Caring for Older Australians Productivity Inquiry Submission

The Productivity Commission currently has two Inquiries running namely, Caring for Older Australians and a Long-term Disability Care and Support Scheme.

The Productivity Commission Issues paper (May 2010) Caring for Older Australians discusses many important issues and raises many questions.

Page 15, Section 3 "Objectives of the Aged Care System" outlines the key themes underpinning the aged care system and poses the question *Should Australia have an 'aged care system'* as currently conceived, or could a broader conception of care and disability policy be more appropriate, with the needs of the aged being one part of this continuum?

I believe the two Inquiries need to work together and look carefully at the benefits of developing an integrated system that will meet the needs of all Australians no matter when, at what age or how they develop the need for care and support.

Why is this so?

- 1. We currently have three systems and many programs: one for the elderly, one for people with disabilities and one for carers. All are inadequate and need fixing.
- 2. Anyone, anytime can acquire a disability, mental or other health condition or become a carer
- 3. To fix the care systems we need more resources, an entitlement system based on need, flexible and innovative service provision as well as a consumer directed system with individualised budgets where appropriate.
- 4. If the outcome of both Inquiries were to recommend a Medicare type levy to provide a social insurance model approach, a universal scheme would be much more acceptable to the community when the government introduces it.
- 5. Other factors that need to be taken into account when fixing the care systems is the interaction of these systems with the health system and current reform proposals; the role of the HACC services which currently service people with disabilities, frail aged and carers; and the need to have an early intervention/prevention focus as opposed to the current crisis driven intervention framework that is currently in place.
- 6. All people who require care and support whether they acquire their disability through an accident, inherited disorder, chronic illness or frailty no matter at what age this occurs need to be treated with dignity and equitably.
- 7. Carers are the people who provide the majority of care to those with a disability or who are frail. They require support in their own right if they are to have life choices outside of caring. Carers are the foundation of our aged and community care system, and the annual replacement value of the vital care they provide is over \$30.5 billion (Carers Australia).

Section 4. Who should pay and what should they pay for? is a difficult issue. As pointed out in the Issues paper, people who remain at home and receive community care packages or HACC services cost the tax payer less than a third than for those who require residential care. This is mainly because the cost of accommodation is not separated from the cost of the care and support.

The Australian Government recently announced that it would take over the management of HACC services. On one hand I believe this is a good idea as having a system of service provision funded by one level of government will make for a much more unified system across Australia and will hopefully result in services being portable if a client wishes to move interstate or to simply have the right to the service in another state if they go away on holidays interstate. So on one level I support this move. However, HACC services do not only have aged care people as their clients. They also service people with disabilities and carers of people who may be frail aged or have a disability. It is not clear how people with disabilities and all carers would fare under the proposed changes.

The provision of suitable accommodation is an issue for both aged care people and people with a disability.

Most people would prefer to remain in their own home as they age. In a report profiling carers (ABS 2008) it is stated "Carers enable older people to 'age in place' and people with a disability or long-term illness to remain in the community." Community care packages such as CAPS, EACH and EACHD assist people to remain in their own home, but the majority of the recipients of these packages also rely on additional support from carers. Often it is the inability of family or friends to provide that additional support that makes it impossible for an older person to remain in their own home and have to move into either a low or high care residential facility.

I would like to see the Productivity Commission look at other ways of supporting older people to remain in their own home. A few years ago the Benevolent Society in NSW ran a pilot Homeshare program and produced a "do-it-yourself" guide (Benevolent Society 2007). Wesley Mission in Melbourne runs an Agency Assisted Homeshare model and there are programs in SA, Tasmania and WA. The Homeshare concept is based on the principle of mutual benefit that brings together an older person who provides accommodation in exchange for companionship and help provided by another (often younger) person (maybe a student) who needs accommodation. This concept does not preclude the older person (or homesharer) using formal service providers to provide additional care.

In 2007 an evaluation of the Wesley Mission by *Social Ventures Australia*¹ attributed the following outcomes to Wesley Homeshare:

- Savings in rent for homesharers
- Improved happiness and quality of life for participants and families
- Benefits outweigh cost of the program by approximately \$120K p.a.
- Improved quality of life for householders
- Savings to respite care

• Homesharers (from overseas) can feel part of a family in Australia

• Peace of mind for the families of householders unable to provide the level of care

¹ http://www.givewell.com.au/project_spotlight_feb08.asp

This concept is one that could be expanded. While the "do-it-yourself" approach may be preferred and be of benefit to some people, it would be beneficial for wider implementation to have not for profit organisations who can recruit both potential homesharers and householders and provide the support to match people and to step in and help provide an independent arbiter if the relationship strikes a "rough patch". Having Homeshare as an option which service providers could offer along with, or as an alternative to packaged care, would provide more choice for older people, people with a disability or their carer. While this scheme was established to match older people who have their own home but need some support with a younger person, there is no reason why it could not work on a similar basis for a person with a disability who may own or be renting their own home or have accommodation provided via a Special Disability Trust. Indeed, the Wesley Mission program has been extended to provide such a service.

By encouraging Not for Profit service providers to provide Homeshare as a service by providing adequate funding will help service providers to provide diverse, flexible, efficient and responsive services that facilitate independence and choice for consumers.

Consumer Choice

Under the current system packages of care (CACPs, EACH and EACHD) are allocated to a provider who in turn provides the service to the consumer. What the service provider offers is up to the service provider, and is not necessarily what a consumer wants. For example, the consumer does not have a choice of the care worker who comes into their home; may not receive the service on the days or at the time most suited to the consumer; or indeed be able to have a service that they really want. As an example, if a person wants to be showered on Sunday morning so they can attend church or a family outing, it is very likely that the service provider will not be able to offer that service (reason: they only offer a service on a weekday).

By providing the care consumer with a direct (or notional) monetary amount for a package of care it would enable him/her with choice of what services they most need, who the service provider would be and when the service could be provided. It is likely that many consumers (be they the person with a disability or their carer) would want to be responsible for organising the service provision themselves, but they could purchase the services of "case manager" to organise this. However, it would be up to service organisations to offer a wider variety of services that would actually meet the needs of the consumer and consumers could "shop around" for a service provider who meets their needs. This would also help overcome existing barriers of moving onto higher levels of care. At present, many HACC funded services do not provide packaged care (EACH, EACHD and CACPs). Many older people who require increased care refuse a package of care because it means losing their trusted care worker.

Funding should also be such that consumers can change the services providers easily. This will enable older people to move house, move interstate and go away for periods of time on holiday and still retain the right to the level of assessed care.

Carers

Any care and support scheme needs to provide adequate support for the person with a disability and the people who care for them. Carers need to have a choice as to whether they wish to care fulltime or to combine care with either fulltime or part time work. There are often many people in a family who provide care. At present there is an artificial "count" of primary carers as the ABS data collections ask the family to nominate the person who "provides most care" and then designates that person as the primary carer. Often husbands, wives, sons and daughters, and siblings, friends and neighbours all provide care. All carers' needs should be taken into account when assessing the needs of the person with a disability and they should be provided with the support that they themselves need to manage their responsibilities.

People can become carers at any age: from young children to an older person. The care and support that they require will depend on:

- 1. The disability and the level of disability the person they are caring for has. This may change over time. It may increase over time, decrease over time or be of an episodic nature (ie for a person with a mental illness; chronic, severe asthma; MS etc)
- 2. The age and health status of the carer
- 3. The level of external support they can have for the person they are caring for.
- 4. The age of the person they are caring for and any critical incidences that may
- 5. Life transitions such as going to school, leaving school getting employment, moving into supported accommodation for either the carer or the person with a disability.

Carers should not have to navigate two systems if they are caring for both a young person with a disability and an older person.

- 1. There are many carers (usually women) who provide care for a younger person with a disability as well as an older person at the same time. They are often referred to as the "sandwich generation" of carers or "sandwich carers".
- 2. There needs to equity for all people with a disability, no matter what their age.
- 3. Services for both older and younger people with a disability could be provided by the same service provider. That would make the system much more efficient and also provide greater choice for consumers (be they people with disability or a carer). It may also help with workforce issues. If care workers' training encompassed working across all age/disability groups it would enable an individual worker greater employment choice and choice whether to specialise or remain a generalist. This broadened education would improve career prospects for care workers and in turn would offer career pathways which may attract and retain workers in the care industry.

Accommodation requirements

1. Many baby boomers will not be happy with the low and high care style accommodation that is currently available. There will be an increasing need for a real change in the way supported accommodation is provided for older people as well for younger people with a disability.

- 2. Currently there is an extreme shortage of supported accommodation and social housing options for young people with a disability who want to leave home and live independently from their parents. This leaves ageing parent carers in a difficult situation. While this is not a direct issue for this Inquiry, by looking at supported accommodation and social housing options as an issue for both younger and older people with a disability, different models may become a more generalised issue for which different groups may come up with innovative solutions.
- 3. For ageing parent carers who want to continue to live with their adult disabled child, maybe there could be a trial of supported accommodation for the whole family who all need support. This could be done by combining the "packages" of care for all residents in the home and provide combined support. There may be a need for an injection of capital funds to modify the existing accommodation.
- 4. There is currently a strong push to move younger people in nursing homes out into more suitable accommodation. Many old people with good cognitive functioning also do not want to be in this type of accommodation. There needs to be a review of the type of care offered so that people's real needs are met. I can see no reason why the type of accommodation that is being currently provided for younger people who require high level care and are being moved out of nursing homes could not be provided for older people who have good cognitive functioning.

Additional Issues

As the number of older people increase there are some important factors that have not been addressed in the Issues paper that may ease the ageing process for people.

Advanced Care Directives²

An Advance Health Care Directive is a document that states your wishes or directions regarding your future health care for various medical conditions. It comes into effect *only* if you are unable to make your own decisions. The notion of increasing the awareness of the importance of people thinking about how they would wish to be treated if they could no longer make those decisions themselves, talking about it with family and friends and producing an Advanced Health Care Directive is one which needs to be promoted widely in the community. To ensure that an Advanced Health Care Directive is carried out, it is also important that people appoint a Power of Attorney and have an Enduring Guardianship in place. There needs to be some work done to promote these concepts so that the majority of people have these in place. Even more importantly, there needs to be a change in the legislation in all states and territories across Australia to remove current differences. One way may be to have Federal Government legislation that overrides any differences in the state and territory legislation.

Advocacy

There will be a need to retain, and indeed strengthen, strong advocacy organisations both at an individual level and at the systemic level. As the ageing population

² Who Cares?... - the Aust Health Ministers' Advisory Council is currently progressing the development of nationally consistent guidelines for advanced health care directives

increases and families continue to live a long way apart, having access to independent advocates will become increasingly important, both for older people and their family and carers.

Entitlement

Under the current system there is no notion of entitlement to care and support. This leads to the perverse situation where people who gain access to care and support will not relinquish it, even if their circumstances change and they could manage with less care. This comes about because if they may need the help in the future, often they cannot obtain that assistance. If there was a notion of entitlement built into the allocation of services, then people would not feel the need to utilise services unless they really need them. Indeed, knowing that they are entitled to have a service if it becomes necessary will probably result in less overall service use and therefore be much more efficient.

References

www.carersaustralia.com.au

ABS A Profile of Carers in Australia 2008 4448.0

The Benevolent Society, April 2007 Homesharing: a Do-It-Yourself Guide

http://www.givewell.com.au/project_spotlight_feb08.asp

Who Cares?...Report on the Inquiry into better support for carers 2009