Submission to

ACT Legislative Assembly Standing Committee on Health and Disability

From: Women's Centre for Health Matters Inc.

April 2008

A. Introduction

Women's Centre for Health Matters Inc (WCHM) works to improve the health and wellbeing of women in the ACT and region, with a focus on women who experience disadvantage. As women are the focus of WCHMs work, this submission looks at care and support for vulnerable women in the ACT.

This submission is based on WCHM research (summarised in Section B), a brief literature review, discussions with women from ACT services and networks, information from the 3rd International Congress on Women's Mental Health (Melbourne, March 2008) and on principles from three national and international standards and conventions.

These principles are:

- Universal Declaration of Human Rights, especially Article 25(2) which states that *motherhood and childhood are entitled to special care and assistance.*
- Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW), in particular Article 12(2) which ensures that women receive appropriate services in connection with pregnancy, confinement and the post-natal period, granting free services where necessary, as well as adequate nutrition during pregnancy and lactation.
- ACT Human Rights Act Section 8, which states that, *everyone is equal before the law and is entitled to the equal protection of the law without discrimination. In particular, everyone has the right to equal and effective protection against discrimination on any ground.*

B. Vulnerable women of the ACT

WCHM published a report in February 2008 *Marginalised and Isolated Women in the Australian Capital Territory*[1] which presents a range of data aimed at exploring the nature of women's marginalisation and isolation in the ACT. WCHM commissioned this research with the specific purpose of facilitating greater understanding of women's marginalisation and isolation in the ACT, and working towards improved support for women within this target group.

The first section of the report examines the concepts of marginalisation and isolation, and the risk factors that have been identified as prevalent amongst marginalised and isolated ACT women. It also provides estimates of the number of ACT women who are at risk of, or are experiencing marginalisation and isolation. Homelessness, poverty, drug and alcohol misuse, mental health issues, disabilities, violence, age, culturally and linguistically diverse backgrounds, and Aboriginal and Torres Strait Islander backgrounds are all identified as risk factors that may result in ACT women's marginalisation and isolation. In addition, women

[1] Maslen, Sarah (2008) *Marginalised and Isolated Women in the Australian Capital Territory: risk prevalence and service provision* Women's Centre for Health Matters Inc. Canberra.

who are primary carers, have been institutionalised, are at home with children, or have gambling problems have also been identified as being at risk.

Often women experience these risk factors concurrently, increasing the risk of their marginalisation and isolation. Due to a lack of accurate, gender-disaggregated data available for the ACT, and the concurrent experience of many risk factors, it is difficult to quantify the total number of women who are experiencing marginalisation and isolation.

While this report provides some estimates using a combination of statistical data, service access statistics and anecdotal information, further research[2] is currently being undertaken by WCHM using gender disaggregated data purchased from the Australian Bureau of Statistics (ABS).

The second section of this report provides an overview of the work WCHM is currently undertaking to support marginalised and isolated ACT women. In the ACT, women's services and the community sector at large have instituted numerous programs to support marginalised women in the ACT and reduce their social isolation. WCHM's current role within this framework is advocating for ACT women's health and wellbeing needs, as well as providing skills and social groups, secretariat and governance support for organisations that support marginalised and isolated women, and information on women's health and wellbeing.

The third section examines current gaps in service provision and policy that exist with relation to marginalised and isolated ACT women. Inadequate housing, transport, access to health care, and other services that support marginalised and isolated groups have all been identified as key areas that need to be addressed within the ACT.

Similarly, difficulty in supporting women with complex needs, access to affordable health and wellbeing professionals, and the provision of information on health and wellbeing for marginalised and isolated women are identified as areas that require policy development and further services.

C. Antenatal and postnatal care and support services currently available for vulnerable women and their children – strengths and weaknesses

Please note that this section is not a comprehensive discussion of all antenatal and postnatal care and support services currently available for vulnerable women and their children in the ACT. Rather it is the presentation of a range of issues as raised by women consulted for this submission.

The understanding amongst women consulted in the preparation of this submission is that there are many good government and community services in the ACT, but there are insufficient resources, lack of collaboration across sectors

[2] This report is expected to be published in June 2008

and a service system that is mainly confined to the traditional working week (i.e. 9am-5pm, Monday to Friday).

ACT Health

ACT Health is a major provider of antenatal and postnatal care and support for vulnerable women.

Feedback from women consulted for this submission is that:

- Many vulnerable women do not access maternal and child care clinics for a number of reasons including:
    - Their perception that they do not fit the target group;
    - Feeling uncomfortable in mixing with women who appear not to have complex needs;
    - It may be difficult to access information about the services offered because of their complex needs.
- There is limited follow up if women do not keep appointments.
- Midwives currently provide a range of services including information, support, education and counselling.
- There is a complex form to complete when a woman first visits the hospital. This includes questions in relation to issues such as drug and alcohol use and mental health status, all of which assist in assessing a woman's individual needs.
- There is no support to assist women in negotiating the hospital system if they do not understand it.
- Maternity and Child Health nurses are critical in picking up issues with mothers and their children.

The report, *Maternal and Perinatal Health in the ACT*[3]*,* provides information on the relevance to the inquiry by the Standing Committee on Health and Disability. We would like to highlight some of that information.

Antenatal Care is important for providing comprehensive preventative care, promotion of normal pregnancy, detection and treatment of existing diseases and early detection and management of complications. According to the report, 78.3% of women presented for their first antenatal visit in the less than 20 weeks gestation period. 16% of women presented for their first antenatal visit at more than 20 weeks gestation. A question arises from this statistic as to the other 5.7% of women. Did they access antenatal services at all? If not, it is likely they received little information about the services available to them. Similarly 87.6% of women reported having at least one ultrasound during their pregnancy. The other

[3] Population Health Research Centre ACT Health (December 2007) *Maternal and Perinatal Health in the ACT 2000-2004* Health Series Number 44 ACT Health

12.4% presumably either didn't have an ultrasound, or didn't provide this information. This is a significant number, and a cause for concern.

A variety of services are available to women after leaving the hospital, including Midcall (an early discharge program) and Canberra Midwifery Program (CMP). 51.6% of women were referred to Midcall or CMP for additional care at home.

ACT Maternal Perinatal Information Network exists with membership representatives from each of the ACT birthing facilities including hospitals, child, family and youth services, Health Policy Unit, ATSI Health Unit, consumer representatives and a homebirth midwife. The Network aims to encourage and facilitate communication between bodies and organisations and to improve data collection.

Care and Protection Issues

Many issues relating to Care and Protection Services in the ACT and the impact of interventions on vulnerable mothers were raised by women in discussions for this submission. It is clear that many vulnerable women who have previously had children removed are fearful of having a child removed again. The Care and Protection system can be seen as adversarial, punitive and judgmental. This can mean that when women need support, they may not access the system due to fear. It is important that there are considerations for care and support to the mother as well as for protecting the child.

It was noted that if women currently have a good relationship with their Care and Protection Worker it is easier to raise issues, and if the child is removed working towards restoration is a more positive and easier process.

Another point raised is that the system is not adequately transparent. Women do not know what the assessment and criteria is for keeping their children, removal of children, restoration of relationships and regaining custody. There is a need for clearly identified procedures and goals to be agreed to and understood by the woman.

Organisations consulted raised the issue that when a child is removed from the mother, foster carers are offered support that is not offered to the parent (e.g. assistance with medical care, funds to purchase clothing, respite care). If this support was offered to the mother, it may be enough to assist her to maintain care for the child.

Community support

There is a wide range of support for vulnerable women in the ACT. This includes, but is not limited to:

- women specific services such as homelessness services, Canberra Rape Crisis Centre, YWCA and WCHM
- community centres, such as Belconnen Community Services, Woden Community Services and Communities at Work

- self help organisations such as those supported by SHOUT and Women with Disabilities ACT
- services to women from culturally and linguistically diverse backgrounds, such as Migrant Resource Centre and Companion House
- services to people with disabilities that are not targeted specifically for women
- services to women with mental health issues that are not targeted specifically for women
- services to Aboriginal and Torres Strait Islander women such as Winnunga Nimmityjah Aboriginal Health Service
- health services such as general practitioners and other health professionals, including allied health.

However there are a number of issues which act as barriers to services including;

- insufficient capacity to provide support to all women requesting it
- long waiting periods
- tendency to respond to crisis, rather than provide early intervention support
- lack of holistic women centered support

Housing

Inadequate housing adds to the stress of vulnerable mothers. Amongst issues raised the following were identified:

- Housing in areas where there is a congregation of people with complex issues such as drug and alcohol addiction and/ mental health issues. It is identified that adequate safe housing is crucial for vulnerable women.
- Living upstairs in a block of flats, and having to carry babies, young children, prams etc. This difficulty is further increased if the child has a physical disability.
- Overcrowded housing is identified as a particular issue for refugee families.

Mental Health Support

Mothers with mental health issues who are admitted to ward 2N at Calvary Hospital are able to keep their baby with them if the baby is under 6 months old. No other provisions for mothers with mental health issues are available in relation to their children and hospital admission. It should be noted that the risk of separation is not as great if the woman has a partner or family to support and take care of children.

Professor Anne Buist gave a keynote address on *Maternal mental health* at the International Congress in Melbourne in March 2008. Professor Buist is a

Melbourne clinician and researcher in the area of postpartum psychiatric illnesses and womens mental health. Findings from her research are that:

- Suicide is the leading cause of maternal death
- Ante-natal depression has a higher impact on offspring than post-natal depression
- Women have said that they want professionals to continually ask how they are during pregnancy

Women with mental health issues who are required to take medication express the need to know more about the effects of that medication on their unborn child and also when breastfeeding.

Peri-natal mental health support is very limited. Women reported difficulties with accessing psychiatrists, counsellors and support services due to long waiting lists and not enough resources to support women who would benefit from the service.

The Maternal and Perinatal Health in the ACT[4] report provides some information on post-natal depression. The report states that 1 in 7 women suffer post-natal depression to some degree. Support services available include particularly the Post and Ante Natal Depression Support and Information (PANDSI) program. 88-110 support groups are held each year by this program, averaging 5-9 attendees per session. There are also 25-30 information presentations each year. It is not clear from the information if these programs are offered only in English. If so, a substantial number of vulnerable women could be left out of receiving important information. It is also unclear how women found out about the program, and if it is unlikely that vulnerable women would have been aware of the program's existence. A telephone support service is also offered, but may face the same issues of language barriers and an inability to be accessed by disadvantaged women.

Prison System

Women in prison and women with partners in prison have reported that there is not adequate provision for maintaining contact with their children. Prisons have at their discretion withdrawn visiting times, and care and protection services have stated to women that the visiting environment is not suitable for children. There is positive news however with the Alexander Maconochie Centre (AMC) being built and operated within a Human Rights model. This will include extended visiting times and an appropriate environment for children to visit their parent.

Women with partners who are detained in remand are not able to access support services until their partner is sentenced. This is problematic and women have reported an increased vulnerability for themselves and their children during this period.

[4] Population Health Research Centre ACT Health Op Cit

Refugees

Some refugee women state that they are afraid of accessing any service, as they are concerned about negative interventions. This results in some women not asking for assistance until very late in their pregnancy. The implications may be that if there are any complications, the provision of information, support and early intervention structures will not be in place.

Phone services, such as Health Direct are impossible for women with little or no English to access. The Translating and Interpreting Service (TIS) is not always able to access an interpreter in a particular language. At times women do not want to access TIS as the community they belong to could be very small; therefore the woman could be known to the interpreter and in turn the woman's confidentiality may be jeopardised.

Women who have children with a disability

Whatever their status before giving birth, women who have a child with a disability become vulnerable, and therefore their needs must be considered.

When a child is diagnosed with a disability in hospital, an allied health practitioner (e.g. physiotherapist or social worker) may provide support, following which the woman may be referred to Therapy ACT. Therapy ACT will accept referrals from any person concerned about the development of the child from birth onwards.

The genetic counselor at The Canberra Hospital provides useful information for women who have a child with a disability.

Women with a disability

In a submission to the Queensland Review of Maternity Services[5], Women with Disabilities Australia raised the following issues;

- Information, education and support about sex and sexuality is often limited for women with disabilities.
- Public perception of women with disabilities becoming pregnant and becoming mothers is negative.
- Supports available for women with disabilities who are pregnant are limited due to the negative images.
- Lack of support, information, resources and training coupled with the negative stereotyping of women with disabilities as mothers leads to questioning of parenting abilities and increased likelihood of removal of children.
- Heavy reliance on prenatal testing puts pressure on women to abort due to possible disability, regardless of accuracy of testing, and added pressure on women with genetic disabilities to get screened or abstain from having children.

[5] Web link http://wwda.org.au/matern.htm#three

D. Antenatal and postnatal care and support services needed for vulnerable women and their children

Many women do not have just one challenging issue that makes them vulnerable. It is easy for women with one issue to get into a cycle of difficulties. For example:

i).chronic pain may lead to depression which may lead to alcohol and drugs misuse

ii) a mental health issue may lead to unemployment which may result in living below the poverty line, and then in homelessness

iii) new mothers may experience domestic violence for the first time antenatally or postnatally; when relationships break down in situations like this women are vulnerable and there are many complicating factors. For example the woman may decide to flee but crisis accommodation is difficult to access, resulting in some women remaining in unsafe situations.

The system of antenatal and postnatal care that is needed for vulnerable women and their children is part of an integrated holistic women-centred health and wellbeing service system[6] (for all women) that encompasses the following characteristics:

- strengths based
- provides continuum of care
- collaboration and partnerships
- locally provided
- accessible to all women when they request support
- affordable to all women
- tailored to individual needs
- provides early intervention
- has an education/information component
- information is made available in a variety of formats and languages
- culturally appropriate
- provides support to groups and/or to individual women
- includes an outreach and follow-up component
- recognises the generational impact of vulnerability
- a work force that is trained in and understands integrated holistic women-centred service provision

[6] This system should include government services such as ACT Health, Disability ACT and Care and Protection Services, non government services such as women's crisis accommodation, community centres, recreation services and private services such as general practitioners.

In addition to the above characteristics, vulnerable women need:

- provision of suitable housing
- affordable child care
- adequate income support
- accessible community and public transport system

WCHM will continue to consult and conduct further research into health and well-being issues impacting on vulnerable women in the ACT.

WCHM acknowledges and recognises the importance of understanding and responding to barriers experienced by vulnerable women.

WCHM looks forward to the results of this inquiry and to continuing to work in collaboration with government, community and individual women of the ACT.

Appendix - Organisations contributing to this report

Women from the following organisations and networks contributed to this report:

- ACT Consumer Mental Health Network
- ACTCOSS
- ACT Women and Mental Health Working Group
- Advocacy for Inclusion
- Canberra Rape Crisis Centre
- Companion House
- Inanna Inc
- Karinya House
- Raja
- RSI and Overuse Injury Association of the ACT Inc
- Therapy ACT
- Women's Centre for Health Matters Inc.
- Women with Disabilities ACT
- YWCA of Canberra