Submission to:

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whm!
women's centre for health matters

Submission to Flexible Care Packages for People with Severe Mental Illness

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 Flexible Care Packages for People with Severe Mental Illness

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 and WMHWG welcome this opportunity to participate in the 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 living with mental health issues.

WCHM and MWHWG support the release of additional funding for Flexible Care Packages for People with Severe Mental Illness (FCPs) as implemented through the Access to Allied Psychological Services (ATAPS) component of the Better Outcomes in Mental Health Care Program.

However, it has several recommendations regarding how to better implement the delivery of the care packages in order to respond to the needs of, and to support, women living with mental health issues and their carers in accessing the packages.

1. Barriers to access for ACT living with women with mental health issues

The discussion paper on FCPs proposes that only GPs and psychiatrists can refer to care packages. From WCHM 's research we know that access to GPs and psychiatrists in the ACT is a significant barriers for many women with mental health issues especially those from disadvantaged groups.

Barriers to accessing mental health care services, including preventive programs, and the right information to make decisions are a part of the social determinants of women's lives which can lead to health inequalities, even in the ACT. These include:

- shortages of general practitioners and psychologists;
- the cost of accessing the services and the lack of bulk billing in the ACT;
- services being ill equipped to deal with the complexity of the health, social and emotional wellbeing and cultural needs of women from disadvantaged groups;
- a lack of gender sensitive services and information.

Out of pocket expenses are greatly impacting on many ACT women's access to health care, and many are forgoing basic services and provisions to cover their health costs or missing recommended follow up visits, not having treatment or deciding not to visit their doctor, or buy their medicine. This is exacerbating mental health problems and costs to themselves and the health system. As respondents stated:

> *"I've been in a position where I've needed to see the GP for depression and anti-depressants, but because they don't bulk bill I haven't been able to afford to go and get the care that I needed. Even with the Medicare rebate or whatever, you've still got to [pay] because they don't bulk bill, and then you've got to have the money to get your prescriptions. …."*
>
> *Cost of services, often wait too long to seek medical assistance, or try to 'do it myself' (mental health issues)*
>
> *Cost of health services in Canberra, in particular a lack of bulk-billing GPs. As a result, the waiting times experienced when using "drop-in" clinics.*
>
> *Money. Often I can't afford to go to the GP or other practitioners to get help.*

Time is a further barrier for many women in the ACT to accessing GPs, especially waiting times for appointments and delays in getting an appointment.

> *Doctors don't have enough time to look at your health holistically*
>
> *GPs are rushed and don't have the time I require to discuss what's really bothering me.*
>
> *Doctors on a tight schedule. They don't have time/energy to engage with their patients thoroughly or address problems rigorously.*
>
> *A lot of the time it feels like they're trying to rush you out the door due to the volume of clients they have to see, so attention to detail can be lacking and they don't spend*

as much time listening/asking questions - often doesn't feel like they value the patient's input or take it seriously.

Alternative referral pathways which are accessible to women would assist vulnerable populations in accessing FCPs.

To address the barriers that ACT women experience in accessing GPs for mental health care alternative options should be included to allow referral from other clinicians for FCPs, rather than GPs and psychiatrists alone. ACT women living with mental health issues may access other clinicians as first points of contact rather than GPs including Social Workers and mental health nurses.

For example alternatives to GPs could include upon discharge from ACT Health to community services, referrals through case managers in organisations which women access such as domestic violence and crisis services or other services.

A preference would alsobe the use of case coordinators acting as the initial FCP contact and then linking the client to the GP and other services to meet their needs. GPs would still play a vital role in the management of the FCP however would not be the first 'port of call'.

Recommendations

1. Investigate alternate referral pathways for FCPs to address the barriers of cost and access that women experience in accessing GPs and psychiatrists in the ACT.

2. Delivering gender sensitive mental health services

The discussion paper outlines that allied health providers engaged through ATAPS should be "appropriately credentialled" in delivering mental health services.

WCHM believes that gender sensitive practice is vital in delivering high quality mental health services. It is vital that those involved in the delivery of FCPs are gender sensitive, including GPs, case coordinators and other mental health care professionals. This is because gender differences impact on the mental health and the experience and course of women's mental illness.

Women's mental health is best understood by considering not only the biological and physiological contexts of a woman's life, but also the social, cultural, economic and personal contexts.[1] Evidence suggests that practitioners who implement this approach, those who are 'gender-sensitive', achieve better health outcomes for women. In contrast, 'gender neutral' or 'gender blind' approaches neglect the unique needs of women with mental health problems, perpetuating mental health inequalities between men and women.

[1] D.E. Stewart, "Social Determinants of Women's Mental Health" in *Journal of Psychosomatic Research*, Sep 2007

Research has found that the prevalence of psychiatric disorders is greater in women than in men [2]. Further, there are differences in the biological, psychological and social factors which cause the illness; impact on the course and expression of the illness; and impact on age of onset, symptoms and comorbidity with other illnesses.[3] There is also a strong inverse relationship between social status, and physical and mental health outcomes.[4] This greatly affects women, as women's status remains lower than men's in almost every society.

Gender sensitive health services are more than just 'women only' services: they are characterised by availability, accessibility, affordability and appropriateness (see Appendix A for specific principles of gender sensitive mental health service delivery).

A way in which to encourage gender sensitive practice in the delivery of FCPs is to train and support those who refer for packages (proposed to be GPs, psychiatrists) and those who implement them such as ATAPS and case coordinators. It is essential that all staff understand the impact of gender on health and mental health, the concept of 'gender sensitive health service delivery', and the ways in which social determinants impact on women's health and well-being.

Recommendations

2. Educate those who refer for and implement FCPs about gender sensitive practice.
3. Include principles of gender sensitive mental health practice in DoHA FCP guidelines and recommendations.

3. Defining 'severe mental illness'

WCHM agrees with the discussion paper's definition of severe mental illness which acknowledges that it should be flexible and broad to enable clinical flexibility, and dependent on various elements of mental illness including intensity, duration and degree of disability.

However, the definition should also reflect the notion that severity is dependent on the complexity of need which is presented overall, not only the diagnosis of mental illness. For example, for women there may be a complexity of social need resulting from the impacts of domestic violence, caring responsibilities, alcohol and drug dependency, housing status, income, and the state of a woman's relationships and support networks. These factors must be considered in conjunction with the severity of the mental illness symptoms. In doing so, the definition of 'severe mental illness' in assessing eligibility for FCPs should comply with the gender sensitive approach of taking into account a woman's life circumstances.

[2] F. Judd, S. Armstrong, J. Kulkarni, "Gender-sensitive mental health care" in *Australasian Psychiatry,* Vol 17 (2) 2009
[3] Ibid.
[4] B.P. Dohrenwend, "Socio-economic status and psychiatric disorders" in *Social Psychiatry and Psychiatric Epidemiology*, Vol. 25 (1990)

By taking into account key factors which impact on health and wellbeing including income, education, housing, employment and support networks, the definition of 'severe mental illness' should also acknowledge the social determinants of health.

This perspective is vital in ensuring marginalised populations such as women receive appropriate and sensitive services, because a preoccupation with diagnosing the severity of mental illness according to the discussion paper's definition may fail to identify the underlying factors that impact upon a person's mental health condition.

In addition, the definition of 'severe mental illness' outlined in the FCPs discussion paper should be expanded to include information about gender-stereotyping and bias in relation to identifying and treating mental illness, in order to discourage this practice.[5] In seeking advice about their mental health women may be stereotyped as 'emotional', menopausal or suffering from 'PMS'. Recent studies have indicated that women's physiological and reproductive functioning has minimal impact upon their mental health and wellbeing, if psychosocial factors are given appropriate consideration.[6] Alternatively, women are also more likely than men to be diagnosed with depression, "… even if they have similar scores on standardised measures of depression or present with identical symptoms".[7] Therefore, gender sensitivity is required in diagnosing mental illness to ensure the illness and its level of severity is correctly identified for women, and not attributed to stereotypes.

Recommendations

4. Expand the definition of 'severe mental illness' to include the complexity of issues presented from a social determinants of health perspective, not only the medical diagnosis.

5. Expand the definition of 'severe mental illness' to include information about how to avoid gender stereotyping in diagnosis.

3. Navigating the mental health care system

WCHM supports the additional tier of funding for FCPs aimed at supporting people with severe mental illness. However, the FCPs program brings to the ATAPS system another layer of complexity. Issues include how one accesses a package, who is eligible, and what services are included.

[5] I. Broverman, S. Vogel, D. Broverman, F. Clarkson, P. Rosenkrantz, "Sex-role stereotypes: A current appraisal" in Journal of Social Issues, Vol. 28, No. 2 (1972)
[6] L. Dennerstein, E. Dudley and H. Burger, "Well-being and the menopausal transition" in *Journal of Psychosomatic Obstetrics and Gynaecology,* Vol. 18 (1997)
[7] E.J. Callahan, K.D. Bertakis, R. Azari, L.J. Helms, J. Robbins, J. Miller, "Depression in primary care: patient factors that influence recognition" in Family Medicine, Vol 29 (1997); G. Stoppe, H. Sandholzer, C. Huppertz, "Gender differences in the recognition of depression in old age" in Maturitas, Vol 32 (1999)

Enabling women to navigate the new system will be essential for better access to appropriate services – but they will need assistance to get the best possible advice and the most appropriate source for their immediate need.

It is vital that women living with mental health issues, their carers and the professionals within the mental health care system can navigate FCPs easily and understand the tiered support system easily.

There is a need to describe/define simply the tiered levels of intervention that are available within the ACT so that women and professionals understand the options.

Information about various pathways of care must be provided in preferred formats (e.g. the Internet, multiple languages), and assistance for those who experience difficulty in understanding and/or navigating the system must be available. It is especially vital for health care professionals, particularly GPs, to receive education about the FCPs and support in implementing them. For example, information about what community support services there are and how to access them is vital. This is in order to encourage 'no wrong door' practice whereby individuals in need of assistance can obtain information at all points of call.

Recommendations

6. Provide clear information about FCPs to consumers and their carers via preferred and accessible formats.
7. Educate and support clinicians to implement FCPs, and ensure they understand systems of referral and services available.

4. Approaches to service delivery: A recovery framework and peer support

The discussion paper outlines the types of services to be provided by FCPs including clinical care and case coordination for linkages to non-clinical support services. WCHM believes that clinical services delivered should have a recovery focus to understanding and treating severe mental health issues. Traditionally, mental illness has been understood within the context of a medical framework, whereby a consumer's condition is considered biologically based;[i] consumers are subject to a medical interpretation of their experiences and views; [ii] and only the biological and cognitive processes are addressed by mental health practitioners.[iii] A consequence of the medical approach is that it often renders an individual powerless to contribute to their own recovery process.

An alternative way in which to understand and treat mental illness is within the recovery framework (see Appendix B for principles of the recovery framework). The term recovery does not necessarily refer to an absence of symptoms or injury, but "…the opportunity to live a satisfying and fulfilling life (as defined by the person in recovery) in the presence or absence of ongoing symptoms." The recovery perspective aims to transcend the limitations of the medical framework; and reorient the individual as empowered to participate in their treatment and redefine themselves as unique individuals who are not (just) their mental illness.

In addition, one form of non-clinical service which WCHM recommends for women receiving FCPs is peer support. People living with mental health issues often find it difficult to develop and maintain social relationships.[8] It is not uncommon for interactions to be limited mostly to medical practitioners, family members and other peers living with mental health issues[9]; and comparatively, they have smaller social networks than people without mental health issues.[10] Consequently, many report spending a lot of time alone[11], and experiencing feelings of isolation, loneliness[12] [13], a lack of community connectedness,[14] and dissatisfaction with the social support that they do receive.[15] Barriers to establishing and maintaining friendships include the social stigma surrounding mental illness, loss of social roles associated with impairments in functioning, lack of alternative social structures to bring people together in the community, and the social disability associated with the disorder itself.[16]

Furthermore, literature identifies lack of community support, rather than a person's symptomatology to be the dominant factor in re-admission[17], with up to half of all discharged psychiatric inpatients re-hospitalised within twelve months[18]. Therefore, it is vital to develop strategies to facilitate and support people to maintain social connectivity and manage good mental health and wellbeing outside of traditional mental health services and facilities. Low levels of social support are intrinsically linked to poor mental and physical health outcomes.[iv] [v] [vi] [vii] Assisting patients to develop social networks, social skills and good relationships with others can greatly assist consumers, particularly upon discharge from hospitalisations. As one WCHM respondent states:

"I would rather talk to some one than taking four different medications before 10:00 during the day. That's all I needed to do, was talk to people, because I couldn't talk to the people that I had the problem with… but instead, they wanted to feed me up with drugs. And now I won't even…address to the GP my problems because all they think to do is prescribe drugs when I know for a fact all I needed to do was talk to someone."

[8] Larry Davidson et al., "Supported Socialization for People with Psychiatric Disabilities: Lessons from a Randomized Controlled Trial," *Journal of Community Psychology* 32, no. 4 (2004).
[9] Beth Angell, "Contexts of Social Relationship Development among Assertive Community Treatment Clients," *Mental Health Services Research* 5, no. 1 (2003).
[10] Frank Baker et al., "Community Support Services and Functioning of the Seriously Mentally Ill," *Community Mental Health Journal* 29, no. 4 (1993).
[11] L. Davidson and D. Stayner, "Loss, Loneliness, and the Desire for Love: Perspectives on the Social Lives of People with Schizophrenia," *Psychiatric Rehabilitation Journal* 20, no. 3 (1997), L. Davidson, Stayner, D. and Haglund, K.E. , "Phenomenological Perspectives on the Social Functioning of People with Schizophrenia," in *Handbook of Social Functioning in Schizophrenia*, ed. K.T. Mueser and N. Tarrier (MA: Allyn & Bacon, 1998).
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[15] Anita Bengtsson-Tops and Lars Hansson, "Quantitative and Qualitative Aspects of the Social Network in Schizophrenic Patients Living in the Community. Relationship to Sociodemographic Characteristics and Clinical Factors and Subjective Quality of Life," *International Journal of Social Psychiatry* 47, no. 3 (2001).
[16] Davidson et al., "Supported Socialization for People with Psychiatric Disabilities: Lessons from a Randomized Controlled Trial."
[17] Larry Davidson et al., "Peer Support among Individuals with Severe Mental Illness: A Review of the Evidence," *Clinical Psychology: Science and Practice* 6, no. 2 (1999).
[18] WD Klinkenberg and RJ Calsyn, "Predictors of Receipt of Aftercare and Recidivism among Persons with Severe Mental Illness: A Review," *Psychiatric Services* 47, no. 5 (1996).

Recommendations

8. Promote a recovery rather than medical framework in clinical mental health services delivering FCPs.
9. Ensure peer support groups are considered accessible services through FCPs.

5. Participation: Consumer feedback and mental health carers

The discussion paper outlines that quality assurance is an integral component of delivering FCPs. Firstly, WCHM believes that seeking consumer and carer feedback regarding service delivery is vital in promoting best practice and developing innovative service models.

Secondly, WCHM belivees that mental health carers should be included and supported in services delivered through FCPs. Women mental health carers in the ACT identify that they are often excluded from care planning due to privacy and confidentiality issues and the attitudes of service providers. Yet care-giving is a gendered phenomenon, and women are the predominant care-givers in contemporary Australian society.[viii]

Research indicates that "caring has consequences for people's lives, it restricts their opportunities, it imposes burdens, it can cause distress".[ix] In particular, women who are mental health carers experience significant disadvantage both as a result of their gender, and persistent community stigma and misinformation relating to mental illness. Negative effects on health and wellbeing include issues of employment and income, isolation, decreased mental and physical health, and difficulties accessing appropriate support services.

Recommendations

11. Services who deliver FCPs to integrate consumer and carer feedback into their service.
12. Services who deliver FCPs to support and include carers.

Conclusion

In conclusion, this submission highlights issues identified in relation to the delivery of tier three flexible care packages for women living with severe mental illness in the ACT, and their carers. WCHM looks forward to participating further in the consultation and implementation process,.

Appendices

Appendix A: Characteristics of gender sensitive mental health service delivery

- A holistic approach to mental health, where women are treated as whole individuals rather than as their illness or diagnosis – using a social model rather than medical model.
- Offer women choices about the type of support they receive, and who provides it to them (i.e. the choice between a male or female doctor). This is of particular importance for some CALD women, Aboriginal and Torres Strait Islander (TSI) women, women who have suffered trauma, and/or women who may feel uncomfortable disclosing personal information to a male practitioner.
- Provide women with opportunities to be actively involved in their own care and treatment, including service planning and delivery (i.e. advanced directives).
- Offer women choice in treatment options, which may include medication, talking therapy and/or other community-based services like peer support.
- Have staff that treat women with respect, give them time to talk and listen to what they have to say, including the provision of long consultations and more preventative health measures and counselling where needed.
- Have staff and practitioners with qualifications in women's health and/or are trained to understand the impact of gender on mental health and well-being.
- Are culturally sensitive.
- Understand that all health issues and life events may affect men and women differently across their lifespan and use a life course approach in service planning and delivery.
- Take into account the 'social determinants of health', that is, they acknowledge the way that women's personal circumstances and socio-economic status affects their mental health. For example, a woman's child and/or other caring responsibilities, her relationships, housing status, income, age, sexuality, ethnicity, religion and cultural and linguistic background, all have the potential to negatively impact upon a her mental health and wellbeing.
- Employ a holistic, individual approach to service delivery that recognises that women often have a multitude of concurrent challenges, which often lead to a cycle of difficulties.
- Pathways of care are easy to navigate, information is provided in preferred formats, and for those women who experience difficulty in understanding and/or navigating the health system, assistance is provided.
- 'Women only' spaces within their buildings.
- Provide family-friendly and more specifically child-friendly environments, and services are inclusive of family.
- Keep women's personal information confidential at all times.
- Have a stable and secure funding base, which allows them to offer consistency and longevity in the support they provide. [x]

Appendix B: Characteristics of a recovery framework

- Focus on redefining self (i.e. being more than your mental illness);
- Promote hope and optimism (i.e. You **<u>can</u>** live a safe, happy, healthy and fulfilling life);
- Promote self-management and personal responsibility;

- Promote and protect human rights;
- Non-judgemental and the language used by staff, patients and visitors reflects this[xi];
- Incorporate illness and manage symptoms, and
- Encourage people to support one another.

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