ECCV Submission to the Australian Government Department of Health on *Future Reform – An Integrated Care at Home Program to Support Older Australians* Discussion Paper

August 2017

Introduction

The Ethnic Communities' Council of Victoria Inc. (ECCV) is the voice of multicultural Victoria and the peak policy advocacy body for eight regional ethnic community councils and up to 220 members including ethnic and multicultural organisations across Victoria since 1974. For over 40 years, we have been the link between multicultural communities, government and the wider community. ECCV has a strong history in advocating for the rights of Victoria's multicultural communities.

We aim for a culturally diverse and harmonious society that is just, fair and inclusive where all people have the opportunity to participate in and contribute to community life. We advocate for freedom, respect, equality and dignity for multicultural communities and strive with others, to build a strong, vibrant Victorian community.

ECCV is pleased to have the opportunity to contribute to the Department of Health's discussion paper on *Future Reform – An Integrated Care at Home Program to Support Older Australians*. We applaud the Department's commitment to continual improvement in the area of aged care, and its concern for ensuring that Australia's aged care system serves the interests of all Australians, including those with diverse needs and from diverse backgrounds.

Response to Questions in Department of Health Discussion Paper

We would welcome your views and feedback on the February 2017 *(Increasing Choice)* reforms.

ECCV has consulted widely with members, stakeholders and other interested parties on how they have been affected by recent changes to the aged care sector. ECCV is concerned that the pace of reform has created difficulties for some customers and Service Providers, and that not all issues arising from previous reforms have been settled at the time of writing.

It is important that new policies and procedures should be well-regulated in the initial stage, to facilitate careful evaluation of how they are functioning, before the market matures and new practices are standardised. ECCV hopes that the Department will continue to engage with customer groups, Service Providers and peak bodies to evaluate the achievements of the integrated system in fulfilling its objective to improve the quality of aged care available to older Australians through customer empowerment.

ECCV also encourages the Department to consider the difficulties caused by rapid changes to a sector in which customers often have changing needs, and can have difficulties comprehending how they are expected to engage with the system and make directives about their own care.

Are there any other key policy objectives that should be considered in a future care at home program?

In addition to the objectives listed in the Discussion Paper, ECCV suggests that the following further objectives be considered for the Care at Home Program:

1. Recognition that a whole-of-community approach is the most appropriate way of ensuring aged care that meets the needs of older Australians.
2. A future program should aim to ensure that seniors remain a part of their community.
3. Recognition that aged care is more than just a business.
4. Support for customers and their carers to make informed choices, maintain two-way communication and ensure respect for the diversity of customers and their carers.

What do you believe could be done to improve the current assessment arrangements, including addressing variations or different practices between programs or care types (e.g. residential care, home care and flexible care)?

ECCV believes that an integrated Care at Home system requires as single integrated and consistent assessment process.

Current processes can be confusing for customers, especially those from Culturally and Linguistically Diverse (CALD) backgrounds. [1] As an entry point to the system, My Aged Care has improved somewhat since its introduction, but is still not an ideal gateway for accessing the system. In particular, many seniors from non-English speaking backgrounds have reported that that the My Aged Care website is difficult to understand, and also to navigate, with an abundance of hyperlinks to new pages that can rapidly cause users to become disoriented and unable to process the

[1] For the purposes of this submission, the term "CALD" is used throughout the document to describe cultural, linguistic and religious diversity.

necessary information. The language on the website is at Level 12 English. ECCV believes that Level 6 English would be more appropriate for CALD customers to comprehend.

In order to ensure CALD community members are aware of their rights, obligations, understand their options and the terms and conditions to which they are agreeing, it is important that all information provision, fact sheets, arrangements and agreements are written in plain English. Complex English is also more difficult for interpreters and translators to use to provide preferred-language support.

The My Aged Care hotline is also quite intimidating for some people from diverse backgrounds. Interpreting is provided, but often involves a long wait period and therefore is not friendly to customers. The interpreting is generally directly interpretation of relatively complex English, and is therefore often not readily understandable even in a customer's preferred language.

ECCV hopes that the future integrated program will make allowances for the lack of digital literacy of many CALD seniors, and have appropriate support in place as they move through the system, so as to ensure that they are not disadvantaged.

Prior to the introduction of My Aged Care, customers in Victoria first made contact with the aged care system by contacting a local Service Provider, who could refer them for assessment. This built a link between local providers and their community, and was often a more reassuring way for CALD seniors to learn about what the aged system offered.

ECCV recommends that the Department consider creating a physical space ("Hub") where seniors and the families/carers could talk to My Aged Care staff and receive advice about how to access and engage Service Providers. Ideally these could be created by existing providers, and also function as social space with support from block funding.

An integrated assessment process could also be made more responsive and supportive of customers by taking a multidisciplinary approach. Under such a model, assessors should possess skills and qualifications roughly equivalent to those of current ACAT assessors, or alternatively, assessors would be able to effectively triage clients, and health professionals would be available for referral if deemed appropriate by assessors.

It is vital that the aged care system can communicate with people in their preferred language. An appropriate use of translating and interpreting is necessary to ensure equity of access and full consumer engagement in the assessment process. Translating and Interpreting Services are funded for assessments, but customers are not always aware of this, and assessors do not always advise them of this entitlement. ECCV has observed that some customers from CALD backgrounds are not confident to ask questions or request interpreters, and believes that the Care at Home system must provide clear information in multiple languages to inform customers of their rights.

ECCV suggest consideration of the possibility that a Care Plan could be drafted immediately after an initial assessment. This would serve as a basis for discussions about a Care Plan between the customer and Service Provider, and better empower clients to understand the options they are likely

to be presented with. At present, Service Providers tend to undertake their own assessments, and these serve as basis for creating Care Plans that are independent of the initial assessment. This can be particularly problematic for those with limited or no English, who may struggle to understand discussions, their options, and what the nature of the agreement that they are signing. An initial draft Care Plan may also help reduce the need for customers to repeat information to multiple providers, which can often lead to frustration and an inefficient use of time and resources.

Finally, consideration should be given to how it can be ensured that assessment standards are maintained. In particular, ECCV believes that assessors should not be paid per assessment, as this incentivises assessors to complete assessments as quickly as possible, which presents difficulties in maintaining appropriate standards.

Recommendation: That the integrated Care at Home program consider ways to take an inclusive and multidisciplinary approach to assessment in order to ensure equity of access for diverse groups to minimise barriers that discourage full engagement with the system and to ensure that the needs of CALD seniors are identified and supported as early as possible.

Would you support the introduction of a new higher package level or other changes to the current package levels? If so, how might these reforms be funded within the existing aged care funding envelope?

Any proposal to introduce a new higher package level (Level 5) would require very careful preliminary research regarding costs. ECCV would recommend careful examination of whether such a package could deliver value for money compared to the costs of residential care.

An innovation that would make a new package level valuable would be provision of care at night in customer's home. Night is often the time when customers are most at risk and feeling most vulnerable, so an extension of Home Care here would make sense, and help reduce the feeling among some customers that they can only have their needs met in residential care. Whether a new higher-level package is required to supply the funds for customers to access this is not something ECCV is in a position to determine. It may be most productive to allow such a provision to be more widely available for customers in receipt of support through current higher-level care packages.

Which type of services might be best suited to different models, and why?
What would be the impact on consumers and providers of moving to more individualised funding?
Are there other ways of funding particular services or assisting consumers with lower care or support needs, e.g. a combination of individualised funding and block funding, vouchers, etc?

ECCV has observed that current aged provision though the Commonwealth Home Support Programme and Home Care Packages involves some inconsistencies with regards to customer fees and subsidies. Client contribution towards CHSP services are largely at the discretion of the Service Provider, are often nominal, and there is a lack of consistency about how these are collected. There is also often a lack of transparency about the fees that will be charged, and the exact nature of the service that is being purchased. (Exit fees in particular are not clearly communicated to customers prior to purchase of services.) Some providers make this information easy to access and interpret, but others do not. ECCV feels that regulation is needed in this area to assist customers to make properly-informed choices under the principle of consumer-directed care.

Current pricing structures and practices with regard to fee collection and income testing can often create a disincentive for customers accessing CHSP to move to Level 1 and 2 Home Care Packages, even if they are assessed as eligible for them. Since CHSP is charged as a fee per service, and HCP is funded through a daily fee (currently $10.10 for a full pensioner, with an additional income-tested fee for part pensioners and self-funded retirees), some customers prefer to remain on CHSP, or access private Home Care instead of lower-level HCP. ECCV hopes that a future integrated package will provide a consistent, transparent fee structure, that is considerate of customer capacity to pay, and free from any disincentives for customers to access the care they need.

ECCV recognises that it is reasonable to expect customers to contribute to the cost of their care, in line with their capacity to pay, but recommends that the Department of Health be mindful that there are some customers receiving services who are accustomed to not being required to make any contribution, and may be affronted at being asked to pay to continue to receive the same service. Sensitivity will be needed in communicating with these customers.

ECCV hopes that the Department will involve stakeholders from the aged care sector in discussions around changes to the Client Contribution Framework, and provide an opportunity for comments.

ECCV acknowledges that a model of consumer-director care (CDC) can provide customers with an opportunity to choose the care they believe is most suitable, and provides an incentive for Service Providers to meet the needs of customers. However we also believe that there are certain services for which block funding is the only sustainable funding model. These include clubs, community groups and Planned Activity Groups (support groups providing activities that promote social inclusion and build capacity in the skills of daily living) that provide services and support for specific population groups, in particular those from CALD backgrounds. These organisations fulfil a vital social function in helping combat loneliness and isolation in older Australians, and also act as conduits for providing information to seniors.

Ethno-specific Service Providers are often best-placed to deliver the care that can maximise wellbeing and reablement, health, and nursing services. Block funding best serves these organisations, as they deliver to large groups, are often ad-hoc and difficult to plan as part of an individual's package of funding. They therefore provide a service analogous to a public good, whereby customers derive significant benefit from the service, but lack an individual incentive to contribute towards its cost. It is likely that many such services would not be able to survive in a model funded entirely through consumer-directed care. CDC therefore increases the risk of already-isolated customers becoming even more so, and losing the support they are accustomed to receiving from community hubs. This may have significant negative effects on mental health, and require them to receive more intensive support in future.

Recommendation: That the Department acknowledge the important role played by smaller, niche and ethno-specific aged care Service Providers, and consider measures such as ongoing block funding to ensure that these organisations have a sustainable future in a program of consumer-directed care.

How could a wellness and independence focus be better embedded throughout the various stages of the consumer journey (i.e. from initial contact with My Aged Care through to service delivery?

Given the objective of allowing people to live independently for as long as possible, program reforms need to carefully consider the triggers that tend to result in people moving to residential care. The general triggers (such as falls, acute illnesses, general health deterioration and increased pressure on carers), can often be overcome with the help of assistive technology. However the cap of $500 a year on the purchase of assistive technology[2], often cannot purchase the necessary technology. ECCV believes that an increase in the annual cap would help seniors to remain at home for significantly longer periods, and therefore help ease access and funding pressures on the residential aged care system.

[2] Department of Health, *Commonwealth Home Support Programme Manual 2017*, p.50

How can we make the care at home system work better for specific population groups, particularly those whose needs are not best met through current CDC models and administrative arrangements?

The difficulty that people from CALD backgrounds have in navigating the aged care system and making informed choices must always be considered in the design of an integrated home care program. ECCV feels that the tailored approach and goal-setting under CDC is positive, as a way of engaging and encouraging clients to focus upon strengths and positive pathways. However, given the difficulties CALD seniors can have in understanding and accessing the choices available to them, a rigorous CDC approach may discourage engagement, and potentially leave some older Australians removed from the system until they reach a crisis point. ECCV strongly hopes that an open, transparent and inclusive Care at Home system will encourage engagement by diverse customer groups, and remove the risk of isolated groups failing to take advantage of the services available.

Senior members of CALD communities would benefit greatly from having the option of bilingual and culturally-appropriate care. CALD seniors often find it hard to understand the nature services, fees, and terms and conditions, and therefore may require special assistance to compare Service Providers and take advantage of the competitive market. An appropriate availability or translating and interpreting services is necessary to assist CALD to make informed choices. In the absence of this, many non-English speakers will engage with assessors, Case Managers and other staff through informal interpreting from family members and carers. ECCV believes that as the interests of customers and their family members/carers may not coincide, lack of sufficient interpreting leaves customers susceptible to elder abuse.

The potential for abuse should be considered carefully in designing an integrated system, and ensuring that is understandable and navigable for those with limited or no English. ECCV hopes that there can be further consultation with the aged care sector to ensure that the integrated system has sufficient capacity to support clients and minimise the risk of elder abuse.

ECCV has observed a hesitation amongst some older Australians from diverse backgrounds to engage with the aged care system and reach out to mainstream Service Providers, due to notions of large bureaucratic and government bodies as untrustworthy, which is likely an inheritance from the political culture of countries of birth. A system which is moving more towards a philosophy of self-help can therefore be particularly intimidating to certain sectors of the population. This increases the extent to which children and carers may become involved in assisting customers use the system. This raises another consideration for members of CALD communities, in that as many migrated to Australia as young adults while their parents remained in their countries of birth, they do not have the experience of having assisted their own parents engage with aged care, and therefore do not have the understanding that comes from this. They may also find their own children less sympathetic to their needs, as it will be the first time they have seen a family go through the ageing process, and may not appreciate the challenges and opportunities. ECCV hopes that the Department

will be mindful of these matters and create a Care at Home system that is considerate of the particular issues facing older CALD Australians.

Another aspect that must be considered is that CALD seniors (as with other groups with diverse needs), benefit greatly from continuity of care and workforce. The move to CDC has seen an increase in the casualisation of direct care staff, and in many cases services are only delivered between 9:00am and 5:00pm. This creates uncertainty which many seniors find disorientating and stressful.

Members of CALD communities would benefit greatly from having staff to help them navigate the aged care system. In Victoria, Access and Support (A&S) Workers provide a particularly valuable service in helping people to navigate the aged care system, and ensuring equity of access to people with special needs. This is line with the wellness and reablement philosophy of the reforms, as A&S workers play an important role in supporting people who would otherwise often go without support until finding themselves in a crisis situation.

Recommendation: That the Department of Health explore ways in which an equivalent to Victoria's Access and Support Program could be embedded in the nationwide assessment process of the integrated Care at Home system in order to ensure people with diverse needs are not disadvantaged in accessing the system.

What additional supports could be considered to ensure that people with diverse needs can access services and make informed choices and exercise control over their care?

ECCV believes that a supportive and inclusive Care at Home Program should incorporate the principles of consumer protection and provider awareness into its framework. Members of CALD communities face a greater risk of falling victim to unscrupulous Service Providers, particularly in relation to lack of transparency of fees, explanation of options, and insufficient translating and interpreting. For example, customers currently must be offered interpreters during the assessment process, and any request for an interpreter must be met. However some providers do not inform customers of their rights in this regard, and it is often difficult for CALD seniors to discover and digest all the terms and conditions of the aged care system for themselves. This is not only necessary to mitigate against the risk of exploitation, but also to ensure that customers can understand the choices they have, and thus take full advantage of consumer-directed care.

The lack of cultural awareness/competence of many mainstream Service Providers means that people from CALD backgrounds can be reluctant to engage with them. ECCV believes that there is sometimes a lack of awareness of Quality of Care principles, as stated in the *Quality of Care Principles 2014* made under section 96-1 of the *Aged Care Act 1997*[3]. Mainstream Service Providers

[3] Australian Government, Quality of Care Principles, Aged Care Act 1997

should be encouraged to recruit bicultural and bilingual staff to help facilitate more culturally appropriate service provision.

An example of best practice in Care at Home provision for a group with specific needs is in South Australia, where Service Provider ACH Group has partnered with the Islamic Arabic Centre, to provide culturally and religiously appropriate Home Care to elderly Muslim Australians.[4] This is also an example of the value of supporting customers by supporting their children and carers, and making best use of their willingness to remain key participants in providing care to their elderly family members.

The foremost opportunity that the move to an integrated Care at Home program provides is however for the language across the system to be made plainer and easier to understand for both English and non-English speakers.

Recommendation: That the aged care system be designed so as to allow communication with customers in their preferred language through free access to interpreters for clients and Service Providers where necessary and through provision of all materials in plain English and with translations available.

How might we better recognise and support informal carers of older people through future care at home reforms?

ECCV is pleased to see that the Department is concerned with better recognising and supporting the role of informal carers in its reforms. We believe that the unacknowledged role of informal carers is particularly relevant to the CALD community, as carers in many diverse communities may be less willing to engage with or less aware of the support services available to them. In many CALD communities it is a cultural imperative for younger family members to care for their elders, and they may believe that it is inappropriate or reflects badly on the carer to require governmental support to perform this task. CALD communities may also have a higher level of stigma attached to the conditions of the person they care for, and this can also contribute to a reluctance to engage with carer support services. Culturally appropriate aged care assessments should therefore include an appraisal of the needs of informal carers.

ECCV also believes that the role played by formal carers must also be recognised, and formally included in Care Plans. It would be preferable if carers were able to access funding directly from a customer's allocated budget, rather than receiving funds *ad hoc* as part of the services acquired through the direction of the customer. ECCV hopes that the Department will recognise the

[4] http://www.islamicsocietysa.org.au/age-care

importance of respite services to CALD communities, given the widespread and often hidden role that and informal carers play.

How can address the unique challenges associated with service delivery in rural and remote areas?

ECCV believes that the Department has correctly identified that aged care provision in rural and remote areas has always presented a special set of challenges. There is a particular scarcity of culturally appropriate care in regional Australia. This is exacerbated in many areas where older community members have children who have moved to cities for employment or lifestyle reasons, and therefore do not have support from the younger generation in meeting the challenges of ageing.

There is a likelihood that a move to a fully individualised funding model will leave significant gaps in the aged care needs of many seniors Australians living in regional areas, particularly those from CALD backgrounds. It is likely that some combination of supplements, grants and block funding will be required to ensure that sufficient and sustainable service provision is maintained into the future.

Ethnic Link Services, run by UnitingCare Wesley Port Adelaide in South Australia provides an encouraging example of a Service Provider delivering services specifically targeted at CALD seniors in rural and remote areas[5]. It recognises that many of these people suffer from loneliness and isolation, and that social support groups are particularly important in this context. ECCV believes that Ethnic Link Services provides an example of the sort of culturally appropriate care and support that can be provided with the assistance of direct government support.

What are some examples of current gaps or duplications across the aged care and health systems, and how could these be addressed?

ECCV is concerned that there is in many ways insufficient data about the number of people from CALD backgrounds who are accessing Home Support and Home Care. The only gauge that is consistently collected is "*Country of birth*", and while this is important, it will often not capture a person's English ability or capacity to engage with mainstream services. This can make it difficult for government and Service Providers to appropriately design service delivery that is aligned with the needs of particular communities. ECCV recognises that data collection around the profile of aged care customers comes from a variety of collection points, but hopes that in future a more thorough and centralised approach to data collection can be introduced.

More appropriate data items that could be systemically collected and analysed to guide aged care provision would be "*Main language spoken at home*" or "*Main language other than English spoken at home*", "*Preferred language*", and "*Need for interpreter*". ECCV encourages the Department to work with the Australian Bureau of Statistics and the Australian Institute of Health and Welfare

[5] http://www.ucwpa.org.au/aged-care/ethnic-link-services/

(AIHW) to explore ways in which data about how CALD seniors access aged care can be better captured. ECCV supports the key findings outlined in AIHW's 2016 Working Paper *Next Steps in Exploring the aged care use of older people from culturally and linguistically diverse backgrounds: a feasibility study*[6].

ECCV believes that a more consistent approach to capturing relevant data will have a profound effect on the ability of all stakeholders to provide the most appropriate aged care to culturally and linguistically diverse communities.

Conclusion

ECCV acknowledges and commends the Department of Health on its ongoing efforts to engage with a wide variety of stakeholders in designing a national integrated Care at Home Program for older Australians. ECCV believes that a carefully-designed program can lead to many positive improvements and efficiencies in the delivery of aged care in Australia, and considers that the needs of customers from culturally and linguistically diverse backgrounds can be successfully met with sufficient care and consideration. These needs will be most likely to be fulfilled by creating a program that is open, transparent and inclusive, able to communicate with customers in a manner and a language that they understand, and by taking into consideration the limitations as well as the benefits of consumer-directed care.

ECCV thanks the Department for considering its recommendations, and looks forward to continuing to work with it to ensure that Australia has an aged care system that provides the most appropriate care for its culturally and linguistically diverse communities

For further information, please contact James Houghton, Aged Care Policy Officer, on 03 9354 9555 or jhoughton@eccv.org.au.

[6] Australian Institute of Health and Welfare, Exploring the aged care use of older people from culturally and linguistically diverse backgrounds: a feasibility study, Working Paper 1, 2016

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- Victorian Arabic Social Services
- Victorian Aboriginal Community Controlled Health Organisations
- Aged & Community Services Australia
- Jewish Care (Victoria)
- Individual carer's representatives

Special thanks to the members of ECCV's Aged Care Policy Sub-Committee. The Aged Care Policy Sub-committee consists of representatives from ethno-specific, multicultural and mainstream aged care providers, ethnic community organisations, stakeholders and peak bodies with an interest in equitable access to ageing and aged services as they relate to Victoria's multicultural population.