ECCV Submission to DSS:

Retaining the Benefits

of

Victoria's HACC Access and Support Program

In the

Commonwealth Home Support Programme

April 2015

Ethnic Communities' Council of Victoria Inc. (ECCV) is the voice of Multicultural Victoria. As the peak body for ethnic and multicultural organisations in Victoria, we are proud to have been the key advocate for culturally diverse communities in Victoria since 1974. For 40 years we have been the link between multicultural communities, government and the wider community.

Background and Context for the ECCV Access and Support Networks

ECCV appreciates the opportunity to support the implementation of Diversity Planning and practice by the Victorian Department of Health and Human Services through its HACC Access and Support program (A&S).

The A&S roles have been developed and funded across the HACC sector to provide flexible and direct client support to those with complex needs and barriers due to their diversity. The A&S program aims to improve access to services, provide support and build client capacity so that clients can remain living independently within their communities. A person-centred approach, including responsiveness to cultural and linguistic diversity is integral to the A&S program.

ECCV's HACC Sectoral Development Officer facilitates two state-wide networks, one for the A&S Officers and one for their Managers, which provide opportunities for sectoral development, capacity building, peer learning, problem solving, information dissemination, partnerships and policy representation.

This Submission includes:

1. Perspectives of the ECCV HACC Access and Support Networks.
2. ECCV Recommendations.
3. Consultation summary of ECCV Access and Support network response to DSS CHSP Manual, National Fees Policy Consultation Paper, and Good Practice Guide for Restorative Care Approaches.

1. Perspectives of the ECCV HACC Access and Support Networks

According to the Productivity Commission Inquiry Report: Caring for Older Australians (Australia Government, 2011), there is a growing diversity in aged care needs, and people from culturally and linguistically diverse backgrounds over 65 year old are projected to grow another 43 per cent nationally in the next 15 years. Consequently, a large proportion of the Commonwealth Home Support Program (CHSP) and My Aged Care (MAC) clients nationally will experience significant barriers in accessing services due to their cultural and linguistic diversity.

Many frail and older clients from non-English speaking and culturally diverse backgrounds will also experience the negative effects of compounding vulnerabilities or low capabilities when accessing aged care services. Please refer to Appendix 1 for elaboration of these vulnerabilities and low capabilities and to Appendix 2 for reals case studies that demonstrate some specific barriers to access that these vulnerabilities and low capabilities cause.

In commending the Australian Government's commitment to deliver "Client Centred Assessment and Care", ECCV's A&S network raises the importance of integrating and embedding a diversity framework and diversity strategies within CHSP and MAC. ECCV believes that cultural safety, inclusion, sensitivity and responsiveness to individual diversity must be integral to "Client Centred Assessment and Care" within CHSP and MAC, and not an add-on feature.

ECCV's A&S network identified that the CHSP Manual does not explicitly outline any mechanisms aimed at ensuring that clients with compounding vulnerabilities or low capabilities will be supported in their interaction with MAC and CHSP. ECCV's A&S network believes that many clients with compounding vulnerabilities or low capabilities will not be able to access MAC and navigate the CHSP without specialised assistance, even though their care needs maybe addressed in the entry-tier CHSP.

ECCV's A&S network emphasises that the Victorian HACC Access and Support program has proven expertise in working with people who experience barriers due to their diversity. A&S Officers work flexibly, responsively and in line with a Person-Centred and Wellness approach to support clients to access services. A&S Officers also work with the service system to assist clients to remain independent in the community and reduce the premature termination of preventative CHSP services. The A&S program often incorporates a combination of assertive outreach, community education and engagement, capacity building and direct client support, working with the aged care service providers and system to enhance continuous service improvement.

The HACC A&S program has the potential and required expertise to assist clients experiencing barriers due to their diversity throughout their whole client journey, including capacity building prior to enter the MAC service system, entering the MAC Gateway, and accessing the CHSP and other preventative entry-tier aged care services.

In line with the views of the Productivity Commission in relation to enhancing the quality of aged care (Australia Government, 2011, XLVIII), A&S Officers have a demonstrated capacity to provide cultural expertise and secondary consultations to "enhance greater recognition by providers, staff and trainers of the needs of culturally diverse groups and those with special needs". Responsive early support and intervention for clients with diversity barriers will ensure that there is equity of access, that individuals' wishes and preferences to remain living in the communities are met, and that premature entry into the costly residential aged care system does not occur.

Please refer to Appendix 2 for case studies that demonstrate how the HACC Access and Support program can add value to the CHSP by ensuring equity for vulnerable seniors from non-English speaking and culturally diverse backgrounds.

2. ECCV Recommendations

The following recommendations are based on the perspectives of the ECCV HACC Access and Support Networks.

Recommendation 1

That the Commonwealth Government develop and pilot an operational roadmap to integrate the Victorian HACC Access and Support program into the MAC Gateway, CHSP, and Linkages system.

Recommendation 2

That the Commonwealth Government integrate the Access and Support program within the CHSP to establish an interface and link between the national end-to-end Aged Care service system and vulnerable and disadvantaged community members from culturally and linguistically diverse backgrounds.

Recommendation 3

That research evaluating the outcomes of Victoria's HACC Access and Support program be undertaken to determine its potential to improve the CHSP's responsiveness to diverse needs, provide continuous improvement for MAC, RAS and CHSP services, and improve outcomes for clients from culturally and linguistically diverse backgrounds.

Recommendation 4

That the Commonwealth Government make an ongoing commitment to resource the Victorian HACC Access and Support program in order to safeguard equity in access and services for people who have diverse and complex needs.

3. Consultation Summary

The following is a summary of responses from ECCV's A&S network to the Commonwealth Home Support Programme (CHSP) Draft Manual, National Fees Policy Consultation Paper, and Good Practice Guide for Restorative Care Approaches. Two consultations were convened by ECCV in March 2015. Participants included A&S Officers and their Managers representing twelve community agencies, including ethno-specific and multicultural organisations, organisations working with people from Aboriginal and Torre Straits Islander backgrounds, homelessness specialist agencies, community health organisations and local government.

ECCV and its A&S network recommend continuous development in innovative strategies to ensure equity in policy and responsiveness in practice throughout the CHSP Manual, National Fees Policy and Good Practice Guide for people who experience barriers because of their diversity, including but not limited to cultural and linguistic diversity.

ECCV and its A&S network believe that the A&S program will add value to the national end-to-end aged care system by addressing some of the equity issues in the CHSP, MAC Gateway and Regional Assessment Services. Integrating the A&S program within the CHSP to establish an interface and link

between the national end-to-end Aged Care service system and vulnerable and disadvantaged community members with diverse characteristics will help to redress inevitable issues of access and equity.

3.1 Integrating a service type similar to Victoria's HACC A&S program will help to ensure that the CHSP realises its underlying vision by

- Providing flexibility in engagement activities, building trust, and carrying out assertive outreach and community engagement with vulnerable and disadvantaged community members with diverse characteristics.
- Working innovatively and creatively to overcome access barriers due to client diversity and vulnerability.
- Committing to provide support to the service provider, client and carers after the initial referral to address issues that arise and prevent premature withdrawal from the system by vulnerable and disadvantaged community members with diverse characteristics.
- Capacity building for vulnerable and disadvantaged community members with diverse characteristics through:
    i. culturally sensitive community education about the aged care system and wellness and reablement
    ii. information about the importance and availability of preventative and restorative services including but not limited to allied health and carer respite
    iii. strengthening clients' confidence to engage with the services system
    iv. supporting clients' preference to live in the community
- Enhancing continuous service improvement of services for vulnerable and disadvantaged community members with diverse characteristics through localised partnerships, secondary consultations and case conferences with assessment teams.
- Identifying strategies and gaining resources from community, other service providers to address concerns about the service delivery.
- Negotiating innovative and responsive ways of delivering and improving services through existing peak body networks.

3.2 On vulnerable and disadvantaged community members with diverse characteristics entering into CHSP system via My Aged Care Gateway

- The client scenarios in the CHSP Manual did not realistically reflect the barriers that vulnerable and disadvantaged community members with diverse characteristics would encounter when accessing and navigating the MAC Gateway and their need for assistance.
- Those from Special Needs Groups often experience significant barriers in building trust and engagement with the service system and require specialised assistance.

3.3 On the need for explicit safety nets, policies and procedures to safeguard the equity, access, wellbeing and healthy ageing of the most disadvantaged and vulnerable clients

- Policy must outline the minimum cultural and diversity competences required by all RAS and MAC officers and compulsory training modules in cultural and diversity competences must be implemented.
- Flexible models should be implemented for culturally specific RAS through partnerships or sub-contracting arrangements with local specialist organisations and their accredited assessors.
- A nationally standardised framework, guidelines and pathway detailing how to work with clients in Special Needs Groups who experience barriers due to their diversity should be developed.

- Cultural Self-Assessment and Audit tools should be implemented to enhance the accountability and monitoring of cultural and diversity responsive practices.
- The existing knowledge, expertise and experiences from the Victorian Diversity Network and Sectoral Development should be utilised.
- Strategies and resources should be established to support the continuous development of the ethnic and multicultural aged care sector and culturally specific service types (including culturally responsive respite and a culturally diverse workforce).
- Policies to safeguard "Priority of Access" for clients with multiple compounding vulnerabilities need to be developed to ensure timely service provision, especially in relation to allied health services.
- A national indicator or rating system to enhance standardised approach to determine "priority" should be developed.
- Resources for community representatives in the position of support and advocacy should be provided.
- There needs to be clarification for the CHSP Case Management service and the eligibility criteria for the service; support must be available for clients at the first point of contact and throughout the lengthy and confusing service pathway.

3.4 On the provision of language services

- The CHSP Manual does not clearly outline the availability of language services and the process for accessing language services.
- Concerns were raised about:
    v. increased demand on the TIS language service and its capacity to provide adequate and timely supply of translating and interpreting services.
    vi. lack of secondary translating and interpreting services in situations where TIS are unable to meet client needs.
    vii. "capping" of language services acting as a disincentive for generic organisations to access language services and disadvantaging organisations that are responsive to clients' linguistic needs
    viii. lack of safety net for unforseen rises in language service needs: "what will happen if organisations needed more language services than their allocated amount"?; "how will organisations negotiate an additional allocation or language supplement?".

3.5 On service sector's readiness for MAC Gateway and CHSP

- Need for Government to work with sector peak bodies, utilising current sector development positions where appropriate and existing networks to enhance sector's readiness in transition into CHSP and MAC gateway system.
- Need for Government to provide resources, forums, workshops and ongoing IT support for ethnic and multicultural organisations and community organisations to strengthen their capabilities to register in MAC Gateway and understand and use the MAC portals.
- Need for Government commitment to support ethnic and multicultural aged care organisations in line with the National Ageing and Aged Care Strategies for people from Culturally and Linguistically Diverse (CALD) backgrounds (Australian Government, 2012).
- Need for Government to work with specialist organisations to retain and enhance the invaluable specialist expertise, collective capital and existing localised relationships with their communities.
- Need for strategies to enhance a more diverse aged care workforce and continuous professional development to strengthen competence with diversity.
- Need for Government commitment to resource sectoral development position and networks that support peer support and learning, workforce capacity building, and initiatives that

coordinate and enhance systemic partnerships, including but not limited to the ECCV HACC Access and Support networks.

3.6 On the readiness of vulnerable and disadvantaged community members for MAC Gateway and CHSP

- Need for Government to effectively utilise existing networks and relationships between community members and community organisations to disseminate information about MAC and CHSP
- Need for Government to resource community organisations, including ethno-specific and multicultural organisations, to deliver community education programs and capacity building initiatives
- Need for Government to build in policy and resources to ensure information dissemination about MAC and CHSP in community organisations. For example, funded positions for the period of one year to conduct promotional activities in a localised, targeted manner to ensure equity of access to information for people from non-English speaking and culturally diverse backgrounds, Aboriginal and Torre Strait Islanders Communities, and people living in remote and rural areas.

3.7 On dementia related services

- There is currently a gap in the provision for dementia specific support services with availability not meeting rapidly increasing demand. This includes support for people living with dementia to enter MAC Gateway and CHSP, and other dementia specific services.
- Older people from non-English speaking and culturally diverse backgrounds may revert to their first language, and ethno specific and same culture dementia services are pivotal for the wellbeing of older people from diverse backgrounds living with dementia.
- Concerns with the lack of centre based support and opportunities for social participation for people from non-English speaking and culturally diverse backgrounds with dementia, and the lack of targeted resources for dementia and culturally specific planned activity groups.
- Need for Government to resource and strengthen dementia specific CHSP services in ethno-specific and multicultural organisations to ensure availability of language specific choices for clients.
- Need for Government to resource dementia training for workers from ethno-specific and multicultural organisations.
- Concerns about the eligibility of people living with early onset dementia under NDIS/Aged Care system funding split; need for CHSP Manual to clearly outline eligibility criteria and available services types for people living with early onset dementia.

3.8 On CHSP and carer recognition

- Need for clarity in relation to the carer's eligibility to access CHSP sub-program that is outside of the Care Relationship and Carer Support Sub-program.
- Need to ensure access to respite through Planned Activity Groups that support socially isolated clients and improve access to CHSP allied health services so that carers can maintain reasonable physical and mental health to continue to provide informal care.
- Need for Government commitment to continue Victoria's HACC Access and Support program or provide a similar resource that will continue to support carers in the community in an assertive outreach manner and enhance the capacity of the carers to self-care and continue their caring role.

3.9 On CHSP assistance with care and housing sub-program (ACHA)

- Significant concerns were raised about the service type that is funded in this sub-program.

- Community stakeholders have concerns about the lack of flexibility in the Community and Home Support Sub-Program and its service types. The lack of flexibility will have significant negative impact on clients who are experiencing homelessness and require a flexible drop in services or outreach model of care.
- There is concern that the proposed CHSP Assistance with Care and Housing Sub-program is a referral service only and will be redundant without adequate resources at the end of the referral service.
- Specialist organisations are often required to respond to unforseen emergency situations and the CHSP Manual has not outlined any strategies for emergency support and relief.
- Some flexible funding streams through the current Victorian HACC infrastructure have allowed homelessness specialist providers to provide bond support and initial rent to support people experiencing homelessness and at risk of homelessness to enter and access long-term secure housing. The CHSP Manual has not mentioned any similar flexible funding stream for the purpose of supporting people into long-term secure housing.

3.10 On CHSP's interaction with vulnerable clients at risk of elder abuse or experiencing elder abuse

- Older people from non-English speaking and culturally diverse backgrounds who are at risk of or experiencing elder abuse may have compounding vulnerabilities and additional challenges including:
    ix. language barriers, including low levels of English and low levels of literacy in their first language, meaning access to information and awareness of options is limited and there is often an over-reliance on adult children for information that leaves people more vulnerable to abuse.
    x. significant cultural barriers, stigma and feelings of "shame", including stigma around seeking help outside the family; stigma of admitting family relationships have broken down; stigma and lack of understanding around mental illness, depression and dementia; and expectations around ageing and the role of family.
    xi. lower awareness and relevant literacy about senior's rights than their English speaking peers, including lack of awareness of rights, options and services available, often compounded by a lack of relevant of culturally sensitive services. Cultural factors may affect understanding of "individual rights" and older CALD people may be less likely to consider options that separate them from family or community supports.
    xii. long term care arrangements may be made on the basis of trust alone, with an increased dependency on adult children in the post-migration period and due to language barriers or cultural expectations.
    xiii. social isolation, caused by smaller networks of friends and family post-migration, compounded by lack of services, lack of awareness of options, lack of transport and lack of understanding of the service system.
    xiv. difficulties in establishing trust and confidence to seek external and formal support.
    xv. fear of losing informal support when family members or carers are the perpetrators of abuse.
- It is unlikely that these clients will be able to access MAC Gateway or CHSP unassisted and the provision of additional support is paramount for healthy ageing.
- Need for the provision of additional support through preventative and capacity building measures that enhance clients' capacity to remain living independently in the community.
- Concerns raised about:
    i. the potential discontinuation of culturally responsive support in the community including the VIC HACC Access and Support program and access to bilingual staff via ethno-specific or multicultural agencies.

ii. the lack of housing options and crisis and long term secure accommodations for the growing older population, especially vulnerable groups that are resource poor and need to leave an abusive situation, including older people who have migrated through the Contributory Parent Visa and older single women.

iii. potential issues with the provision of information and support to non-English speaking and culturally diverse clients about elder abuse and situations of elder abuse where a family member is both the perpetrator and the person controlling access to service provision via packaged care.

iv. lack of a consistent referral pathways or consistent service responses regarding elder abuse

v. Lack of training for care workers on how to respond to suspected situations of elder abuse.

3.11 On CHSP and its provision for continuous professional training and development

- Need for a wider range of professional training opportunities to cover the full workforce spectrum (i.e. from primary care worker to allied health practitioners) and the knowledge continuum from minimal CHSP program requirements to specialist knowledge including but not limited to diversity competences and dementia specific modules.

3.12 On avenues for client complaints

- It is unrealistic to expect vulnerable and disadvantaged community members with diverse characteristics to "contact the RAS manager in the first instance" if the client has a complaint about the assessment process or outcome.
- Some of these clients will require the support of a HACC Access and Support Officer or an external representative to support them through the complaint process.

Appendix 1: Summary of vulnerabilities of frail and older people from culturally diverse backgrounds

There are negative effects of compounding vulnerabilities and low capabilities that include a combination of the below mentioned factors.

1. Low capabilities:
    a. Capacity to communicate verbally
    b. Literacy in English
    c. Literacy in Information Communication Technology
    d. Reduced cognitive abilities
2. Diversity characteristics that indicate higher vulnerabilities
    a. Cultural diversity, including experience of cultural stigma, or cultural belief of creating "shame" for the family if seeking Age Care Support Services, or feeling of "un-deserving" of support because of post-war migration history
    b. Cultural disempowerment, including having difficulties in:
        i. Initiating and building trustful working relationships, social engagement
        ii. Speaking up about the significance of their cultural and spiritual preference
        iii. Understanding informed consent and giving consent over the phone (for example: post war immigrants who experienced torture and trauma will be suspicious of authority and have difficulties giving out personal information over the phone, because of significant past terror imposed on them by authority)
    c. Experiencing or at risk of social isolation, including negative impacts of migration
    d. Health Literacy, basic understanding of health, "wellness and reablement" and ageing healthily
        i. Lack of availability of linguistically and culturally appropriate information about healthy ageing and a wellness approach to ageing
    e. Lack of understanding about the complex Aged Care Service system, eligibility criteria, how to access services, rights and responsibility, interaction between the Aged Care system with the Human Services system – Centrelink
    f. Experiencing mental health issues
    g. Being in remote and regional area, including access to IT may be a problem, and lack of services availability
    h. Homeless or at risk of homelessness, including premature ageing and priority for secure housing precede "wellness and reablement"
    i. Experiencing or at risk of elder abuse, may include fear of repercussion from perpetrator (i.e. carers, other family members) if seeking support from Aged Care Services
    j. Dementia including lack of understanding about dementia, changes in cognitive ability
    k. Diversity in sexuality, cultural safety and inclusive services for LGBTIQ
    l. Other diversity characteristics including experience of torture and trauma, disability, religion, support network as outlined in RDNS diversity framework: Policy, planning and practice (2012-2017) may also increase clients' vulnerability and exacerbate disadvantages.
    m. Clients with chronic and complex health and aged care needs

Appendix 2: Case studies

The following two case studies demonstrate how Access and Support Officers support vulnerable and frail older people from culturally diverse backgrounds with complex needs to access aged care services.

Case study 1

Client profile:

An elderly Greek woman with severe dementia named Joanna who lives at home with her husband. Joanna has reverted to her first language due to severe dementia and only speaks Greek. She carries a baby doll with her at all times and talks and sings continuously. She is experiencing mobility issues and requires intensive support with toileting.

Carer profile:

Joanna is cared for by her husband, Tselios. Tselios is experiencing a prolonged lack of support and a build-up of chronic stress. He continues to care for her at home by himself.

Case Episode:

The pair is referred for respite at a local council's Planned Activities Group (PAG) specifically for people living with dementia. Tselios has trouble accepting the services as they need a Greek speaking PAG for Joanna. It is too difficult looking after her in the PAG if there are additional language and cultural barriers. From his experience, the workers will not be able to manage her care needs.

PAG staff from the local council decline entry to the pair as they have significant concerns about how they will communicate with Joanna. Joanna needs one to one support for mobility and the PAG activities are not centre based. The staff members believe that Joanna will be too disruptive during their outing.

A&S Intervention and Case Management:

The HACC Assessment Officer refers the pair to an ethno-specific Access and Support (A&S) Officer.

The A&S Officer recruits a Greek woman from their own Greek Orthodox Church as a volunteer to provide Joanna with one-to-one support at the PAG.

A&S continue to develop a very thorough Social Inclusion Support Plan and discuss the strategies with the PAG staff. PAG staff are reassured by the A&S officer that the A&S Officer will provide short term support and find solutions if any problems arise.

A&S Officer went on to provide support to the volunteer; Tselios (Joanna's husband) and family were involved. A&S shows Tselios photos of Cora Graves Centre (a community centre), the staff and the PAG group out in action at the Botanical Gardens. A&S Officer invites Tselios to meet the PAG group and the staff prior to Joanna attending the PAG activities.

A&S Officer gets the support and involvement of extended family members to encourage Tselios, who is at breaking point, that it is alright for Joanna to join the PAG. The combination of the above mentioned innovative and flexible strategies, and client plan were able to comfort Tselios and make him understand that Joanna will be well cared for and supported in the PAG activity.

Tselios and PAG staff have now accepted referral after the Access and Support intervention. Tselios will now have every Tuesday off to take a break and have time for self-care. Good outcomes were achieved for Joanna and Tselios who experienced significant barriers to access the service and remain in service due to their diverse characteristics. Without the A&S intervention, the pair would have missed out on preventative aged care support. This may contribute to premature entrance to residential care for Joanna due to carer fatigue and burn out.

Case Study two

Client profile:

Mrs Zhu is 68 years old and lives with her 78 year old husband, Mr Zhu, who she was previously caring for. Mr and Mrs Zhu do not speak any English and have very little to no informal support networks that she can gain support from.

Mrs Zhu was independent with all activities of daily living until she was diagnosed with breast cancer in August 2014. Since commencing chemotherapy she is experiencing a decline in overall physical and mental health, which negatively impacts on her ability to manage everyday tasks. She is unfit to continue to care for her husband and is heavily reliant on her husband for everything, inculding transport to regular medical appointments and weekly radiotherapy sessions.

Her husband has Chronic Obstructive Pulmonary Disease (COPD), a lung disease that prevents him from breathing properly and affects his sleep during the night. In addition to that, Mr Zhu has had two heart attacks followed by major heart operations, has a chronic back problem, and has high blood pressure.

A&S Intervention and Case Management:

The ethno-specific A&S officer referred the clients to Aged Care Asessment Service (ACAS) to be assessed for aged care packages and provided support to get a higher level of HACC services to help support them. It is fundamental that the pair can get preventative support that can help maintain their current quality of life and give the Mr Zhu, who has complex health issues himself, a bit of relief and support through his reverse caring role for his wife who is undergoing cancer treatments.

The request for a home care package for provision of flexible support services whilst Mrs Zhu is undergoing treatment were rejected. A&S Officer continues to work with the clients to explore different avenues that can be provided for short to medium term support in order to meet their overall care needs and prevent further deterioration in health.

Conclusion:

Due to their various compounding vulnerabilites and limited capabilities, Mr and Mrs Zhu most likely will *not* be able to utilse the end to end My Aged Care Gateway without specialised assistance. They do not have the abilties to express and articultae their complex care needs and compounding health issues within a one to three hour RAS assessment. Ethno-specific A&S Officers are able to provide additional episodic flexible support in the community for people like Mr and Mrs Zhu so that they do not fall through cracks in the system. A&S Officers have demonstrated expertise and experience, and have established realtionships with the communities and knowledge about the service system to provide referrals, initial needs identification, and support for the most vulnerable and disadvantaged people within our community.

For further information contact:
ChenSu Ooi, HACC Sectoral Development Officer
at email cooi@eccv.org.au and on telephone 03 93494122