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House Standing Committee on Legal and Constitutional Affairs Inquiry into Older People and the Law Public Hearing, Canberra

22 May 2007

House of Representatives Standing Committee on Legal and Constitutional Affairs Inquiry into Older People and the Law – Public Hearing 22 May 2007

Appearing: Ms Joan Hughes CEO Carers Australia

Introduction

Carers Australia is the peak body for the 2.6 million family carers in Australia. Of these family carers, over 710,000 provided support to people aged 65 years living at home while 27,900 older people live in residential aged care.

Carers Queensland provided a submission to this Inquiry in December last year, which was endorsed by Carers Australia. I value this opportunity to further support our submission in regard to ageing and disability, Aged Care Planning and Directives, Barriers to older Australians accessing legal services, Succession planning for ageing carers, and the need for ongoing community education about the need to plan for ageing and disability.

Convergence of ageing and disability

It is well known that Australia's population is ageing and that people are living longer. Perhaps, what is less known in the community and by governments is that a proportion of these extra life years will be spent with a disability. AIHW data indicates the average Australian male (in 2003) can expect to experience 18.6 years of life with a disability (5.4 of which are expected years of life with a severe or profound disability). Females can expect 20.7 years of life with a disability (8.3 years with a severe or profound disability). These figures will increase as the population ages.

AIHW data indicates that 41% cent of people aged 65-69 and 92% of people aged 90 and over have a disability, while only 4% of children aged 0-4 years have a disability.

NATSEM (2006) indicates that in the next 25 years the ageing disabled population will increase from:

- 350,000 to 882,000(150%) of Australians will be aged 65 years plus
- 80,000 to 260,000 (200%) of Australians will be aged 85 years plus

This raises the need for community education to raise people's awareness while they are younger that acquiring a disability is a normal part of ageing, and like other aged planning disability planning should be an essential consideration.

Australians are encouraged to plan for their financial security in their retirement, but little encouragement is given to plan for ageing with a physical or mental disability, including advanced health care directives, family agreements and enduring power of attorney.

Discussions about the convergence of ageing and disability is starting to occur at a national level and in some states.

Carers Australia recommends the Australian Government implements a regular community education campaign to alert people to the need to plan for ageing and disability. This should be developed in conjunction with Carers Australia, Alzheimer's Australia and other aged care and community organisations.

Advanced Care Planning and Directives

Alzheimer's Australia has included the need for Advanced Care Planning and Directives in its submission to the Inquiry, and this is an issue that the National Aged Care Alliance is currently considering. Carers Australia is a member of the Alliance. I understand that this is now on the agenda of the Australian Health Ministers' Conference under the broader National Framework for Action on Dementia 2006-2010. However, Advanced Care Planning needs to extend further than people with dementia and their families. It also needs to extend to people with terminal illness, very frail aged people, on for sudden onset illness, such as stroke.

Carers Australia supports these initiatives around Advanced Care Planning and Directives, particularly the need for consistency in legislation across states and territories to make it easier for older people and their families. I understand that the Standing Committee of Attorney-Generals is pursuing this issue and five states already have mutual recognition of Powers of Attorney. Carers Australia also supports the need for a national Advanced Care Planning registry and regular reviews of all Advanced Care Directives. However, Carers Australia believes that Advanced Care Plans and Directives should be developed with family support and knowledge.

Again I refer back to my previous comments about the need to normalise ageing and appropriate ageing and disability planning for individuals and their families. Just recently, a previously healthy older parent of a friend suffered a severe stroke, and was not expected to survive. This person and their spouse have separate bank accounts and superannuation, and each contributes to specific household expenses. Neither had an Advanced Care Plan nor a Power of Attorney in place.

Because of the severity of the stroke, this person was unable to sign cheques or withdrawal forms which meant that their spouse, who was already anxious and concerned about their partner's illness, had the added stress of insufficient income to meet household expenses, such as electricity and rates.

As well as having to make decisions about their parent's future care because of the stroke, the family was also having to rush around establishing authority to access bank accounts to pay bills and to make other decisions on behalf of both their parents.

Specialist legal-advocacy services for older people

As our submission to the Inquiry indicates, Carers Australia believes that family and friends are usually the best substitute decision makers. Older people and their families prefer for this decision-making responsibility remains within the family.

There is a prevailing belief in some legal jurisdictions that this is best managed by the appointment of a statutory authority. This could be reinforced because there appears to be limited knowledge amongst older people, their family members and family carers of the range of available substitute decision-making arrangements and the legal obligations they imply.

While many older people may be bewildered by the legal documents to establish Enduring Power of Attorney or other provisions, they also have limited incomes and are reluctant to seek expensive legal advice.

These illustrate the need for older people and their families to have access to affordable specialist legal advisory services. As well as being able to provide older people and their families with information about Family Arrangements, Enduring Power of Attorney and Advanced Care Directives they should also be able to assist them with the process to establish these before the need arises.

These services should be easily accessible to older people, particularly low income people, people living in rural and remote Australia, and people with culturally and linguistically diverse backgrounds.

Succession planning

Another important factor in ageing for the Australian Government is the ageing of carers who are now caring for an ageing son or daughter with a disability. People with disabilities are also living longer due to improved health care. This means that their parents are required to care for a much longer period. This adds another legal dimension for these ageing carers – what provisions do we make for our adult children with disabilities when we can no longer care for them or we die.

The Australian Government Department of Families, Community Services and Indigenous Affairs introduced an initiative in the 2005-06 Federal Budget with a \$230 million allocation over four years for parents and immediate family wishing to make private financial provisions of up to \$500,000 for the current or future accommodation and care of a son or daughter with severe disability. However, because of the narrow guidelines on what the trust can be used for many families feel that this is not an adequate vehicle to provide future care for their children. Also this initiative excludes many families with low incomes, especially family carers and their family which have been dependent upon government income support over many years. These are some of the reasons for the very low uptake of this initiative.

This raises the issue about how best can the Australian Government assist all ageing carers of an ageing son or daughter with a disability in their succession planning, and also maintain a legal interest in their son or daughter's future care and emotional support. Carers Australia believes that this is an important issue for the Australian Government to investigate and to develop appropriate strategies.

However, FaClSA's website does have some useful information about this initiative which could easily assist ageing Australians and their families in establishing family agreements and power of attorney. <u>http://www.facsia.gov.au/internet/facsinternet.nsf/via/disabhome/\$File/Planning_for_the_Future_2007.pdf</u>. Similar information could become standard for ageing Australians through Centrelink's Senior Centres, and other avenues including the proposed Specialist Legal-Advocacy Services for Older People.

Thank you