Caring for older Australians

Formal submission to the Productivity Commission Public Inquiry into the Care of Older Australians July, 2010

UnitingCare
Community Options

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UnitingCare Community Options is a not-for-profit provider of services for older people, people with disabilities, and the unpaid carers that support them. Our goal is to provide the support people need to remain living at home. Each year we work with over 3000 people across the eastern metropolitan region of Melbourne.

Established in 1987, UnitingCare Community Options first provided in-home support to older people with dementia. We now support a broad cross section of the community with a range of services including information, planning assistance, case management, community development activities and respite services. We are supported by Commonwealth and Victorian Government funding.

Our staff are dedicated to helping people realise their personal goals and dreams and living as valued members of their local community. We employ a strengths-based approach that focuses on the humanity, strengths, capacities and interests of each individual rather than on any limitations imposed by a person's condition. Where possible we work with people to help them take control of their own lives with the assistance of planning, positive right relationships, facilitation, guidance coordination and support. We believe that informal and community networks are essential to helping people achieve their goals and reducing their dependency on formal services.

Our Vision is to achieve a Good Life for All. We work to ensure that people have what they need to sustain their lives in the community and to create positive futures.

Our Mission is to work with vulnerable and disadvantaged individuals and their families so that they can live a valued and meaningful life and remain connected to their community. We Value the uniqueness and value of every individual; right relationships that allow people to be influential in their own support arrangements; the strengths and abilities of all; creativity and innovation in pursuit of our goals, transparency and accountability.

UnitingCare Community Options is auspiced by the Uniting Church in Australia. We are part of the wider UnitingCare Australia Network, which consists of more than 400 organizations and provides over 25,000 residential and community care places.

Introduction

This submission is designed to be read as a complementary submission to that made by the UnitingCare Australia network, of which UCCO is a member and played an active role in the submission's development.

The purpose of this submission is to give particular attention to the issues related to community based care, which is UCCO's primary focus.

UCCO understands that addressing the care and support needs of older Australians requires a comprehensive and integrated evolution of those sectors which are responsible for or have a connection with aged care.

In examining the necessary reforms and changes which would assist in delivering optimal outcomes for our participants, we have separated the issues into those which are related to systems and higher-level, strategic issues, and those which are more focused on service delivery.

Systems-level Issues

1. Australia should have an integrated subsidy system which provides funding at a range of levels according to people's care needs, regardless of the source of funds.

Aged care currently operates in a fragmented way, with a focus on the practicalities of service delivery, rather than the needs of individuals. This adds complexity and trauma to the decisions being made by individuals and families at an already stressful point in time. Funding needs to be provided according to the care needs of the individual and their family (rather than according to an established 'package'), which will vary depending on location, level of ability, informal supports and other demographic features.

The integration of the system, regardless of funding streams, requires policies to be developed from a whole of government approach, rather than being limited to just DoHA, whose role should focus on the administration of funds and contracts.

Service delivery and client outcomes would benefit from the breaking down of government silos in policy planning and delivery to include and allow access and entry at a local level to such services as:

- Ageing (including HACC, residential and community care)

- Health
- Community services
- Carer support
- Disability
- Mental health
- Early Childhood and Family Services
- Youth services

2. The system should be accessible with easily identifiable points of entry.

Entry to and negotiation around the aged care system would be significantly improved with the provision of points of entry and information which are recognised widely across the community. The Direct2Care (Access Points) model in Victoria has been a successfully demonstration of such an approach, and expanding this model is recommended.

Following the entry into the service system, there needs to be a comprehensive approach in regards to the provision of services and activities, composed of:

i. Entry
ii. Provision of activities associated with basic support (HACC basic and NRCP)
iii. Comprehensive assessment and care planning (packaged care)
iv. Complex specialist assessments (acute/sub acute)

Within this approach (and subject to privacy principles), assessments and information should be shared so as to avoid multiple assessments and the confusions and stress that this places on participants.

3. The first consideration should be the person's preferred living arrangement and seeking to meet their needs in the most cost-effective manner.

As providers of community based care across the Eastern Metropolitan Region of Melbourne, UCCO has witnessed the value of people being able to remain in their preferred living arrangements – which in most cases is the home in a community-based setting. The decision to move from the home to a care facility is most often one based on need rather than the choice of the individual. It is therefore in the interests of the sector to ensure that community based care is able to provide for

the needs of an individual for as long as possible (with access to the acute sector as required for episodic care and respite), even with increasing care needs, so as to avoid the disruption and cost implications of moving an individual to an aged care facility.

With the decision to move out of a community setting, greater options need to be developed in terms of living options, and the potential to remain as independent as possible and maintain as much of their existing lifestyle as possible – Be that in a residential care facility, independent living unit, social housing or other arrangement. These options need to be developed with the consideration of upholding basic human rights such as a right to privacy, freedom of movement, the right to family life (including the opportunity for couples to remain together regardless of differing care needs), and to be protected from inhuman or degrading treatment.

In regard to human rights, it is important to note that Victoria and the ACT already have Charters of Human Rights in place (with other states and the Commonwealth under consideration), which places obligations on public authorities such as aged care providers to uphold these rights. The current provision of aged care, especially in terms of preferred living arrangement, has the potential to not be compatible with the Charters.

4. New models of service should be developed in response to changing community and consumer requirements.

With the changing demographics of our communities there is an expectation that models of service will reflect the expectations and requirements of those needing or desiring services, and most importantly that services will reflect needs – rather than dictating what a client can receive or is eligible for.

Support (including housing) needs to increasingly be individualised so that community aged care packages are person-directed (and where possible, person-controlled) and access to housing is affordable and secure.

UCCO believes that it would be of great value to bring participants together at a strategic level to discuss and consider the current models of service and propose new, innovative models drawn from their direct experience and not bound by historical, cultural or bureaucratic constraints.

In addition, investment in further research (outside of current NHMRC processes) would benefit the sector in providing strong, evidence-based models and in evaluating the effectiveness of those models that we currently use or are in the process of developing.

5. Facilitation of the continuum of care is seen as a necessary activity in caring for or supporting anyone accessing a community service. It should not be identified as another service type.

The aged care system is linked to a broad range of generic service types and infrastructure systems which, while not being considered 'aged care systems', are critical to the welfare of people who are ageing. The integration of the aged care system with these other systems and service types is critical to overcome the unnecessary duplication of service, confusion or barriers to service that some participants currently experience.

This includes not only other forms of care (eg. GPs, community health, activity programs, etc) but also extends to basic community infrastructure, such as public transport, street lighting, accessible standards for commercial and government facilities, and appropriate recreational facilities. All of these need to be considered as important in the provision of care to older Australians, and despite their perception as a peripheral activity in the aged care spectrum, are critical in regards to early intervention and prevention, which has important health and economic outcomes across the sector.

6. Consumers should be provided with choice through linkage across residential and community streams.

There is scope for the sharing of resources and improving of linkages across community and residential arenas to enhance the quality of life and care outcomes for the consumer. Community and residential care and their respective clients can benefit from linkages which enable people to move back and forth as their needs and levels of support change. Improving linkages assists and empowers the sector to develop a restorative approach to aged care, where a decision to enter an aged care facility is not a 'one-way door', but come with the possibility of setting goals related to returning into a community setting (be that at home, an independent living unit or some other form of accommodation) as health outcomes improve or as informal supports increase.

Despite the intention of community care packages to provide the same level of care as that received in a residential facility (including high care through EACH and EACHD packages), there is a limitation in not only the availability of such packages but also their inadequacy in providing a package which fully supports someone to stay at home. This gap can be reduced through the innovative linkage of residential and community care, providing not only appropriate choices for individuals but also a reduced load on the residential care sector and associated health services (and the subsequent workforce and funding restrictions that they currently face).

Service Delivery Principles

Based on over 20 years of working with those who are ageing and their families and carers, UCCO (and the broader UnitingCare network) has a number of key principles which we believe are foundational in providing quality community care:

1. Person-Centred Care

- Support needs to be individualised (person and family centred) and allow for flexible service responses. As much control as possible should be given to the individual and their family, and efforts made on building the capacity of individuals to manage and control their own care, up to and including service planning and the administration of funds. However, we are aware that for some participants this will not be their preferred choice, and appropriate case management systems need to exist to cater for this.
- The person should be the focus of service delivery - wherever they sit in the continuum of care settings - rather than the programs and/or service types.
- The level and complexity of the individual needs of people should be a primary consideration in designing care services, rather than fitting individuals to the categories of services that can be offered.
- The inclusion of personal outcome-based measures for community and residential aged care in the quality system, to ensure that quality is directly related to the experience of participants and their improved wellbeing.

2. Support for Families and Carers

- A primary aim of care services should be to support family (and other) carers, including the provision of a range of carer support services including respite care and entitlements to material support such as allowances and benefits.

- Services for a care recipient and their carer are integrated given the inextricable link and dependence between the two, including flexible models of respite and integrated health care.
- Services need to balance the sometimes conflicting desires of the carer and the person they care for, seeking to develop services that offer a balance of outcomes for both.

3. Quality of Life

- Recognising human interdependence, older people should be supported to maintain a balance of independence and social connectedness in their life, and to achieve the best quality of life possible, regardless of how they choose to live and their accommodation options.
- Care subsequently needs to extend beyond physical, mental and emotional needs, and increasingly focus on social and relational needs.

4. Location of Choice

- Individuals should be able to remain within their preferred environment in the location of their choice (their own home, a family member's home, a retirement unit) and receive support to remain in that setting commensurate with their level of need.
- The option of a more secure and supported environment should be available if their needs cannot be met in their home environment.
- Individuals who have difficulty in financially maintaining accommodation should be assisted and supported in accessing affordable and secure housing which is appropriate to their needs, if that is their desire. With that aim, public/social housing needs to be made accessible and appropriate for an ageing population.

5. Wellness and Independence

- Services should have a focus on promoting independence, health and wellness with a restorative focus aimed at realising their potential maximum functional gain and rehabilitation.
- Informal networks and systems should be encouraged and supported as much as possible to provide complementary care to the aged care sector, and increase an individual's social connectedness.

6. Prevention and early intervention

- Services should consider preventative approaches and community education that strengthen natural and informal supports, ensure appropriate nutrition and physical activity, and support for carers.
- Where possible services should ensure the early detection and pro-active management of conditions such as dementia, depression, incontinence and mobility disorders which are factors that could contribute to entry to residential aged care.
- There should be timely identification of and intervention to provide appropriate supports that will minimise crisis events.
- Community capacity building in regards to social inclusion, community leadership, and the building of healthy, connected communities needs to be recognised as valuable prevention and early intervention activities.

Case study

Asanka (name changed) is a professional who migrated to Australia from Sri-Lanka with his wife and son several years ago. Soon after arriving in Australia, he was diagnosed with Parkinson's disease and due to the disease's quick progress unable to work.*

Asanka's wife became his carer and due to the family's financial situation also had to find paid employment. She currently works 4 days a week. As a proud Sri-Lankan man, Asanka finds both his condition and the fact that he can not provide for the family shameful. Even though Asanka's wife is working, the family's combined income is small and the family was provided with an Office of Housing property in which they currently still reside. The past year saw them finally being able to afford a new bed, all other furniture was purchased from various Opportunity shops.

As the Parkinson's symptoms progressed, Asanka's shame increased. After a while, Asanka's combination of muscle stiffness, slowness of movement and uncontrolled trembling became obvious. Asanka's shame effectively disconnected him from the community at large. He preferred to stay at home for weeks on end, not talking to or seeing anyone other then his wife and the Sri-Lankan paid carer who comes in twice a week to spend time with Ashanka.

This in turn had its own consequences, adding pressure to the marriage, contributing to his feelings of self inadequacy and decreasing his ability to exercise, which consequently has a negative impact on his condition.

Asanka has an excellent case manager who administers a Community Aged-Care Package. In the past few years the package assisted the family in:

- *Providing someone to come to the house for 3 hours per week to cook a week's worth of meals*
- *Some assistance in performing domestic tasks*
- *The purchase of special dishes (anti spill)*
- *The purchase of a bidet (culturally appropriate for a Sri-Lankan man who is no longer able to safely perform the task)*
- *The purchase of a wheel chair*

The case manager linked the family to various services, including the Michael J Fox Parkinson's research foundation; a link which Asanka first believed to be shameful but later concluded that it was good to assist research so that it may help people who are afflicted with his condition in the future. The package also provides a Sri-Lankan carer who is able to come to the house and spend some time with Asanka. Asanka appreciates the visits. In summary, the case manager has done much to assist the family to remain both intact and in the community. Asanka's shame about his condition has proved enduring and continues to allow him to isolate himself in the house.

The Community Liaison Worker met with the family and in the course of their conversation, they talked about how Asanka used to play table tennis. Asanka said that he has a table tennis table in the yard and they went to have a look. When the worker saw the table, he saw that the damage the weather had inflicted onto its surface had made the table unusable. To observe Asanka's skill and commitment levels, the worker suggested that they go and play table tennis in a local community centre. In the first session, it became apparent that Asanka's skills were considerable and that his Parkinson's became less pronounced during play (a well documented effect of a combination of increased adrenalin production during a period of excitement and concentration). The people at the centre were welcoming and although Asanka could not play doubles (not able to control his condition in a smaller space), he could play one on one well enough. He also seemed to be less self conscious while playing. Talking to his family, it became apparent that Asanka's brother could play with him and would do so regularly if Asanka had a table tennis table at home. There is also a neighbour who has played with Asanka in the past and who would like the opportunity to do so again.

After a bit of research about which tables and where to buy, the whole family went with the community liaison worker to its purchase a table tennis table. The family's bargaining skills became apparent when they were able to purchase a table at 70% of the marked price.

Asanka looks forward to regular exercise, a reconnection to his brother and neighbour on a different level and also, as he gains his skills back, a game or two in the community centre.

Addendum: Five days after this case study was written, Asanka's partnership worker / case manager was calling the family in regard to a home help shift. As she spoke to Asanka's wife, she heard a noise in the background. When she enquired about the noise, the case manager was told that Asanka was playing table tennis with his son for the first time in years. As they talked further, the case manager was also informed that a neighbour popped in for a game the day before and Asanka's brother was in to play during the week. Further to that, there are several games organized for the near future. Asanka reports that this is tiring him out but he is enjoying the exercise and has already started to feel the benefits of it in his body movement.

This simple example illustrates clearly the difference that can be made with the 'right intervention'. Although we suspected that the table tennis table would lead to many changes in Asanka's life, the real measure of the permanence of change is measured when the worker steps away. We have now been able to observe the beginning of the change.

The positive physical effects of exercise are also complemented by the positive psychosocial effects of reconnecting with family members as an equal, starting to connect with the table tennis centre and generally leaving the house to enjoy something that is just good fun to do.

7. Balance of Care

- The balance between long or short term care/support and/or therapeutic/restorative services should be totally dependent on the needs, aspirations and personal circumstances of the individual and not on funding program parameters.
- Episodic support should be available for short periods of time when there are higher levels of need.

8. Control and Risk

- People wish to be in control of their environment and able to influence service delivery, enabling some dignity of risk. The need to protect individuals from harm needs to balanced with a respect for their individual sovereignty and the emotional and social benefits in taking some risks.
- Consumer choice should be facilitated by encouraging innovation in service provision and recognition of individuals to determine personal risk.
- Consumers are able to be involved in the design, management and evaluation of services, and are recognised as experts in their own care planning, management and delivery.

9. Strengths-Based

- Services should be designed on the philosophy of strengths based care. This means that services should recognise the strengths and capacities of consumers and not only focus on deficits and disabilities.
- Services should promote a positive image of older people and people with disabilities. This can begin with the modification of the language that we use (both in working with our participants, other organisations, and publicly) and ensuring that client participation is taken seriously.

10. Coordination

- Where people have complex issues, need higher levels of support and are receiving multiple services, service providers should ensure that services are co-ordinated or case-managed in a way which enables the person to deal with one care manager or co-ordinator and seek to avoid the duplication of coordination functions.

Contact Information

UnitingCare Community Options
Ground Floor, Building 5
Brandon Office Park
530- 540 Springvale Road
Glen Waverley VIC 3150

www.ucco.org.au

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