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HCCA Submission on "What Women Want in Maternity Care", *ACT Maternity Shared Care Guidelines*

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The **Health Care Consumers' Association (HCCA) of the ACT** was formed over 30 years ago to provide a voice for consumers on local health issues and now provides opportunities for health care consumers in the ACT to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

- Consumer representation
- Consultations
- Training in health rights and navigating the health system
- Community forums
- Information sessions about health services
- Advocating for issues of concern to consumers

HCCA welcomes the opportunity to respond to the "What Women Want in Maternity Care" section of the ACT Health Directorate's *Maternity Shared Care* (MSC) *Guidelines.* In the past, HCCA has received strong indications of consumer support for shared care in maternity services and is pleased to see that the program is continuing to be comprehensively developed and implemented.

Core to consumer expectations of care provided within the health system is the **quality and safety of services**, including the **appropriateness of interventions** and the need for **good health information** to make **informed decisions**. Consumers have been the drivers of many reforms around quality and safety and HCCA would like maternity services to be considered within the framework of the six key dimensions of a quality health care system:

- Safety and risk minimisation
- Effectiveness: to be measured from the consumer perspective as well as the perspective of policy makers, population health and health professionals
- Appropriateness of interventions
- Consumer participation that enhances acceptability
- Access that is equitable and based on need
- Efficiency in resource utilisation

Specifically, HCCA was asked to support the review of Section 5 of the *MSC Guidelines,* entitled "What Women Want in Maternity Care". We have also included a

few comments on other sections of the guidelines based on the principles of consumer-centred care and feedback received from the HCCA membership. HCCA commends the ACT Health Directorate on making reference to the woman's overall well-being in multiple sections of the *MSC Guidelines*, but we are concerned that the section on "What Women Want" is very brief, and does not elaborate on the ways the issues discussed can be addressed by health care providers. If consumer-centred maternity care is to be safe and effective, these guidelines need to clearly state the specific ways in which these items will be incorporated into the maternity shared care process. The list of items included under each heading could be considerably expanded. HCCA has also suggested the addition of two further subheadings, namely 'Safety' and 'Respect'. HCCA's comments will appear in the following sections:

- those outlined original document (Information, Choice, Control, Personal Care);
- two new sections (Safety, Respect);
- proposed additional topics; and
- further comments.

Information

When providing clinical information to consumers, it is essential that health professionals recognise when a woman may require an interpreting service. Pregnancy can become very stressful for the woman if she is unsure of what maternity services and options are available to her. A lack of understanding can also lead to a loss of control over the birthing process, as she may be unable to voice her concerns or ask questions. As such, Culturally and Linguistically Diverse (CALD) issues are of crucial consideration within this context. The section should be reconfigured to include determining the need for an interpreter as part of using a language a woman understands.

It is also important to recognise that language will not be the only barrier to effective maternity care for women with culturally diverse backgrounds, as they are likely to have different views and beliefs about maternity practices. It may be worth noting in the *Guidelines* that health professionals need to be sensitive to these beliefs. If possible, extra provisions could be made to connect these families with health practitioners familiar with their cultural values and traditions. A broad social health model recognises the range of health determinants that impact on a woman's life and that can contribute to poor health outcomes for both the woman and her baby. A strict bio-medical approach is unlikely to adequately reflect or accommodate the broader health picture for women.

In 2009, HCCA ran a discussion group with the Asian Women's Friendship Group on perceptions of maternity services in Canberra. One of the strong messages was that women equated the ACT health system with the public health services in their own

countries, which are generally perceived as being inferior to private health services. This example demonstrates the need to develop better communication with CALD women to educate them in regard to the way the ACT health system works and the services available to them.

It may also be worth re-wording a number of the points in this section to reflect a more sensitive approach to discussions with pregnant women. For instance, HCCA suggests that health professionals could be advised to 'be patient' when answering the woman's questions, and to ensure that they do not come across as being coercive or threatening when promoting particular birthing options. It is also important to keep in mind that some mothers will be feeling particularly vulnerable at this time and so may be more likely to interpret language (verbal or physical) as being threatening.

When answering a woman's questions, it is important to consider what the woman may be asking unconsciously or be too embarrassed to discuss. For example, when asking about labour procedures, they may also be seeking information about how their privacy and dignity will be maintained and how they will be supported, not just the mechanics of procedures.

Finally, information should also be provided to the woman's partner if they are present during consultations. They should also be encouraged to ask any questions they may have so that they can become actively involved in the birthing process and effectively support the mother.

Choice

Health practitioners need to respect the woman's choice of prenatal, antenatal and postnatal models of care, and support the mother once her decision has been made. It is equally important that the mother is enabled to make an informed decision based on unbiased and accurate information. Along with the safety of the mother, these need to be of primary concern of maternity service providers. Although our members have expressed a range of views as to their preferred model of maternity care, the importance of choice and informed decision-making has been consistently emphasised.

Again, doctors need to ensure that their choice of language is non-threatening and supportive so as not to undermine the mother's confidence in her ability to make her own decisions.

In accordance with Commonwealth Government policy, women also have the right to choose where they have access to services, i.e. at home or in the hospital. As such, the woman must be given the option of giving birth at home if there are no anticipated delivery complications or serious safety concerns. We are keen to explore the establishment of a homebirth service within the Community Midwifery

Program similar to the hospital-supported home birth program in Northern New South Wales Local Health District

Control

HCCA has also received consumer feedback suggesting that where possible, the choices made by the woman need to be documented electronically and made available to other maternity service providers. In this way, if a woman needed to attend a new clinic or hospital for any reason, they would not have to repeat the decisions they have already made. The introduction of the Person Controlled Electronic Health Record (PCEHR) presents opportunities to facilitate this. It is also important that this section make reference to the woman's need for control over her own body.

Personal Care

The section beginning 'Ensure that the woman's whole being is considered during her pregnancy…' is a little ambiguous. While these are definitely important issues to be considered, it would be worth stating explicitly that the woman should be offered information and advice in this regard. For instance, referrals to mental health services should be offered if the woman is showing signs of emotional disturbance. It could also be noted that health practitioners need to consider the physical toll that consultations and appointments can take on the woman, particularly as they approach full term. To address this, some consultations could occur in community settings rather than the hospital campus.

Safety

Safety and quality of services is an integral aspect of consumer-centred care and is also of the utmost importance to women and their families. It is essential that all women have access to high quality maternity care in order to ensure the safety of both themselves and their babies. Women also need to be assured of the emphasis that is being placed on their safety and have the opportunity to question the safety of the services and medications they are receiving.

Respect

Although respect is referred to in the subsections of choice and control, HCCA believes that this is an important consideration that deserves separate recognition. This is consistent with the focus on respect in the Charter of Health Care Rights that has been endorsed by the ACT Government. All health care consumers have the right to be treated with respect by health care providers when they are receiving

treatment, requesting information and making decisions. Pregnant women need to be treated as 'well' individuals who are more than capable of participating in their own health care. This needs to be conveyed through health practitioner behaviour and language at all times.

These changes have been incorporated into a new version of Section 5, which has been included as an attachment with our feedback.

Additional topics

HCCA strongly supports the broadening of the guidelines to include topics such as genetic counselling and assisted pregnancy programs in the *MSC Guidelines*, as this promotes a more holistic approach to maternity care. Some of these suggested topics would also be appropriate for a separate section directed at health professionals on pre-natal care, which could also cover preparation for pregnancy and pre-conception information, as well as information about pregnancy itself, including nutrition. A number of the suggested topics are covered elsewhere in the *MSC Guidelines,* such as post-natal depression (Section 12.8), so it may be worthwhile to examine the document for duplication and internal consistency. The development of a consumer fact sheet around this and other key issues would be useful additions to those listed in Section 15.

There is also a pressing need for information and support to be provided to pregnant women with disabilities. In 2008, HCCA made a submission to the National Maternity Services Review. In our submission, we included reference to Women With Disabilities Australia (WWDA), who reported a significant increase in contact to the organisation from disabled women who were desperate to find any sort of information, support or service to assist them in their role as mothers and/or potential mothers[1]. Women contacted them asking about a range of issues including locating adaptable equipment, information on pregnancy and birth, and information about accessing assisted reproductive technologies. They consider this to be a major, unaddressed area.

HCCA has also attached a list of additional topics that may be worth including the revised edition based on consumer feedback. These include breathing techniques during labour, water-birthing options and exercise during pregnancy. HCCA also suggests that information be provided to consumers about the services available to them after having a baby, such as the Maternal and Child Health Clinics. Many consumers indicated that there was a disconnect in service provision after they had

[1] WWDA Policy Paper: 'The Role of Advocacy in Advancing the Human Rights of Women with Disabilities in Australia', April 2008

left the hospital. New mothers should be well informed about the plethora of services that they can access and assisted, if required, to make the necessary links.

Within the *Guidelines,* it would be useful to provide direction, via web link or title, of existing consumer information resources that address these additional topics. The web resources discussed in Section 13 are limited, which is an issue with the internet increasingly becoming the first point of contact for consumers in search of information.

Further comments

While we appreciate the importance of recognising consumer perspectives and needs, HCCA considers that for these to be effectively fulfilled, they need to be reflected throughout the entire *MSC Guidelines*. As a general comment, HCCA would like to suggest that wherever possible, reference be made to 'woman-centred care' as opposed to 'midwife-led' or any other terms used to describe maternity services.

Although we are aware that these guidelines are not designed to be distributed to consumers, the language used in the document still needs to be sensitive, as it may affect the way in which health professionals convey this information to the women they are working with. Front-line health service staff must be provided with the appropriate tools in order to communicate effectively with patients and consumers.

2. Communication and Access

In Communication and Access, the section entitled 'Difficulties, Violence, Grief and Loss' contains contact numbers for postnatal depression services. HCCA suggests that either the word 'difficulties' be changed or the contact number for mental health services be provided under a separate heading. Often feelings of guilt and failure are preventative factors for women seeking help for postnatal depression, making it important that phrasing reflects an understanding that the woman is in no way at fault for any 'difficulties' they are experiencing.

3.2. Additional Services for Vulnerable Women

HCCA notes that 'women who require extra social support' are being referred to the Step Ahead Program. If this section is intended to include those women at risk of social violence, it may be worth also referring these women to additional social support services so that they are able to continue their pregnancy safely and have access to protection for their child following the birth.

It is also understood that the Step Ahead Program is being recommended for CALD and young (under 21 years) women. However, this section does not explain how this

program works and can benefit these women. Information on this Program is also difficult to locate online. It may be worth considering including information for CALD and young women on the Step Ahead Program as well as any other services available to them for maternity care support. This information needs to be offered to pregnant women as early as possible so that they can gain access to appropriate services and receive adequate care throughout their pregnancy. HCCA recommends that this be provided in the form of additional fact sheets in the MSC guidelines.

6.1. Schedule of Visits (Preconception)

During the preconception phase of maternity care, it is important that GPs and other service providers be supportive towards women, who may be feeling apprehensive about fertility tests and questionnaires. For women who have difficulty conceiving, this can be a particularly stressful time. As such, any problems identified regarding conception need to be discussed with delicacy. It may also be worthwhile including a note in this section that women should be provided with referrals to assisted conception programs if required.

9. Miscarriage

At the beginning of this section, health professionals are advised to carefully consider their wording when discussing miscarriage. This is an important point and HCCA commends the ACT Health Directorate for including it. In order to assist with this process, it may be worth also including suggestions for more sensitive terminology.

11. Caesarean Sections

While HCCA understands that health professionals are working to monitor and reduce the number of caesarean births, it is also important that women who require an 'elective' caesarean are given the appropriate support and respect. On the other hand, women who are unable to have a vaginal birth may feel guilty or as though they are not a 'natural mother'. It is important to be sensitive of this issue when discussing caesareans.

12. Post Partum Care

It is essential to consider the impact that maternity services can have on determining the health of children. Maternity services, including preconception and antenatal care, are the foundations for a healthy start to life for children. It can reduce the risk of prematurity and also low birth weight. These account for the majority of infant deaths and childhood disabilities. Nurturing relationships build and strengthen children's brain architecture, which is particularly important in relation to the impact that antenatal and postnatal depression can have on infant development. It is important that maternity service providers support women during and after birth so that they are able to establish a strong bond with their baby. As such, we suggest that this section of the MSC Guidelines emphasise the importance of social support

for women and their babies. This could also include reference to breastfeeding support options, as this is another area that affects the health of children. Ultimately, we would like to see all Australian maternity facilities (public and private) accredited under the Baby Friendly Health Initiative (BFHI), which aims to ensure that all maternity facilities become centres of breastfeeding support[2].

Important Reference Documents

There are also a number of existing documents that these *Guidelines* should consult, such as the National Maternity Services Plan. In addition, the National Health and Medical Research Council's (NHMRC) *National Guidance on Maternity Care* outlines several key issues, including the importance of continuity of care in a collaborative approach to maternity services. The principle of woman-centred care allows for the maximisation of collaboration between services, and the NHMRC's document introduces the idea of the appointment of a 'maternity care coordinator' to facilitate transition between different services. The adoption of the framework outlined by this document provides sturdy base for development around delivering collaborative maternity care services to the highest level of quality and in the safest way possible. This document outlines a number of key principles, including the idea of a woman being able to nominate a 'maternity care coordinator' in order to maximise a women's continuity of care when using a collaborative maternity care approach. This idea is one that I think is important for consumers when considering one of the other principles, which is to place the woman at the centre of her own care when using a collaborative approach. My suggestion would be that reference could be made to these guiding principles early in the shared care guidelines as a useful framework for considering how to go about providing best-practice collaborative maternity care.

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[2] http://www.unicef.org/programme/breastfeeding/baby.htm Accessed 20 October 2008