and the alcohol and drug field. Drug and Alcohol Review. 13, 447-454.

⁴ Hidden harm. Responding to the needs of Children of problem Drug . Executive Summary of the Report of an Inquiry by the Advisory Council on Misuse of Drugs. June 2003. Scotland.

⁵ Lester, B., Andreozzi, L., Appiah, L. Substance use in pregnancy: time for policy to catch up with research. Harm Reduction Journal 2003. 1:5.

The mandate of King Edward Memorial Hospital is to provide optimum care to the pregnant woman and her newborn. The Recommendations reflects this focus and we strongly belief that measures to support the alcohol misusing woman enhances her ability to contribute to the well-being of her family.

Therefore our recommendations are:

Education and Research

1. Funding for improved health education programs for the community and health professionals, both rural and metropolitan.
2. Education regarding the effects of alcohol misuse and pregnancy and families should be included in school health education programs.
3. The Commonwealth and associated funding agencies (eg NHMRC) should demonstrate increased interest and financial support for high quality research into longitudinal studies concerning children within these families and establishing best management practises.
4. In order to understand the scale of the problem experienced by children of problem substance users all agencies should record an agreed minimum consistent set of data about the children of the client's presenting to them
5. A programme of research should be developed in Australia to examine the impact of substance misuse on children at all life stages from conception to adolescents, this should include the evaluation of interventions aimed at improving their health and well being
6. Establishment of a national body to coordinate standardised care, research, education with out duplication of services
7. Continued funding to ensure that the National Clinical Guidelines for the Management of Drug Use in Pregnancy and Early Development Years of the Newborn can be maintained and updated to keep abreast of developments in best practice in this area.
8. Funding to link national data bases regarding the outcomes of pregnancies of substance using women with regard to congenital anomalies and pregnancy losses

Service Provision

9. Increased funding for adequate staffing of multi-disciplinary care teams and centres in each state and territory to provide optimum care for substance using pregnant women and their families.
10. Comprehensive, one-stop care programmes which are community based and multi-disciplinary should include family support services such as child care, medical and mental health care, parent role models, educational and vocational planning, crisis intervention and legal help. These programmes need to have an assertive out-reach component and be able to provide transportation to services. An expectation of relapse and skills for its management should be incorporated.

11. Universal mainstream services such as General Practitioners and Child Health Nurses need to be supported with training and extra resources as frontline universal services
12. Increased funding to facilitate adequate staffing for allied health support services, both rural and metropolitan
13. Increased funding to support improved travel and accommodation for women, especially those from rural and in WA, very remote, areas.
14. Improved funding to support Telemedicine facilities which may allow doctors in rural and remote areas to access a sub specialist consultation without the burden of travel and family separation for the patient in question.
15. Contraceptive services should be offered through drug and alcohol treatment services and pregnancy testing should be available to women on initial assessment.
16. Indigenous women have identified, a lack of cultural sensitivity,⁶ within health services, and this has been demonstrated to be a largest barrier to women accessing health services. We recommend increased funding to establish specialist outreach clinics to assist Indigenous women who require assistance coping with drug misuse issues in pregnancy.
17. Continuity of care for ongoing problems is better managed when the responsibility for ongoing support and treatment is identified to a particular service and person. This should be negotiated on a needs basis and where possible provided in ways, which meet the client's current need. In the majority of instances to ensure continuity of care, it may be that the General Practitioner has the primary, and in order for this recommendation to be successful Medicare rebate for this care should be considered.
18. Review the provision of the Maternity Payment as a lump-sum as this creates difficulties for some of these women.
19. Urgent attention is needed to make available low cost housing to this group of vulnerable families. These families additionally need support to enable them to maintain their tenancy.
20. Reducing harm to children as a result of problematic alcohol/substance misuse should be a national focus and should be included in national drug strategies
21. Funding for supported family accommodation in pregnancy, which will provide intervention in early pregnancy to support women with socio economic issues, parenting issues which includes a robust system of care for reintegration into the community with ongoing supporter active service, empowering

⁶ WA Health Aboriginal Cultural Perspective – Implementation Framework

22. Fathers of babies should be offered quick access to treatment matching that of pregnant women, this will improve outcome of women being able to abstain from using illicitly when partner
23. The family needs to be defined as the unit of treatment. Any treatment programme should include partners, siblings and other extended family especially grandparents. This model would present the opportunity of drawing in extended family as resources to support the child as well as providing the opportunity to tailor services to the complex and distinct needs of that family.
24. Appropriate income support or allowance to grandparents that recognise their special circumstances is needed. The Federal Government considers extending the eligibility for the Carer Allowance/Payment from Centrelink to grandparents.