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Aged Care Policy Report

On

ECCV - AAVic Forum

On

New and Emerging Ageing Communities

17 October 2013

I. Executive Summary

The *Forum on New and Emerging Ageing Communities* was facilitated by ECCV Deputy Chairperson and ECCV Aged Care Policy Sub-Committee Convenor Marion Lau OAM. The Forum was organised by the Ethnic Communities' Council of Victoria (ECCV) in partnership with Alzheimer's Australia Vic (AAVic). It was held on 17 October 2013 at ECCV in Carlton, Melbourne.

The Forum's focus has been improving access of new and emerging communities to aged care services. The event brought together more than 70 representatives from service providers, Government and multicultural organisations. The Forum consisted of introductory speeches, a panel discussion and workshops. Feedback has shown that people found the discussions of the Forum useful and increased their understanding on new and emerging communities that are ageing.

The following provides a summary of key issues raised at the Forum. They were:

- ECCV has a role in advocating on behalf of new and emerging communities that are ageing
- It is vital that new and emerging communities build relationships to speak with a more unified voice

- Partnerships need to be facilitated between new and emerging communities and the aged care sector including ethno-specific providers
- It is essential that service providers work in collaboration with ethnic community organisations to develop culturally inclusive aged care services
- It is vital to improve access of new and emerging communities to dementia services
- People from new and emerging communities prefer to stay living at home longer
- It is fundamental to create trust and offer information to seniors on how to access the aged care system
- Government has an important role in supporting new and emerging communities in establishing ethno-specific aged care programs to ensure better access to culturally appropriate care.

ECCV held two aged care Forums in 2013 to consult with the sector on issues new and emerging communities encounter when wanting to access aged care services. In addition to the Melbourne Forum on New and Emerging communities, ECCV held a regional Forum together with the Ballarat Regional Multicultural Council on *Strengthening Diverse Ageing Communities* in September 2013. The feedback from the Forums will contribute to an ECCV discussion paper in 2014 on older people from new and emerging communities.

The following analysis gives an overview of discussions in the workshops, summarises the panel discussions and speeches, provides feedback from participants, and outlines the follow-up.

II. Workshop Discussions

The following section summarises the four workshops of the Forum and highlights key recommendations that have been developed on the basis of the workshop discussions.

ECCV and Capacity Building – Workshop Number One

The discussions in the workshops highlighted that ECCV can play an important role in building the capacity of new and emerging communities in aged care. ECCV has well established partnerships in the aged care sector such as in the area of Home and Community Care (HACC). Organisations representing older people from new and emerging communities need to work in partnership and it is vital that ECCV facilitates these partnerships. As there is no funding available for all community organisations, ECCV's role could be to build a collaborative structure that enables new and emerging communities to better access funding . ECCV is well placed in helping communities set up networks and link them with the aged care sector.

Some new and emerging communities are experiencing division. It is vital that communities speak with one voice. ECCV could assist in building a cohesive community through training of leaders and building the capacity of the community. Generally it is vital that ECCV reaches out to community leaders and encourages them to participate in ECCV community Forums.

Further ECCV could train members from new and emerging communities to be able to cater for their older people. It was suggested that ECCV runs leadership workshops and supports training for community organisations on service delivery and on issues surrounding governance and management.

Further it was emphasised that ECCV's has a role in advocating for new and emerging communities. That includes access to grants in aged care for new and emerging communities. Especially for smaller communities it is challenging to access available funding. Further a member from an organisation representing African communities stated that it is the role of ECCV to act as a bridge between Government and African communities. Communities might also need support in administering their funds.

Seniors from a non-English speaking background may revert to their mother tongue when ageing. People from new and emerging communities should be trained to work as carers for older people from those communities.

Recommendation from Workshop Number One

That ECCV facilitates partnerships among members from new and emerging communities in aged care and builds bridges between new and emerging communities and the aged care sector.

Service Provider Response to Community Needs – Workshop Number Two

Workshop discussions centred on concerns that some service providers rely heavily on input and feedback from their key community workers or contact persons to inform their practices.

Participants stressed the importance of undertaking more research into community needs, levels of awareness of services and service concepts. Such research needs to be evidence-based in order to get a sound understanding of the needs of new and emerging communities.

Further the workshop highlighted the complexity of meeting current Aged Care Assessment Service (ACAS) audit requirements. The current assessment processes require clients to complete complex paper work. It does not take into account cultural concerns and language barriers that people from diverse backgrounds face. For example due to pre-migration experiences of abused trust some people might feel reluctant to sign documents. This makes it difficult for service providers to meet ACAS compliance standards.

Workshop participants emphasised that home care packages are in high demand amongst senior from a non-English speaking background. This is the case as services are often delivered by bilingual staff. Transition to residential care can be very challenging for culturally diverse seniors as people hold a negative view on residential aged care and are reluctant to access these services. Aged care facilities need to work in partnership with community organisations to develop and implant culturally inclusive practices and ensure that the needs of clients from a non-English speaking background, their families and carers are met. The Southern Migrant and Refugee Centre (SMRC) has been proactive in improving access of new and emerging communities to culturally responsive care. The organisation is currently working with a residential care facility to house Spanish speaking clients and to build the facility's capacity in delivering culturally inclusive and responsive care. It includes reviewing the cultural practices of the facility and making suggestions on how to enhance the cultural responsiveness of the facility.

It was highlighted that service providers need to work in partnership with new and emerging communities. This includes reaching out to communities and also listening to them in order to identify preferences of older people. Providers should strongly engage with new and emerging communities in relation to planning, developing and delivery of services.

Further it was suggested that innovative funding options for smaller communities need to be created to meet the needs of smaller new and emerging communities.

Recommendation from Workshop Number Two

That service providers work in collaboration with ethnic community organisations to develop culturally inclusive practices.

Perspective of New and Emerging Communities – Workshop Number Three

New and emerging communities have a limited ability to fulfil the requirements of larger aged care projects, such as building a residential aged care facility. The approval process for becoming an aged care facility is highly complex. It is challenging for new and emerging communities to get access to aged care funding and programs, such as HACC and social support. Further new and emerging communities need facilities for seniors to meet.

Seniors from new and emerging communities are often isolated in existing residential aged care facilities. New facilities that are being build are far away from where the communities live. The Department of Social Services should stipulate diversity standards. The existing mandated accreditation standards need to include requirements to cater for diversity. This might entail same language visiting programs, culturally appropriate food, and cultural activities to overcome social isolation. It was stressed that partnerships between the residential care facilities and ethnic communities are vital to deliver culturally appropriate care. A directory of existing ethno-specific groups would be helpful in linking up communities and service providers.

Seniors from new and emerging communities might not be able to participate in available social activities if transport options are not available. Buses provided by Local Councils don not cross Council borders. For example a senior from a non-English speaking background living in Dandenong might not be able to attend an event in Monash.

The discussion showed that models of best practice in ethno-specific or multicultural aged care service delivery targeting new and emerging communities are scarce. One participant mentioned a program that has been funded by the former Department of Health and Ageing with the title of *Understanding the aged care system*. As part of the program the Government worked with residential care facilities in improving the cultural appropriateness of facilities. Under the same program the Government worked with ethnic communities to better understand the aged care system.

New and emerging communities should use existing infrastructures, such as ECCV, Victorian Multicultural Commission and Local Councils to make their voice heard. It has been mentioned that ECCV's Aged Care Policy Sub-Committee is a vital platform and ECCV should encourage representatives from new and emerging communities in participating. Also communities need have opportunities to build relationships and network in order to speak with a more unified voice. This presents a challenge as communities are often divided.

Also it has been indicated it is vital that service providers talk to community groups on how to navigate the aged care system.

Recommendation from Workshop Number Three

That the Government provides support to new and emerging communities in establishing ethno-specific aged care programs and get better access to culturally appropriate care.

Dementia Services – Workshop Number Four

Participants of the workshop on dementia emphasised the importance of linking members from new and emerging communities to available dementia services. Especially seniors from new and emerging communities encounter difficulties accessing generic services. It is important to recognise that new and emerging communities are diverse in culture, language, and spiritual beliefs.

Understanding this diversity could lead to better outcomes when working with new and emerging communities. Participants stressed the need for more discussion in culturally diverse communities around dementia as it is often hidden or ignored until crisis point. This includes engaging with new and emerging communities in order to raise awareness of dementia, particularly by talking to them about some of the myths and stereotypes associated with the disease.

One of the challenges service providers encounter is that people living with dementia and their carers often isolate themselves and lose contact with the community and friends. Families see it as their obligation to care for the person living with dementia and therefore are reluctant to make use of available services such as home care, personal care, respite and delivered meals.

Participants acknowledged the challenges second generation migrants encounter in convincing their parents to access services, use respite and consider residential care as an option. It puts an enormous amount of pressure on children who are working full time while also caring for their parents. It was highlighted how important it is to engage with younger second generation carers. A targeted approach is necessary and may include the establishment of support groups that meet the needs of young carers. Also it is vital that government, health professionals, service providers, ethnic community groups and people with dementia work collaboratively to develop practical solutions that address service gaps.

Educating the community about services, service access and pathways were seen by participants as decisive in meeting the needs of these communities. A great effort is required in order to energise ethno-specific and mainstream organisations in conveying educational messages and information that reach the whole community. Community education needed to target people living with dementia, families, carers and GP's and aged care professionals. It was also emphasised how important it is that aged care professionals have a good knowledge of dementia in order to be able to initiate conversations about dementia with care recipients.

It is vital that information and resources on dementia are tailored to the diverse needs of communities including smaller ethnic communities. It was suggested to consult with communities first to ensure that resources are culturally sensitive and take into account varying levels of English and literacy. Audio visual resources such as YouTube or DVD clips in community languages that feature experiences of people living with dementia and their carers and families are helpful in encouraging people to speak more openly about dementia. These resources need to also target members from new and emerging communities.

Participants further stated that seniors from new and emerging communities are more likely to listen to ethnic radio. Therefore service providers may utilise this avenue to better reach out to

communities. Participants agreed that ethnic media agencies play a vital role in disseminating information to people who are isolated or have low levels of literacy.

Recommendation from Workshop Number Four

That service providers work towards improving access of people from new and emerging communities to dementia services.

III. Panel Discussion

Marion Lau OAM JP facilitated the panel discussion. Ms Lau asked each panellist one question. Below is a summary of the panel discussion.

Panellist One:

Jenny Semple CEO from Southern Migrant and Refugee Centre (SMRC) in Dandenong was asked the question: How can service providers respond to needs of new and emerging communities? Ms Semple mentioned that the largest Afghan community in Victoria is living in Dandenong. Other new and emerging ageing communities in Dandenong are Tamils, Iraqis, Cambodians and Cook Islanders. There is a difference between these communities and more established ethnic communities. New and emerging communities have no family links to Australia, they are often isolated here and have come as refugees. The communities have no residential care facility and staff do not speak their language. Further new and emerging communities have no access to HACC funding and they are still in the process of establishing their associations. Communities lack trust in the settlement system. To many the Australian service system is a foreign concept. When working with seniors from new and emerging communities it is fundamental to create trust and offer information on how to access the aged care system. It is vital that seniors from new and emerging communities receive funding for their seniors groups. Volunteers from new and emerging communities are able to create trust amongst the community. In the Somali community for example aged care is not seen as an aspiring career. Even small grants to new and emerging ageing communities, such as 200 AUD, would already help them in organising celebrations or outings. The SMRC is regularly consulting with communities. When working with new and emerging communities it is vital to be patient and persistent.

Panellist Two:

Parsuram Sharma-Luital JP, Assistant Secretary ECCV and Convenor of ECCV's New and Emerging Policy Sub-Committee was asked the question: How can we improve access of new and emerging communities to aged care services?

Mr Sharma-Luital mentioned that he is former refugee from Bhutan. He has been engaging with a variety of communities, such as through his work with the Victorian police. The Bhutanese community arrived in Australia in 2008 after having lived for almost 20 years in camps. The community is ethnically Nepalese and are largely Hindu. People in the community prefer to stay at home when ageing as the concept of living away from family in an aged care facility is completely foreign in the Bhutanese community. Therefore it is vital to support them at home. People prefer that their

children look after them while they are ageing. In the community it is seen as a shame if children cannot take care of their parents. It is important to build small community hubs where seniors can grow vegetables as elderly people like to grow vegetables in their backyard. Maintaining the connection to the land and spending time with their family is fundamental to living a dignified life and practising cultural traditions. Older people from the Bhutanese community need rooms or cultural centres in which people can talk about their religion and culture and sing religious chants.

Panellist Three:

Dr Santosh Kumar is President of the Northern Regional Indian Senior's Association, Executive Member Federation of Indian Associations of Victoria, and Secretary of the Northern Federation of Ethnic Senior Citizen Clubs.

Mr Kumar was asked the question: How can we support new and emerging ageing communities in building up an aged care infrastructure.

Members from new communities have put in all their effort to integrate into the Australian community. One day they realise that they are seniors. People from the Zimbabwean community for example encounter difficulties driving in Melbourne. Older people from new and emerging communities do not want to return to their homelands as their children are living in Australia. There was initially capital available from the Government to build an Indian-Iranian multicultural aged care centre. However, that money is not available anymore. Capital support at Government level is crucial to support new and emerging communities to build their aged care infrastructure.

Summary of Q & A from the Audience

People from small communities such as from African communities have experienced stressful situations. Social support groups are vital for these communities. However, communities cannot access grants as the community is low in numbers and due to insurance regulations. Established communities could work together in partnership with new and emerging communities. There would be ways of bridging cultural differences such as by offering a variety of food, catering for the language needs of residents and by having separate tracts within the aged care facility. Further government needs to make funds available to new and emerging ageing communities. The African Australian Welfare Bureau mentioned that the organisation looks after the African community. There are 57 countries in Africa, and just in Congo 134 languages are spoken. The organisation has representatives from the 'four corners of Africa' (i.e. North, South, East, and West). In terms of working with other communities, one challenge is that established communities charge for helping with grants applications. It is vital the people work together as genuine partners. The African community has been advancing and is now able to advocate for themselves.

IV. Summary of Speeches

Two speakers presented at the Forum. The following section provides a summary of the speeches.

ECCV Director's Speech

The ECCV Director Ross Barnett emphasised that older people from new and emerging communities are increasingly ageing. The communities are new in the sense that they settled in Australia comparatively recently. They are emerging in sense that they are yet to experience the peak in their aged populations. These communities need increasingly access to aged care services. ECCV

recognises that the more established communities, such as the Italian community have not reached the peak in their ageing either.

ECCV community feedback indicates that older people from new and emerging communities in Victoria have limited access to aged care services. New and emerging communities are struggling to build an aged care infrastructure that serves their community and to negotiate relevant partnerships with service providers.

The largest new and emerging ageing community in Victoria is the Indian community. According to the 2011 Census, there were 12,500 people from the Indian community aged 55 and over living in Victoria. Older people from new and emerging communities are diverse in culture, language, ethnicity, size, and migration experience.

A proportion of them have experienced trauma in their country of origin. People who have experienced trauma tend to age more rapidly. For these reasons seniors with a refugee background will require access to aged care services before aged 65. ECCV's Health Literacy Paper demonstrated that people who have arrived to Australia during the past five years have lower levels of health literacy compared to the Australian-born population and also migrants who have lived in Australia for longer periods.

ECCV is aware that seniors from new and emerging communities need access to ethno-specific and multicultural aged care services like other, longer established communities.

AAVic's Manager Strategic Indicatives Speech

The AAVic's Manager Strategic Initiatives Jack Sach outlined that dementia describes a set of symptoms that are caused by disorders affecting the brain. It is not one specific disease and not a normal part of ageing. Dementia affects thinking, behaviour and an ability to perform everyday tasks. As the disease develops, brain function is increasingly affected and interferes with normal social or working life. The hallmark of dementia is inability to carry out everyday activities which affects memory, language skills, planning, spatial skills, judgment and attention. People living with dementia may also have difficulty solving problems and controlling their emotions. They may experience personality changes, become agitated and, in some cases, experience delusions. There are over 100 diseases that cause dementia, the most common being Alzheimer's disease, vascular dementia, Lewy body disease and fronto temporal dementia. Dementia is progressive and fatal, and at this stage it is incurable. There are medications to slow down, but not stop the dementing process.

In Victoria there is an estimated 74,600 people living with dementia, 6714 of whom are from Asian, Middle Eastern, African and South American backgrounds. Many of these people will be recent settlers or some from small communities and have limited understanding of dementia or support. Different communities have very different understanding of dementia and many are not familiar with the way services are offered in Australia. Alzheimer's Australia Vic completed a study of the perception of dementia in 13 ethnic communities report which demonstrated a wide range of understandings about the condition. For some languages there is no word for 'dementia', and in many cases dementia is not well understood and negatively portrayed as a 'loss of mind' In the Arabic speaking community for example dementia or 'kharaf' means 'loss of mind or when someone talks nonsense'.

To improve community understanding of dementia and raise awareness of services available to older people from the new and emerging communities, it is important that service providers work collaboratively with these communities and use the support that is available through Alzheimer's

Australia Vic. It has dementia information in 35 community languages that are available free at www.fightdementia.org.au or by calling the National Dementia Helpline on 1800 100 500. Interpreters are also available if required. Alzheimer's Australia Vic staff are also available to speak to communities about dementia and provide resources.

V. Summary of Evaluation

The following section summarise the feedback that has been received from participants.

Survey Participants

37 people participated in the survey out of a total more than 70 attendees. 11 survey participants stated that they were generic service providers and 8 from Government (local, state, and federal). 6 attendees stated they were from an ethnic community organisation and the same number were from an ethno-specific or multicultural service provider. 6 attendees described themselves as 'other'.

Support of the Forum

The feedback from the survey indicates that the Forum was relevant to attendees and that the community supported the Forum. The majority of survey participants found the topics of the panel discussion and workshops to be useful and relevant. Also attendees were able to increase their understanding of new and emerging ageing communities. Participants stated that contacts made at the Forum will be useful. Further, attendees stated that their community benefited from the Forum. Details of responses are displayed in the table below:

Type of organisation/group						
Member of ethnic community organisation		6				
Ethno-specific or multicultural service provider		6				
Generic service provider		11				
Government (local, state, federal)		8				
Other, please specify:		6				

Results from the following responses	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Overall the topics of the panel discussions were useful and relevant	14	22	2		
Overall the topics of the workshops were useful and relevant	19	12	4		
The forum has increased my understanding of new and emerging ageing communities	16	14	7		
The contacts and networks I made at the forum will be useful to me	10	15	9	1	
My community/organisation benefitted from the Forum	13	17	8		

VI. Next Steps

The findings of the Forum will help informing the ECCV discussion paper on older people from new and emerging communities. The paper is expected to enhance ECCV's advocacy on behalf of seniors from a non-English speaking background particularly those who have arrived more recently. It is suggested that ECCV and AAVic meet to discuss the outcomes of the Forum.

The Forum report will be made available on the ECCV website.

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