SUBMISSION ON

A DRAFT SERVICE DELIVERTY MODEL FOR A PROPOSED NEW CARER SUPPORT SERVICE SYSTEM

Developed by the University of Melbourne
and the Multicultural Centre for Women's Health

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ABOUT THE MULTICULTURAL CENTRE FOR WOMEN'S HEALTH

The Multicultural Centre for Women's Health (MCWH) is the national voice for immigrant and refugee[1] women's health and wellbeing.

MCWH is a Victorian women's health service established in 1978 that works both nationally and across Victoria to promote the health and wellbeing of immigrant and refugee women through advocacy, social action, multilingual education, research and capacity building.

MCWH works across Victoria to provide research, expert advice, and professional development to key stakeholders on improving the health and wellbeing of immigrant and refugee women. It does this through research and publication, participation in advisory groups and committees, written submissions, training and seminar programs, and presentations of our work. MCWH also works directly with women in the community providing capacity building and multilingual education on women's health and wellbeing, across a wide range of issues and topics, through the use of trained, community-based, bilingual health educators.

ABOUT THIS SUBMISSION

MCWH welcomes the opportunity to write a submission on the draft service delivery model for a proposed new carer support service system. Between June 2015 and June 2017, MCWH has been funded under the Australian Government's Aged Care Service Improvement and Healthy Ageing Grants scheme to deliver 'Dealing with it myself', a project to support immigrant and refugee carers from five designated communities: Arabic, Burmese, Chinese, Indian and former Yugoslavian. The project engages communities who have traditionally had little access to ethno-specific support or information in relation to caring. Using culturally-engaging narrative approaches, the project delivers in-language community educations sessions and resources to raise awareness about the challenges faced by carers, and to encourage carers and community members to share support strategies and learn about services.

The recommendations in the present submission are based on background research conducted for the project, as well as feedback from carers, community members and MCWH multilingual educators following the community health education sessions. We have completed a literature review, conducted interviews and focus group sessions with 47 immigrant and refugee carers, consulted 14 stakeholder organisations, and run 16 peer education sessions about carer support services with 376 carers, seniors and community members to date. These sessions are currently ongoing.

[1] The term 'immigrant and refugee' refers to people who have migrated from overseas, and their children. It includes people who are a part of both newly emerging and longer established communities, and who arrive in Australia on either temporary or permanent visas.

KEY CONSIDERATIONS

The Gendered Nature of Caring

Caring is a highly gendered activity. While we have included both female and male carers in our project, the majority of carers we have consulted have been women, and much discussion in our community education sessions has revolved around the pressures on immigrant women to engage in both unpaid family caring and paid employment. Immigrant and refugee women face unique challenges, including structural barriers in finding employment, long-term financial vulnerability into old age, and being more likely to be engaged in multiple caring and child caring responsibilities with limited social and family support networks.

These findings are substantiated by academic and grey literature. Studies have consistently found that female carers experience higher levels of distress than male carers – as they are more engulfed in their role; more conscious of the emotional wellbeing of their care recipients; more likely to experience financial burden and be concentrated in low-wage employment with relatively inflexible working arrangements; more likely to juggle competing caring and employment responsibilities, as well as multiple caring responsibilities (including caring for children); more likely to experience violence from care recipients; less likely to receive social recognition or be offered informal support by their families; less likely to be identified as needing formal support by health professionals; and devote more hours to their caring responsibilities than male carers (Gupta and Pillai 2012; Katbamna et. al. 2004; Lymer et. al. 2006; Merrell et. al. 2006; Neufeld et. al. 2008; Perry and O'Connor 2002; Pillemer and Suitor 1992; Team et. al. 2007: 398; Thompson 2007; Ussher and Perz 2010; Ussher et. al. 2013; and Vaughan Brackman 1994).

It is imperative that service providers are aware of the highly gendered nature of the caring, and the unique barriers faced by female immigrant and refugee carers. The integrated carer support service must acknowledge the extraordinary burden of care currently undertaken by women in Australia, and offer support in a way that meets women's needs; for instance by ensuring effective access to childcare as well as respite so women can benefit from education, counselling, coaching and mentoring, and by addressing women's family caring responsibilities holistically.

Immigrant and Refugee Carers

According to the 2011 Census, approximately 30% of people providing or requiring care in Australia come from a culturally or linguistically diverse (CALD) background (Taylor 2013: 29). Despite constituting a significant proportion of the carer and care recipient populations, immigrant and refugee families face multiple barriers in accessing services. This is due to factors such as language barriers, culturally inappropriate service provision, social and family isolation and lack of knowledge about the health system. The new integrated carer support service must offer tailored support and acknowledge the various intersecting forms of disadvantaged faced by immigrant and refugee carers. While we acknowledge the need for economies of scale in delivering services, we also note that generalised services which do not address intersecting forms of disadvantage are much less effective than services which are tailored and targeted to immigrant and refugee families.

Finally, we note that the complexity of the visa system can present a significant barrier to some carers and their care recipients, particularly those on temporary or contributory visas. We strongly advocate for support and welfare payments to be made available for carers and care recipients on

all visa categories in Australia, to avoid a multi-tiered system in which certain groups of residents and citizens have access to more support than others, and in recognition of the immense economic contribution of all carers in Australia, whether they are on permanent or temporary visas.

COMMENTS ON THE SERVICE DELIVERY MODEL

Core Features

- We support **Carer Choice** as a core feature of the model. For many immigrant and refugee carers to exercise genuine choice in the supports they wish to access, they require in-language information and support to navigate the service system, via long-term relationships with a trusted professional who is able to advocate on their behalf when needed.
- The **No Wrong Door** and **Strong Links with other Government Services** approaches are crucial for hidden carers in particular to access support services. For this approach to work, service providers need training in the unique barriers faced by immigrant and refugee families in accessing carer support services; be skilled and sensitive in assessing the needs of immigrant and refugee carers; and have extensive knowledge of the service system (including settlement, multicultural and ethno-specific services) to be able to refer carers to appropriate services.
- In relation to **Outcomes Driven Support,** it is important to note that outcomes cannot always be measured quantitatively, and carers should be able to define *in their own terms* whether or not a particular type of support is working for them (rather than judging outcomes against abstracted, standardised measures).
- We support the focus on prevention and **Support Through the Entire Caring Journey,** not just in times of crisis. Community awareness campaigns, in-language information and positive, ongoing relationships with skilled, understanding staff at first point of contact are vital to identifying and retaining immigrant refugee carers in the service system. This will require adequate funding of multicultural and ethno-specific services, and training and recruitment of skilled bilingual peer workers. Intensive support for certified training (through financial assistance, provision of culturally-appropriate respite and help with transport) is also crucial to helping carers enter the workforce throughout their journey or towards the end of their caring role.

1. Awareness and Community Linkages

- Multicultural and ethno-specific organisations need to be engaged and adequately funded for the **delivery of local awareness raising and outreach activities**. MCWH has over 35 years' experience in delivering health information to immigrant and refugee women. We note that the most effective methods are face-to-face sessions delivered by *trained bilingual and bicultural peer health educators*. In-language talkback sessions on community radio are also effective. For newly-arrived groups and those with limited English proficiency or literacy skills in their first language, face-to-face sessions are vital. Given the complexity of the Australian health system (particularly for families migrating from countries with limited

government-funded social services), it is important that the carer support service is explained in language and in person, giving community members an opportunity to ask questions. Feedback from community education sessions for 'Dealing with it myself' indicates that many newly-arrived families do not understand the definition of a 'carer' in the Australian service system, or how unpaid family carers who receive the Carer Payment and Carer Allowance differ from paid care support workers. This has caused much misunderstanding and tensions within families; which can be avoided with effective and engaging community education and awareness.

- Community awareness around carer issues should also acknowledge the gendered nature of caring and facilitate honest discussions about the expectations placed on men and women. During our sessions, female carers requested that male family members were included so men understood the pressure women are under in terms of unpaid caring and household work as well as paid work.

2. Information and Advice

- **Information and Advice (Tier 1):** Online sources of information must be user-friendly, culturally relevant and multilingual. More multilingual information, podcasts, videos and web pages need to be available on the Carer Gateway, which can be linked to or integrated with platforms which are already in popular use (e.g. Facebook, WeChat). Online sources of information and support such as the Carer Gateway also need to holistically acknowledge diversity in their imaging and messaging, rather than relegating multilingual information to one section of the website.
- We have received feedback for instance, that the current MyAgedCare website is difficult and frustrating to use and navigate. This feedback has come from carers of elderly migrant parents in cases where both the carer and parent are fluent in English and confident using technology. Many other carers and their families to whom we have spoken are unaware of MyAgedCare or unable to use it due to technology and language barriers.
- It is important that all forms of support available online are also available by other means, for those who are unable to use technology due to age, disability, language barriers, geographic location and so on.
- **Information and Advice (Tier 2):** All staff members servicing the 1800 line must be trained in both offering support to carers, and in identifying the need for and working with interpreters. Some immigrant and refugee carers we have consulted have had negative experiences when calling 1800 numbers for help (particularly in relation to My Aged Care), and are unlikely to seek further support after such negative contact.
- **Service Coordination Support:** Many immigrant and refugee carers will require *long term assistance*, not only short term assistance, to navigate, coordinate and access other supports. Staff providing such support must be skilled, have an excellent understanding of barriers faced by immigrant and refugee carers, and develop long term, trusting relationships with carers, whose needs for services and coordination will change over the course of their caring journey. See also below (6. Needs Assessment and Planning).
- Many carers informed us that they 'missed out' on financial assistance and other services because they did not receive the appropriate information at the right time.
- **Information and Advice (existing services):** Please see above comments on adequate funding of multicultural and ethno-specific organisations to deliver information in culturally appropriate formats by trained bilingual and bicultural peer educators.

3. Peer Support

- Please see above comments on making the Carer Gateway more user-friendly and responsive to cultural and linguistic diversity.
- Immigrant and refugee carers have indicated to us that they are particularly time-poor and concepts such as 'peer support' and 'time for myself' do not necessarily translate culturally or linguistically. It is therefore important to present support group options in a culturally-resonant manner. Carers require a number of options that meet their individual circumstances, and have to be supported in terms of finance, respite and transport in order to access the support options of their choice. Many carers we spoke to preferred ethno-specific groups facilitated by a bilingual peer workers; others preferred mainstream groups (to avoid community stigma) or online support via existing social media platforms such as WeChat and Facebook. Many carers of elderly parents would like to be able to bring their care recipients to support groups, so they can also form a peer network with fellow community members. Peer support activities which carers have suggested to us include dancing, walking, visits to recreation facilities such as the zoo and aquarium, massages, and cultural celebrations such as Lunar New Year. Some carers indicated that carer support groups are not an attractive option, and they would rather be supported to access wellbeing-enhancing activities such as massages, meditation and yoga. For carers to have genuine choice, support models and activities must be tailored to specific groups, and organisations adequately funded to provide respite and transport. Many female carers also have childcare responsibilities, and the timing and location of support groups needs to take this into account and/or provide childcare.
- Culturally-appropriate support groups run by bilingual peer facilitators can play an important role in gradually introducing carers to services, provided the groups are adequately funded and carers are supported to attend sessions.

4. Education and Training

- During our education sessions, it has become clear that there is a need for education amongst immigrant and refugee carers about:
    - The definition of the term 'carer' within the Australian service system and how this differs from other cultural understandings and definitions of 'caring' and family roles.
    - The Australian service system, what support services are available, and how to access them.
    - How carer services interact/integrate with the health system and settlement support.
    - Centrelink payments and financial supports for carers.
    - Self-advocacy within the system.
    - Planning for residential care.
    - Advanced care and emergency planning – including accurate information on power of attorney and guardianship laws. Such training will also improve individuals' capacity for self-advocacy and help to mitigate risks of elder and financial abuse.
    - Workplace supports for carers and services and training programs which can help carers enter the workforce.

- As noted above, training is most effective when delivered face-to-face and in language by a trained bicultural peer ducator.
- We spoke to several newly-arrived carers who were unable to successfully complete the Adult Migrant English Program (AMEP) because of their caring and childcare responsibilities. Humanitarian entrants in a caring role need adequate support, including respite, transport and childcare where necessary, in order to attend and succeed in the program, to increase their ability to navigate the service system and their chances of entering the workforce later on.
- We strongly support the proposal to provide carers with certified training and education which recognises their existing skills sets, and provides them with pathways to employment. In addition to training for the aged care workforce, immigrant and refugee carers are particularly well placed to train as bilingual peer support workers in hospitals, and peer group facilitators. As noted above, carers need to be adequately supported to attend such training, including through respite, transport and childcare.

5. Counselling

- For groups who are not familiar with the concept of counselling, counselling must be explained and offered in a culturally appropriate and face-to-face format.
- The new service should make every attempt possible to train and recruit bilingual and bicultural counsellors.
- Many immigrant and refugee carers have informed us that counselling is not an activity or concept which resonates with them culturally. They would prefer to be supported in accessing other wellbeing-enhancing services and activities, such as engaging with religious support, meditation, massage and so on. In order to effectively support immigrant and refugee carers, it will be important for the new service to acknowledge and support alternative cultural concepts and activities related to health and wellbeing.

6. Needs Assessment and Planning

- Many immigrant and refugee carers who are 'hidden' or not currently accessing services will require gradual introduction to services, and help by trained support workers in assessing their needs. Carers need time to trust their trained support workers or service, and develop a relationship with them. Such assessment should be undertaken by a trained social worker who is aware of the barriers and issues faced by immigrant and refugee carers, and who can act as or refer carers to a long-term source of support and advocacy.
- Most carers have highlighted to us the need for a 'one-stop shop' in terms of accessing services. Given language barriers in accessing services, negotiating with multiple service providers can be stressful and impractical, hence the need for ongoing service coordination support that is linked to assessment and planning as carers' needs change over time. Such ongoing support will ensure carers' timely access to services (rather than only at crisis point), which will ultimately reduce strain on the health care system.
- Many carers have indicated to us that they are willing to attend in-language carer education sessions because it helps in learning about services and planning for the future, even if they do not need to use services at present.

- Having experienced conflict and displacement, many refugee carers expressed caution around 'future planning' because they have always experienced the future as uncertain. Staff working with refugee carers need to be adequately trained and sensitive to such issues.

7. Coaching and Mentoring

- Please see above on the need for bilingual and bicultural peer workers to be employed in any coaching and mentoring programs, and the need for adequate support for carers (in terms of respite, childcare and transport) to access the program.
- Please see above for the need for long-term service-coordination, mentoring and advocacy support for immigrant and refugee carers.

8. Respite – Short-term and Emergency

- Many carers we have spoken to are unaware of the meaning of 'respite'. In such cases, it is important that needs assessment occurs in person with a trained social worker, rather than relying on carer self-assessment via an app.
- Carers have informed us that they prefer ethno-specific respite services and bicultural respite workers with whom they can develop ongoing relationships, and who can attend to the needs of their care recipients in a culturally-appropriate manner. Many carers shared negative experiences of respite services, and were reluctant to further engage them. In this regard it is important that service providers recruit culturally diverse respite workers, that workers are adequately trained and supported to carry out their role, and that existing ethno-specific carer support and respite services are given increased funding.

9. Targeted Financial Support

- Carers have expressed the following needs in relation to targeted financial assistance:
    - For the removal of means-testing of the Carer Payment with the income of one's partner, in recognition of the work and economic contribution of the carer, and decreased opportunities for paid employment.
    - For increased financial assistance to access continence aids (although this might be more appropriately addressed under the care recipients' consumer-directed package).
    - Culturally-appropriate and gender-sensitive training for budget management (particularly for newly-arrived carers with low levels of literacy in their first language).
    - Funding for wellbeing-enhancing activities that are culturally recognised but do not fall under the existing service delivery model, which has an emphasis on western wellbeing practices such as counselling.
- As discussed above, any financial support scheme needs to be explained to carers in language and in person, to ensure carers understand the scheme. For many immigrant and refugee carers, this means assessment will also need to occur via face-to-face meetings with a trusted support worker.

COMMENTS ON THE DISCUSSION QUESTIONS

Regional Service Mapping

- The discussion above highlights the need for targeted support for immigrant and refugee carers. The expertise for such support already exists within many multicultural, ethno-specific, women's health and settlement services (including migrant resource centres). Any service mapping by regional hubs should employ an intersectional lens to understand all services with which carers may come into contact during their caring and migration journey. This will be crucial for regional hubs in terms of raising awareness and building partnerships in the community.

Outcomes Measurement

- We support the assertion that outcomes measurement should not place undue burden on carers. Qualitative and narrative feedback from carers in a format of their choice (given that not all carers are literate in English and able to complete questionnaires) would allow carers to identify any needs for extra support, so the process of outcomes measurement also adds value for carers themselves. However, in such a case staff members who are collecting and analysing such data need to be appropriately trained.

Quality Framework

- We advocate for a quality framework that assesses whether services are benefitting carers who face multiple and intersecting configurations of disadvantage. This will require the ability to analyse data and outcomes against factors such as carers' gender, age, region, country of birth, length of time in Australia, and language proficiency. Such data should be readily available via the central carer record (which will presumably be updated as carers provide more information with ongoing contact) with carers' permission.

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