Submission to:

National Carer Strategy
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Submission to National Carer Strategy Discussion Paper

ACT Women and Mental Health Working Group

Women's Centre for Health Matters Inc.

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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 National Carer Strategy Discussion Paper

The ACT WMHWG and WCHM overwhelmingly support the development of a National Carers Strategy. 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, and to support our responses with evidence published by the Centre and its partners on the specific needs of ACT women.

[1] http://www.carersweek.com.au/10/carers.html

1. Care-giving is a gendered phenomenon

The ACT WMHWG and WCHM would like to commend the 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 Australians 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 Discussion Paper 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 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. Recently the ACT WMHWG commissioned the WCHM to commence a research project focusing on women mental health carers – recognising that women mental health carers experience significant disadvantage in our community both as a result of their gender, and persistent community stigma and misinformation relating to mental illness.

There are 18,300 women carers living in the ACT[iii] and 55.7% of primary carers are women.[iv] Preliminary data collected through this research project[2], in conjunction with

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

broader national statistics, support our assertion that the gendered nature of caring has a broader and more significant impact on Australian 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:

- 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 Australian women if they remain unacknowledged, and therefore we urge the Government to give greater recognition to the gendered nature of caring.

The ACT WMHWG and WCHM believe that a preamble that includes a profile of carers in Australia, and acknowledges the diversifying characteristics of carers will go some way to addressing this current gap in the Strategy. Without this, the Strategy will be ineffective in its attempts to *increase awareness of carers' needs and issues at the national level,* or realise its vision, aim and goals.

2. *A gender-sensitive approach to supporting carers*

The ACT WMHWG and the WCHM are concerned that the goals and directions for the National Carer Strategy are not preceded by a set of high level principles that will underpin future policies and programs to support carers. We recommend that the Government consider including principles within a preamble, and suggest that one of these guiding principles be a commitment to gender sensitive practices.

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",[3] for example, and this results in inequitable patterns of health risk, use of health services and health outcomes."[4]

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 others, domestic responsibilities like caring, limit economic resources and can increase women's vulnerability to poverty, affecting her own and her families health.[5] [6] Domestic responsibilities can also limit women's opportunities to weave their private and public worlds effectively,[7] 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".[8] [9]

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.[10]
- 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

[3] World Health Organization, 2002, *Madrid Seminar on Gender Mainstreaming Health Policies in Europe,* http://www.euro.who.int/document/a75328.pdf.
[4] *ibid*.
[5] Margaret Miers, 2002, *op cit,* 71.
[6] Hilary Graham, 1993, *When Life's a Drag: Women, Smoking and Disadvantage*, HMSO, London.
[7] Margaret Miers, 2002, *op cit,* 73.
[8] *ibid*.
[9] 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.
[10] Women's Health Association of Victoria, 2001, *op cit*.

realize equal outcomes compared to other groups or women, and compared to men.[11] [12] [13] 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.[14]
- 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.[15]
- Gender sensitive principles acknowledge the role that service providers and supports may play in empowering or disempowering those in their care. Research has found that women's main complaints against their health practitioners, for example, arose from being objectified or stereotyped as unintelligent, infantile, incompetent or 'unbalanced' and having their illness misdiagnosed or ignored.[16]
- Men and women do have typical patterns in relation to health and wellbeing, employment and study and accessing supports, but these should be understood in tandem with the particularities of individual experience.[17]

Recommendations

1. **To include a Preamble to the Strategy that articulates a profile of Australian carers and recognizes the diversifying characteristics of carers (i.e. age, sex, cultural background) and how these differing characteristics impact on carers lives.**

2. **To include a set of high level principles within a Preamble that will inform the planning, development, implementation and evaluation of policies and programs that aim to improve the lives of carers.**

[11] The Women's Health Council, 2007, *op cit.*, 3.
[12] *ibid*.
[13] Carol Vlassoff and Claudia Garcia Moreno, 2002, *op cit*, 1714.
[14] Women's Health Association of Victoria, 2001, *op cit*.
[15] *ibid*.
[16] Margaret Miers, 2002, *op cit.*, 74.
[17] *ibid*.

3. Acknowledging the Social Determinants of Health

Social inequalities negatively impact on the health and wellbeing of individuals and their communities. According to the social determinants of health, some of the key factors that impact negatively on health and wellbeing include income and its distribution, education and literacy, and unemployment and employment security.

The National Carer Strategy discussion paper acknowledges that work, education and training are pivotal areas within which carers need improved access and support. The ACT WMHWG and WCHM would like to see two of the six goals reworded to fully demonstrate an understanding of the importance of and commitment to supporting carers in securing income, employment, education and literacy.

Rather than emphasising support to help carers work, we recommend that goal two be reworded to address the financial disadvantage that is often experienced by carers and to be geared toward assisting carers to realise financial independence. Goal two should also acknowledge that financial independence can be realised either through work or adequate income support systems, as work is not an option for all carers such as young or elderly carers.

Goal four should then be focussed on ensuring carers have access to education, training and work that is flexible and responsive to their needs. Unless educational and training institutions and employers are encouraged to understand the unique needs of carers, and assisted in accommodating those needs, many carers will not have the opportunity to undertake education and training that will assist them in gaining secure and fulfilling employment.

The ACT WMHWG and WCHM feel that by rewording these two of the six goals, the National Carer Strategy will better recognise the burden of financial disadvantage and the importance of financial independence, and better acknowledge that without access to flexible and responsive education, training and work, carers are unlikely to realise financial independence. Without the opportunity for financial independence, employment security and education and training, carers will not experience improved health and wellbeing.

Recommendations

3. **Reword Goal 2 of the National Carer Strategy to address the financial disadvantage that is often experienced by carers and to be geared toward assisting carers to realise financial independence.**

4. **Reword Goal 4 of the National Carer Strategy to ensure that carers have access to education, training and work that is flexible and responsive to their needs.**

Conclusion

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

References

[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