Submission to:

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Submission to ACT Carers Charter Discussion Paper and Proposed Charter

from
the Women's Centre for Health Matters Inc. (WCHM)
and
the ACT Women and Mental Health Working Group (WMHWG)

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Introduction

The Women's Centre for Health Matters Inc. (WCHM) is a community-based organisation that works in the ACT and surrounding region to improve women's health and wellbeing. WCHM focuses on groups of women who experience disadvantage and uses social research, community development, advocacy and health promotion to empower these women to achieve the highest possible standard of health and wellbeing.

WCHM believes that health is determined not only by biological factors, but by a broad range of social, environmental and economic factors known as the ‘social determinants of health’. We acknowledge that that the environment and life circumstances that each woman experiences have a direct impact on her health, and in many cases, women’s poor health is rooted in social disadvantage. For these reasons, WCHM is committed to taking a ‘whole of life’ and social approach to women's health, that is also firmly situated within a human rights framework.

WCHM provides project and secretariat support to the ACT Women and Mental Health Working Group (WMHWG), whose membership comprises of local service providers, Government representatives, other community organisations and peak bodies, and women living with mental health issues. The ACT WMHWG was established in 2007 to provide a regular forum in which members could work together on matters impacting on women in order to provide improved outcomes for them, and to develop and maintain a full range of women friendly services.

Response to the Discussion paper on the *ACT Carers Charter*

The ACT WMHWG and WCHM overwhelmingly support the move by the ACT government to formally recognise the significant and diverse role that carers play within the ACT community through the ACT Carers Charter. Carers provide vital care and support for those in the community who are in need.

It is an undisputed fact that carers face significant hardship and disadvantage as a direct result of their care-giving responsibilities and we are delighted to see Commonwealth, State and Territory Governments developing and implementing targeted and effective program and policy initiatives that aim to promote better economic, social and health outcomes for carers.

> The caring role is one of immense social and economic value. Carers are the foundation of our health, aged care, palliative care and community care systems. As health care increasingly moves away from ‘institutional’ settings into the home and community, family carers shoulder greater responsibility for managing complex conditions and providing the emotional and physical support for the person for whom they are caring. No future health or community care system will be able to respond to changing

> demographics and health needs, clinical practices and societal influences in the long term without carers.'[1]

We welcome this opportunity to participate in this consultation process and in writing this submission, have chosen to limit our responses to those areas in which we have the most knowledge and expertise. This response is supported with evidence published by the Centre and its partners, including WMHWG, on the specific needs of ACT women, and with the feedback from a variety of ACT women and service providers through focus groups and other consultation processes.

1. Defining Carers

WCHM supports the ACT Government's aim to create an ACT Carers Charter that is applied to all caring relationships. However, this aim is not reflected in the official definition of carers used in the Discussion Paper.

WCHM agrees that any definition of carers should include "people who provide informal care and support to friends and relatives with needs associated with disability, ageing, ongoing physical or mental illness, or substance abuse, as well as Grandparents, Kinship Carers or Foster Carers who provide a caring role to children and young people."

This broad scope, however, is not captured in the Discussion Paper's official definition that a carer is "a person who provides unpaid primary care to someone else who is dependent on the person for ongoing care and assistance". WCHM believes that the former realisation—taken from the Discussion Paper—is more thorough, understandable and inclusive than the latter and recommends rethinking the official definition to be used in the ACT Carers Charter.

WCHM supports the priority focus on Carers from Culturally and Linguistically Diverse (CALD) backgrounds (#4), Aboriginal and Torres Strait Islander (ATSI) background (#5), Young Carers/Young Adult Carers (#6) and older Carers (#7).

However, the Charter does not adequately reflect or address the needs of carers who may themselves have disabilities and may require different care and support. The ACT Caring for Carers Policy already recognises that "carers may have a disability and may require assistance themselves". It is also essential that the Carers Charter recognises the need for access by carers with a disability to appropriate support or care themselves.

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[1] Carers Australia, 2010, Carers Week, http://www.carersweek.com.au/10/carers.html , accessed December 2010.

In 2006, over one-third (35%) of all carers reported that they themselves had a disability and over three-fifths (61%) of older carers (aged 65 years and over) said that they had a disability, and one-fifth of younger carers (aged 15–34 years) had a disability. [2]

The ACT Caring for Carers Policy already recognises that "carers may have a disability and may require assistance themselves". It is also essential that the Carers Charter recognises the need for access by carers with a disability to appropriate support or care themselves.

Recommendations

1. **To revise the definition of carers used in the proposed ACT Carers Charter to ensure that it is as inclusive, thorough and understandable as the Discussion Paper's official definition on page 7.**

2. **To include carers with a disability as a separate priority group with their own needs for support**.

2. Care-giving is a gendered phenomenon

WCHM would like to commend the ACT Government for its acknowledgment of the unique and diversifying circumstances of carers as a population group in comparison to non-carers, and in comparison to one another. We believe that in order to realise equitable outcomes for all Canberrans it is necessary and appropriate to do away with a 'one size fits all' approach, and the recognition of difference is the first step to achieving this goal.

Many Australians are responsible for caring in our community, however women take on the majority of informal caregiving and, in turn, shoulder most of the negative impacts. Unfortunately, we note that within the ACT Carers Charter Discussion Paper and Proposed Charter there is no acknowledgement of gender as a diversifying characteristic with its own unique implications to the lives of carers. **We strongly urge the Government to incorporate its inclusion**.

Care-giving is a gendered phenomenon. Women are the predominant care-givers in contemporary Australian society.[i] They provide care to their children, their ageing parents, friends and extended family, and are more likely to take on a caring role, and at

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[2] ABS - A profile of Carers in Australia 2008

an earlier age in comparison to men.[ii] The gendered nature of caring remains in contemporary Australian society despite record numbers of women accessing education and employment opportunities, and despite women's achievements in 'breaking the glass ceiling' and entering into a public sphere historically dominated and controlled by men.

In the ACT, women are often considered affluent and successful in contrast to women living in other states and territories. Despite this relative affluence, there are still significant pockets of disadvantage and marginalisation within our community. WCHM's role within the ACT NGO sector is to conduct research into the unique needs and experiences of these different groups of ACT women in order to properly quantify the extent of disadvantage; identify the barriers they experience in addressing their health and wellbeing from a social determinants perspective; identify the barriers to female representation in their local community and decision making processes; and better advocate and represent their needs.

Thirteen percent (2.6 million) of all Australians are carers and over half of these - 54 percent - are women.3 There are 18,300 women carers living in the ACT[iii] and 55.7% of primary carers are women.[iv] Preliminary data collected through a recent WCHM research project[4] support our assertion that the gendered nature of caring has a broader and more significant impact on ACT women, in comparison to men. Moreover, our research reiterates much of what we already know about carers, and particularly mental health carers, from a gender neutral perspective, i.e. that caring can often negatively impact on health and wellbeing[v], family functioning[vi], education and employment opportunities[vii] and future financial security.[viii]

> *Caring has consequences for people's lives, it restricts their opportunities, it imposes burdens, it can cause distress.* [ix]

In addition to these gender neutral outcomes, our research also points to gender-specific differences in the impact of caring on women. For example, social and cultural circumstances have a unique and specific impact upon women's health status. There is a strong inverse relationship between social status, and physical and mental health outcomes[x] and this greatly affects women, as in almost every society, women's status remains lower than men's. The social status of women carers in comparison to male carers is no exception. Women carers' low status is reflected in the following outcomes when compared to their male counterparts. They report:

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[3] http://www.qvwc.org.au/info-hub/women-and-disabilities-new
Information from this website is reputable and reliable. The information provided has been reviewed by women and disabilities experts.

[4] See http://www.wchm.org.au/WomenMentalHealthPublications.htm for a copy of the survey findings.

- lower socio-economic status (i.e. equivalised gross household income);[xi]
- lower rates of participation in employment (W 46%: M 58%) and when employed are over-represented in part-time work (W 56%: M 20%);[xii]
- specific negative effects, i.e. feeling weary or lacking in energy more often than men (W 37%: M 25%), and angry or resentful (W 16%: M 9%); [xiii]
- negative effects on their relationship with their spouse (W 37%: M 24%) or other family members (W 37%: M 27%) more than men; [xiv]
- spending more time caring per week, on average, than male carers;[xv]
- lower levels of wellbeing than their male counterparts. [xvi]

These are significant statistical realities which will further compound negative outcomes for ACT women if they remain unacknowledged.

Recommendations

3. To give greater recognition to the gendered nature of caring within the Carers Charter by including women as a priority focus for the ACT Carers Charter and acknowledging gender as a significant factor in the profile of carers in the ACT.

3. A gender-sensitive approach to supporting carers

WCHM recommends that the Government consider including a commitment to providing gender sensitive services to carers as one of the principles of the Charter.

Women and men are different, both as a result of biological differences and because of the differences in the ways that they live, work and play. Because of these differences, men and women have different needs in relation to their health and wellbeing, work and education, and informal and formal support networks. The differences in social roles assigned to women and men affect the "degree to which women and men have access to, and control over, the resources and decision-making needed to protect their health",[5] for example, and this results in inequitable patterns of health risk, use of health services and health outcomes.'[6]

One example is found in the view in our society of women as nurturing, interdependent and family oriented. While these are all positive qualities in that they are protective of

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[5] World Health Organization, 2002, *Madrid Seminar on Gender Mainstreaming Health Policies in Europe,* http://www.euro.who.int/document/a75328.pdf.
[6] *ibid*.

others, domestic responsibilities like caring, limit economic resources and can increase women's vulnerability to poverty, affecting her own and her families health.[7] [8] Domestic responsibilities can also limit women's opportunities to weave their private and public worlds effectively,[9] which can then greatly increase the risk of isolation. Caring demands have also been found to create potential pathways to the "female excess of 'minor' physical and mental ill health, such as tiredness, headaches and chronic pain".[10] [11]

The following is a set of principles that guide gender sensitive practice:

- Women and men are not the same; many factors such as age, race, ability, language, sexual orientation, education and access to resources influence an individual's capacity to achieve optimal social, physical, emotional and economic wellbeing. Gender is no different.[12]
- Service delivery and supports should strive for equity in outcomes. This does not mean that each individual should receive the same treatment and access to services but rather, that they receive the access and treatment they need to realize equal outcomes compared to other groups or women, and compared to men.[13] [14] [15] Equal outcomes between women and men benefit society as a whole.
- Women must be involved in decision-making about policies and programs surrounding service delivery and supports. This includes taking the necessary measures to ensure that disadvantaged women's voices are heard and responded to.[16]
- Staff employed to provide services and support to carers need to be reflective about their own experience and perception of gender and use this to facilitate their understanding of others; never losing sight of the fluidity of gender across time, culture and social position.[17]

The current proposed Charter includes the statement that 'Carers have access to support and services that take account of their own cultural, linguistic and religious preferences', but there is no recognition of gender sensitive services.

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[7] Margaret Miers, 2002, *op cit,* 71.
[8] Hilary Graham, 1993, *When Life's a Drag: Women, Smoking and Disadvantage*, HMSO, London.
[9] Margaret Miers, 2002, *op cit,* 73.
[10] *ibid*.
[11] Jennie Popay and Keleigh Groves, 2000, "'Narrative' in research on gender inequalities in health", in Ellen Annandale and Kate Hunt (eds.), *Gender Inequalities in Health*, Open University Press, Buckingham.
[12] Women's Health Association of Victoria, 2001, *op cit*.
[13] The Women's Health Council, 2007, *op cit*., 3.
[14] *ibid*.
[15] Carol Vlassoff and Claudia Garcia Moreno, 2002, *op cit*, 1714.
[16] Women's Health Association of Victoria, 2001, *op cit*.
[17] *ibid*.

Recommendation

4. To include in the charter a commitment to providing gender sensitive support and services to ACT carers.

4. Recognising the specific needs of mental health carers

Recently the ACT Women and Mental Health Working Group (WMHWG) commissioned the WCHM to commence a research project focusing on women mental health carers. It highlights that women mental health carers experience significant disadvantage in our community both as a result of their gender, and specific issues impacting on those caring for someone with a mental illness opposed to other disabilities. For example, mental health carers are affected by the cyclical and episodic nature of mental illness, and the persistent experience of community stigma and misinformation surrounding mental illness. Distinct barriers are therefore faced in relation to gaining access to appropriate and sensitive support services, participating in employment and income support, and maintaining health and wellbeing. Therefore, we recommend that the ACT Carers Charter reflect the specific circumstances and needs of mental health carers.

Recommendation

5. To recognise the specific needs of carers of those with mental illness in the ACT Carers Charter.

Conclusion

In conclusion, this submission aims to highlight issues from the perspective of women who are carers. WCHM looks forward to participating further in the consultation process, and the development of the ACT Carers Charter.

References

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[i] “Disability, Aging and Carers Australia: Summary of Findings ", ed. Australian Bureau of Statistics (Canberra: Australian Bureau of Statistics, 2004). 11

[ii] "A Profile of Carers in Australia," ed. Australian Bureau of Statistics (Canberra: Australian Bureau of Statistics, 2008). 7

[iii] “Disability, Aging and Carers Australia: Summary of Findings”. 11

[iv] Carers ACT, “Response to the Looking Forward, Informing an New Plan for ACT Women and Girls 2004-2009”, http://www.carersact.asn.au/wp-content/uploads/2010/10/Response-to-the-Looking-Forward-Informing-a-New-Plan-for-ACT-Women-and-Girls-2004-2009.pdf, Accessed 15 November 2010.

[v] "A Profile of Carers in Australia," ed. Australian Bureau of Statistics (Canberra: Australian Bureau of Statistics, 2008).39

[vi] Ben Edwards et al., "The Nature and Impact of Caring for Family Members with a Disability in Australia," ed. Australian Institute of Family Studies (Canberra: 2008). 47

[vii] Trish Hill et al., "Young Carers: Their Characteristics and Geographic Distribution - Report to the National Youth Affairs Research Scheme (Nyars)," ed. Employment and Workplace Relations Department of Education (Canberra: Report to the National Youth Affairs Research Scheme (NYARS), 2009). 77

[viii] Julia Twigg, "Users, Carers and Care Agencies -- Conflict or Co-Operation?," *The Journal of the Royal Society for the Promotion of Health* 115, no. 4 (1995). 257

[ix] Twigg, "Users, Carers and Care Agencies -- Conflict or Co-Operation?." 257

[x] B.P. Dohrenwend, “Socio-economic status and psychiatric disorders” in *Social Psychiatry and Psychiatric Epidemiology*, Vol. 25 (1990)

[xi] "A Profile of Carers in Australia," ed. Australian Bureau of Statistics (Canberra: Australian Bureau of Statistics, 2008).56

[xii] Ibid

[xiii] Ibid. 39

[xiv] Ibid. 39

[xv] "A Profile of Carers in Australia," ed. Australian Bureau of Statistics (Canberra: Australian Bureau of Statistics, 2008).33

[xvi] Cummins et al 20076