



**Response to the Productivity Commission's draft report on  
the Caring for Older Australians Inquiry**

*Sharing the care: the future of aged care in Australia*

**Carers Australia**

**March 2011**

Title: Response to the Productivity Commission's draft  
report on the Inquiry into Caring for Older  
Australians  
Date: March 2011

Carers Australia  
Unit 1, 16 Napier Close  
DEAKIN ACT 2600  
Telephone: 02 6122 9900  
Facsimile: 02 6122 9999  
Email: [caa@carersaustralia.com.au](mailto:caa@carersaustralia.com.au)  
Website: [www.carersaustralia.com.au](http://www.carersaustralia.com.au)

Copyright © 2011 Carers Australia

## **Acknowledgement**

Carers Australia wishes to thank Carers NSW, particularly Elena Katrakis, Colleen Sheen and Alison Parkinson, for the preparation of this submission on behalf of Carers Australia. We also wish to acknowledge the input provided by the other state and territory Carers Associations, which together has provided a strong base on which to develop this final submission.

While this submission represents the national response to the Productivity Commission's draft report, some Carers Associations will also be submitting separate submissions which will focus on issues that are of particular relevance to that state or territory.

## **About Carers Australia**

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a disability, mental illness or disorder, chronic condition, terminal illness or who are frail.

Carers Australia believes all carers, regardless of their cultural and linguistic differences, age, disability, religion, socioeconomic status, gender identification and geographical location should have the same rights, choices and opportunities as other Australians.

They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education. These rights should be mandated in legislation.

Carers Australia's members are the eight state and territory Carers Associations

## **About Australia's carers**

Australia has almost 2.6 million carers, and around 770,000 of these are primary carers – the people who provide the most care. A similar proportion of carers care for a person under 65 years as those who care for a person over 65 years.<sup>1</sup>

Carers are sometimes referred to as 'family carers' to distinguish their role from other caring roles in our society such as paid care providers, foster carers, parents or guardians.

Many carers are termed 'sandwich carers' or 'the sandwich generation' because they care for more than one person – a frail parent, a partner or a child with a disability or chronic condition. Also, other carers care for several care recipients and some carers are juggling employment with their caring responsibilities.

Anyone, anytime can become a family carer and the caring journey be time-limited or can last a lifetime. Caring can begin with the birth of a child and can continue until the carer is unable to care any longer because of age or illness. Carers come from all walks of Australian society and may enter the caring journey at different stages of their life. Carers are young, of working age, or older. They may be Aboriginal or Torres Strait Islanders or they may have been born outside Australia. They live in cities and towns and in rural and remote areas,.

According to the ABS:

- there are 520,500 carers who are aged over 65 years
- a further 536,700 carers who are aged between 55-64 years
- the number of carers aged over 65 years combined with those moving into this age cohort is over 1 million, equivalent to two fifths of all carers.<sup>2</sup>

## Format of this submission

The submission is divided into two parts:

**Part one** addresses three overarching themes which are relevant to all sections and recommendations of the Productivity Commission's draft report. These issues are of the utmost importance to carers and crucial to the development of an equitable and sustainable aged care system:

- compliance with the *Statement for Australia's Carers*
- recognition that carers have needs in their own right and
- the need to address the assumption of wealth that is evident in the draft report.

**Part two** responds to issues arising from four chapters of the draft report:

- *Paying for aged care,*
- *Care and support,*
- *Catering for diversity – caring for special needs groups,*
- *Delivering care to the aged – workforce issues.*

Comments are provided on particular issues relating to these chapters, and discussion follows the order that they appear in the draft report.

## Introduction

Carers Australia welcomes the release of the draft report of the Inquiry into Caring for Older Australians. We acknowledge the progress that the Productivity Commission (the Commission) has made towards a better understanding of the key role of carers in caring for older Australians and particularly the importance of carers and of the need to make caring sustainable. This goes to the heart of a robust and equitable aged care system. Until caring becomes a sustainable and shared practice, true reform in aged care will not be achieved.

Throughout this submission, we raise areas where we believe the Commission should do further work. We highlight several issues of concern in the hope that these will be addressed in the final report.

We are optimistic that this Inquiry will provide the basis for real change for older Australians, and a fairer future for all of those Australians who are or will become carers. The Commission has a rare opportunity to describe a future where:

- care is shared between carers and formal services
- carers have choice in their caring role, including the choice to care, or not
- caring and a career are not mutually exclusive
- carers are treated as individuals, with their own needs and aspirations
- all older people and their carers have access to appropriate, timely and quality services and support, regardless of age, gender, disability, sexuality, cultural or linguistic background, socio-economic status or where they live.

For this to be realised, significant changes will be required. There needs to be a fundamental shift in the way Governments, service providers and the community conceptualise caring, and in the degree of recognition, inclusion, understanding and support afforded to carers.

There will also need to be significant investment in formal care services. Carers will only continue as the 'enablers of community care' if they are able to share their caring responsibilities with affordable and appropriate formal services.

Some of the changes that we recommend go beyond the aged care sector. The Commission must look at the aged care system, older Australians and carers in a total context, and have the courage to make recommendations relating to issues that fall outside of the aged care domain.

This Inquiry is taking place in an environment of change and reform, particularly in the disability, health and mental health sectors. The final recommendations must take these other reforms into account, and ensure that groundwork is laid for future linkages between the Aged Care Gateway, Carer Support Centres, Local Health Networks, Medicare Locals, and the proposed National Disability Insurance Agency, assessors and other relevant stakeholders.

## Part one: Overarching issues in the draft report

### 1. Statement for Australia's carers

The Commonwealth *Carer Recognition Act 2010*, which commenced in November 2010, contains a *Statement for Australia's Carers*. The Statement contains ten key principles that establish how carers should be considered and treated by Commonwealth agencies and relevant organisations funded to support carers. We believe that these principles should be reflected in the Commission's recommendations for a reformed aged care system. It is important that all recommendations, regardless of whether they directly relate to carers or impact on them, should take account of, and be consistent with, the principles in the Statement.

The ten principles are that:

1. All carers should have the same rights, choices and opportunities as other Australians, regardless of age, race, sex, disability, sexuality, religious or political beliefs, Aboriginal or Torres Strait Islander heritage, cultural or linguistic differences, socioeconomic status or locality.
2. Children and young people who are carers should have the same rights as all children and young people and should be supported to reach their full potential.
3. The valuable social and economic contribution that carers make to society should be recognised and supported.
4. Carers should be supported to enjoy optimum health and social wellbeing and to participate in family, social and community life.
5. Carers should be acknowledged as individuals with their own needs within and beyond the caring role.
6. The relationship between carers and the persons for whom they care should be recognised and respected.
7. Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.
8. Carers should be treated with dignity and respect.
9. Carers should be supported to achieve greater economic wellbeing and sustainability and, where appropriate, should have opportunities to participate in employment and education.
10. Support for carers should be timely, responsive, appropriate and accessible.

It is unfortunate that the Commission did not make any recommendations about the need for greater flexibility in the workplace, as embodied in the ninth principle relating to the right of carers to economic wellbeing and participation in employment and education. (See section 7.5 for discussion of this issue.)

It is disappointing that the Commission has not acknowledged or explored the implications of the *Carer Recognition Act 2010*. This should be rectified before the release of the final report. The *Statement for Australia's Carers* provides the Commission with a useful tool to review its draft findings in relation to the rights and needs of carers. By taking account of these principles the Commission will contribute to the development of a more sustainable and equitable aged care system.

**Recommendation 1:** The Commission’s final report and recommendations must be informed by and be consistent with the principles contained in the *Statement for Australia’s Carers* included in the *Carer Recognition Act 2010*.

## 2. Carers’ needs are separate to those of the care recipient

Carers should be acknowledged as individuals with their own needs within and beyond the caring role.

(Principle 5 from the *Statement for Australia’s Carers*)

Carers are individuals who have their own needs, priorities and responsibilities independent of their caring role. The Commission’s failure to appreciate carers as individuals in their own right is evident throughout the draft report. The Commission consistently focuses upon carers as a resource in the care of the older person, and its discussion of carer support is often underpinned by the goal of enhancing the “ability and willingness of carers to continue caring”.

We continue to strongly advocate that recognition of the interdependence of the carer and the person requiring care is essential to the provision of appropriate support in every caring situation.

However, the Commission must develop a greater appreciation for carers in their own right if it is to create an aged care system in which carers are not significantly disadvantaged or harmed by their role. Instead of focusing solely on enhancing the capacity of carers to continue caring, the Commission must look to fundamentally change the experience of caring, and create a system in which the negative impacts which are often associated with caring are prevented, rather than remediated. For example, if more affordable formal care services such as day centres were available, care could be more fairly shared between the carer and the community, and carers may be less likely to need services such as counselling, income support and emergency respite.

An understanding of the carer as an individual is crucial if the proposed Carer Support Centres are to make a real difference to the lives of carers. As discussed below (section 4), it is unclear whether carers can access assessment and services if the care recipient is not engaged in the system. The fact that the older person may not have been assessed or is not receiving services does not mean that the carer should be denied the opportunity of support – or assumptions made about the carer’s needs. But will they be able to access services?

Stronger acknowledgement of carers as individuals, separate to the care recipient will also ensure that the rights of carers are upheld in the reformed system. The final report must make it clear that a carer’s right to choice will be supported, and that being assessed as capable of providing care does not mean that one is required or expected to do so.

**Recommendation 2:** The Commission must strengthen its understanding and recognition of carers as individuals with their own rights and needs, separate to those of the care recipient.



### 3. Assumption of wealth

The Commission identifies that:

Many older Australians have substantial wealth, which gives them the capacity to meet their lifetime accommodation costs and to make a greater contribution to the costs of their care.<sup>3</sup>

Although the Commission acknowledges that a safety net will still be needed for “those with limited means”, we are concerned that an assumption of wealth skews the discussion and recommendations of the draft report. The Commission does acknowledge and explore the need to ensure that those older Australians who are not wealthy are able to access the services they need. This is evident in the discussion of the proposed co-contribution scheme, which the Commission acknowledges will need to “take into account the variability of the capacity of older people to pay”.

Our concern is that the Commission could have a better understanding of the financial disadvantage and financial stress experienced by some members of the community, and by many carers in particular. Carers Australia in its first submission to the Commission’s Inquiry cited findings from the ABS 2003 Survey of Disability, Ageing and Carers that indicated over 50 per cent of carers are over-represented in the lower household income quintiles and under-represented in the higher quintiles, particularly primary carers.<sup>4</sup> This is linked to reduced levels of paid employment by carers because of their caring responsibilities.

The Australian Unity Wellbeing Survey Index 2007 found that the average household income of a carer is much less than that of the general population. Carer satisfaction with their ability to pay for household essentials, to afford the things they would like to have, to save money, to have financial security, and to not worry about income covering expenses, are all severely compromised compared with the general population.<sup>5</sup> These findings are supported by evidence from a 2008 report *Negotiating Caring and Employment* published by the University of New South Wales, which found that employed intensive carers had a rate of financial stress that was twice their income poverty rate.<sup>6</sup> (See section 6.4 for further discussion.)

What these findings demonstrate is that income or asset levels alone will not always correctly assess the capacity of older Australians to pay for their care. Situations are often more complex than these figures indicate. In the case of carers the high costs that are associated with caring means that income and asset levels do not indicate the true level of financial disadvantage and stress being experienced. There are other factors that may also be missed; for example, if an older person has dependent family members, or there are family members who co-reside in the family home. (These issues will be discussed further in section 4.)

We acknowledge the Commission’s concern to protect the many older Australians who are not wealthy, but believe that more work should be done to ensure a better understanding of financial disadvantage informs the mechanisms that will be proposed in the final recommendations of the Inquiry.

**Recommendation 3:** The Commission should review the assumption of wealth in its draft report and recommendations and consider the full impact of these

recommendations on carers and other family members who may co-reside with the older Australian entering a residential facility.

## Part two: Specific issues arising in the draft report

### 4. Paying for aged care

Carers Australia is not opposed to the separation of the costs of aged care, nor the proposition that older Australians, generally speaking, should be expected to meet their own accommodation and everyday living expenses, as in other stages of life. However, it is of the utmost importance that adequate and comprehensive safeguards are in place to ensure an equitable system in which all older Australians and their carers are able to access quality services and supports as necessary, without undue disadvantage or difficulty. Service access must not be determined by factors such as socio-economic status, geographic location or cultural background.

#### 4.1 Family home

The Commission's proposal to include the family home in a 'comprehensive aged care means test' has received some criticism since the release of the draft report. We are not opposed to the inclusion of the family home in the income and asset test, as long as there are adequate and carefully considered safeguards in place to protect vulnerable families and individuals.

We are particularly concerned that there be protections in place for individuals who are dependent on the older person and co-reside with them in the family home, for example, an adult child with a disability. The family home should be excluded in this circumstance to ensure that vulnerable individuals do not lose their home, and subsequently may require public housing and other publicly-funded assistance.

Another potential impact of the inclusion of the family home is on carers who reside in the home of the older person because of their caring role. These carers may have given up their own place of residence and reduced or given up paid employment in order to provide care and support. Protections should exist in these cases to ensure that individuals who have been made vulnerable by their provision of care do not lose their home and become further disadvantaged by their caring role.

Existing protections for such cases must be retained and strengthened in the reformed system. Currently, the regulations state that the value of a resident's former home will not be counted as an asset if, at the time of the assets assessment or the date of entry into residential aged care (whichever is earlier):

- the partner or dependent child is living there
- a carer *eligible* for an income support payment has lived there for at least two years
- a close relative who is *eligible* for an income support payment has been living there for at least five years.<sup>7</sup>

This provides protection for a co-resident carer's place of residence at the time of the older person's entry to residential aged care. However, this protection needs to be extended beyond the initial period of entry. Currently, Centrelink review the assets test after two years for the purposes of assessing the resident's eligibility for the Age Pension. Even if only assessed on their half share of joint assets, this can have the effect of the resident losing eligibility for a full or part aged pension, therefore

increasing the daily care charge. Families may then need to sell the family home in order to afford this. This is even more likely if the carer remaining in the home is not one of the owners. Although there are hardship provisions available through Centrelink, few families appear to be informed about or make use of these.

There are no protections at all for carers residing in the family home under the draft report's recommendations. There appears to be an assumption that the "family home" is the asset of one person as opposed to a joint asset. Where a home is a joint asset, it will not be appropriate to sell it for the purposes of purchasing an Australian Pensioners Bond and the proposed Aged Care Equity Release Scheme can only apply to the older person's half share (or other proportion in the case of tenants in common) of the value. Given their contribution of unpaid care to the aged care system and Australia's economy, carers must not be further financially disadvantaged in housing or in access to assets in order to pay for their own aged care services when the time comes.

**Recommendation 4:** The Commission's model for paying for aged care should retain current protections of the family home from the assets test and remove the requirement for Centrelink to review the assets test after two years where there are carers or adult sons/daughters with a disability continuing to reside in the family home.

## 4.2 'Tradeable' quota of supported accommodation places

We have some reservations regarding the option the Commission presents of a 'tradeable' obligation for supported residents between providers within the same region. The issue is complicated by the fact that the Commission gives no indication of how regions will be defined, or what size they will be.

The immediate concern raised by the prospect of a tradeable quota of supported accommodation places is that older Australians who require a supported place may have no choice but to enter a facility which is removed from their community, family, friends and carer. Depending on the size of the regions, accepting a place on the other side of their region could mean a significant and isolating move for the older person, and an additional strain on the carer's capacity to continue providing support.

The Commission must develop a safeguard to protect older people who require supported accommodation places to ensure that they will be able to access services in their own area, and maintain links with their community, health and service providers, family, friends and carers. The ability to pay co-contributions should not determine whether or not older Australians can remain in their local community.

**Recommendation 5:** The Commission should incorporate safeguards to ensure older Australians can remain in their local areas, regardless of their capacity to pay for services.

## 5. Care and Support

### 5.1 Carer Support Centres

Support for carers should be timely, responsive, appropriate and accessible.

(Principle 10 from the *Statement for Australia's Carers*)

We strongly support the Commission's proposal to develop Carer Support Centres. We envisage that these Centres, if well conceived and adequately resourced, will have the potential to bring about significant change to the experience and lives of all carers.

The capacity of Carer Support Centres to make a real difference to carers will be dependent on several conditions. The Centres must:

- provide a broad range of supports, broader than those currently provided by the Commonwealth Respite and Carelink Centres (CRCCs). This should include carer counselling, carer advocacy, peer group support, education and training, respite services, in-home support and an alternative care program for employed carers.
- be resourced to provide ongoing preventative support and assistance, particularly for intensive caring situations, instead of focusing solely on the relief of stress and burden.
- support all carers, including carers of people with a disability (as indicated in the Productivity Commission's Disability Care and Support draft report). Carers should be able to access support, regardless of whether the care recipient receives services or is eligible for services under either of these two schemes.
- be effectively linked with Medicare Locals, Local Health Networks, mental health services, and relevant bodies in the disability sector (e.g. the proposed National Disability Insurance Agency and assessors).
- receive significant and ongoing funding to ensure their sustainability and capacity.
- be effectively governed, and operate and perform consistently in all jurisdictions.

**Recommendation 6:** The Commission should ensure that the proposed Carer Support Centres are adequately funded and resourced to provide a broad range of services and supports to all carers.

The Commission must give careful consideration to a model for the Carer Support Centres that will result in a more holistic, streamlined and cost effective system for carers and providers. Commissioner Robert Fitzgerald when presenting to the Carers NSW 2011 Biennial Conference<sup>8</sup> indicated that the Commission is leaning towards Carer Support Centres as the access point for carer assessments, and that they would receive block funding for their programs.

Also apparent, and identified by the Commission at the Conference, is the question: "Where does mental health fit?" At this stage there is no clear direction.

The model must also ensure that Carer Support Centres are aligned with and incorporated into other reforms currently underway in the health, disability and mental health sectors. Streamlining and cost effectiveness may also result from integrating services for older people, people with a disability, people with a chronic condition, people with mental illness, and their carers and families rather than maintaining separate aged and community care systems.

**Recommendation 7:** The Commission should ensure that the proposed Carer Support Centres are aligned with, and incorporated into, other reforms currently underway in the health, disability and mental health sectors.

The Commission should also clarify its understanding of the current context of carer support. The draft report demonstrates some lack of understanding regarding the National Respite for Carers Program (NRCP) and the Commonwealth Respite and Carelink Centres (CRCCs). The report uses the two terms interchangeably which is incorrect as the CRCCs are just one component of the NRCP. The NRCP is funded by the Australian Government Department of Health and Ageing and funds community based respite services, the CRCCs, the National Carer Counselling Program (NCCP) and the Carer Advisory Service. The NCCP and the Carer Advisory Service are delivered by Carers Australia through the state and territory carers associations, whilst CRCCs are run by a wide variety of community organisations, including (in some areas) by carers associations.

Carers Australia and the state and territory carers associations have extensive expertise, knowledge and experience in supporting carers through provision of NCCP services, operation of the Carer Advisory Service, carer research, and delivery of specialist carer education to carers and service providers. We are prepared to assist the Commission in every way possible to ensure that a sound and effective model for Carer Support Centres is developed and realised.

## 5.2 Carer Assessments

Carers should be supported to enjoy optimum health and social wellbeing and to participate in family, social and community life.

(Principle 4 from the *Statement for Australia's Carers*)

We welcome the Commission's recognition of the importance of carer assessment, and the proposed inclusion of carer assessment in the reformed system. According to the draft report, there would be several points at which carer assessment could occur, and the assessment used would build upon the foundation of several existing initiatives, including the Australian Community Care Needs Assessment (ACCNA) and the Carer Eligibility and Needs Assessment (CENA).

We strongly support the inclusion of a comprehensive, holistic and nationally consistent assessment of carers needs. This was a recommendation of the *Who Cares...? Report on the inquiry into better support for carers*,<sup>9</sup> and has been repeatedly advocated for by us and other organisations.

Although we welcome the inclusion of carer assessments, there are several issues which the Commission should consider and develop in more detail in the final report. We have the following concerns, which require further clarification.

*Will carers who have the capacity to care, be required to care?*

The Commission's discussion of carer support and carer assessment is focused very much on assisting carers to remain in the caring role, and responding to the needs which arise from this role. What is missing from the Commission's discussion is an understanding or acknowledgement of the right of carers to choose not to care, and to choose how much and under what circumstances they are prepared to care. Carer assessment should not focus solely on what the carer can do. Carer assessment must also address what the carer is willing to do, and for how long.

*Can carer assessment occur independently of assessment of the care recipient?*

The draft report does not make clear whether carer assessment is contingent on the care recipient undergoing assessment and/or the result of that assessment. Carers' needs can be related or separate to those of the care recipient, and their access to services and support must not depend on the willingness of the care recipient to have contact with the aged care system. Nor should it depend on the eligibility of the care recipient for services in the aged care or other system.

Given the proposed changes to co-contribution arrangements for aged care, it is of even greater importance that carers are able to access support independent of the care recipient. There are already various reasons why some older Australians resist engagement with the aged care system. The prospect of significant financial costs will mean that some individuals refuse to enter the system. The carers of these individuals must not be excluded, particularly given that their needs are likely to be heightened by their lack of engagement with the formal aged care system.

*At what points can/will assessment occur?*

Neither the draft report nor attachment B 'New aged care model options' make clear when carer assessment *can* occur and when carer assessment *will* occur. Clarification is needed as to what mechanisms or triggers will be in place to ensure that assessment occurs in a timely fashion. (See section 5.1 relating to outcomes from the Carers NSW 2011 Biennial Conference about carer assessment.)

The Commission should consider at what point carer assessment may need to occur. For example, when an older person is to be discharged from hospital a carer assessment should take place *before* discharge occurs. Carers may need significant support prior to discharge to assist them to plan and prepare for caring responsibilities, and their capacity to take on or continue the caring role must be assessed. Many carers who are new to caring, or whose responsibilities may be more intense post-discharge, may not know what to expect or how to deal with the new or changed situation, nor will they have the services and supports they need in place. This could result in significant changes and impacts, including to their living arrangements and employment.

A study of carer involvement in hospital admission and discharge processes commissioned by Carers Queensland in 2007 demonstrates the need for assessment and support pre-discharge. Common experiences identified in the study included:

- disagreements about discharge options, with the carer being treated poorly as a result.
- premature releases from hospital resulting in negative outcomes for the carer and care recipient.
- discharge being conducted in a cavalier manner, without follow-through on discharge plans, at a time inconvenient to the carer and in some cases without the carer being informed.
- unrecognised impacts of the caring role.<sup>10</sup>

In our 2008 submission to the National Health and Hospitals Reform, Carers Australia cited research by the Independent Living Centre WA about the adverse impact on carers once their caring role commenced. An unnecessarily high

proportion of these impacts, (e.g. injury caused by lifting or lack of training) could have been alleviated or avoided through appropriate assessment, training and support prior to or at the commencement of the caring role.<sup>11</sup>

Pre-discharge is just one point where carer assessment should be triggered. It should not preclude further assessment post-discharge.

*Will assessment consider the capacity of carers across the life course?*

The 'life course perspective' outlined by the Commission should not just apply to older Australians; it must also apply to carers. Carer assessment should be informed by the understanding demonstrated here that individuals age differently, influenced by factors such as genetics, gender, ethnic and cultural backgrounds, and general life experiences.<sup>12</sup> Caring is one such life experience which can have a significant effect on the health and wellbeing of an individual, their 'functional capacity' and their own experience of the ageing process.

Carer assessment and carer support must be informed by the same life course perspective and person-centred approach that is being applied to older Australians in this report.

**Recommendation 8:**

The Commission should provide greater detail regarding carer assessment, and clarify that:

- a) individuals who are assessed as being able to care will not be obliged to do so
- b) carers' access to assessment, services and support is not contingent on the position of the care recipient
- c) carer assessment can and will occur when required, for example, pre-discharge
- d) carer assessment will consider the capacity of carers across their life course.

### **5.3 Diversity of carers and their needs**

All carers should have the same rights, choices and opportunities as other Australians, regardless of age, race, sex, disability, sexuality, religious or political beliefs, Aboriginal or Torres Strait Islander heritage, cultural or linguistic differences, socioeconomic status or locality.

(Principle 1 from the *Statement for Australia's Carers*)

The draft report demonstrates greater understanding and recognition of the role of carers in the aged care system than was evident in the issues paper or the initial terms of reference of the Inquiry.

While it is encouraging to see greater consideration and recognition of carers in the draft report, there needs to be a greater understanding and exploration of the diversity of carers and the diversity of their needs. Just as older Australians are a diverse group with different experiences, expectations and needs, so too are carers a heterogeneous group whose needs vary accordingly.

#### **5.3.1 Diversity of carers**

The draft report provides very little focus on older carers (older Australians who are carers), and older parent carers, that is, older Australians who care for their adult child with a disability, in many cases since birth with little or no support from formal services. Older carers are caring at a time when their own health may be

deteriorating and they may have their own care needs in addition to their needs as carers, and the needs of the care recipient.

According to the 2009 Survey of Disability and Carers (SDAC) there were at least 520,500 older carers in Australia, over one third of whom were primary carers.<sup>13</sup> The 2003 SDAC\* indicated that 50 per cent of older primary carers spent 40 hours or more actively caring for or supervising the care recipient.<sup>14</sup> The experience, contribution and needs of these individuals deserve greater consideration and exploration in the report and recommendations of the Inquiry.

Older carers are not the only example of carer diversity missing from the draft report. Other carer population groups, such as young carers, rural and remote carers, male carers, veterans and carers of veterans, Aboriginal carers, carers from culturally linguistically diverse communities, and gay, lesbian, bisexual, transgender and intersex (GLBTI) carers all have diverse experiences of caring, diverse needs and diverse experiences and expectations of care and support services. Consideration must be given to the types of services and supports that these individuals may require, and also to the design and delivery of mainstream services to ensure that they are accessible and appropriate to all.

### **5.3.2 Diversity of care environments**

The relationship between carers and the persons for whom they care should be recognised and respected.

(Principle 6 from the *Statement for Australia's Carers*)

Diversity is evident not only in the individuals providing and receiving care, but also in the context and environment in which care is provided. Informal care does not only take place in a co-resident home environment. The care recipient may live in a private residence not shared by the carer. They may also live in a residential aged care facility, whilst continuing to be supported by the carer.

It is important that there is greater recognition that caring relationships do not necessarily end when an older person enters a residential aged care facility. There needs to be greater recognition and support of caring relationships within residential aged care facilities and of the benefits of these to residents and the facility, and better inclusion of families and carers.

In their first submissions to the Inquiry, Carers Australia and Carers Victoria highlighted the importance of the active and positive involvement and support of carers in residential aged care facilities. Carers Victoria suggested the following changes need to be made to achieve this:

- the requirement for aged care facilities to provide private space for the continuation of relationships
- the requirement for care involvement in the development of care plans unless they specifically opt out
- the extension of complaints and comments procedures to include issues relating to the treatment of carers, family and friends by the facility
- a requirement for, and development of, a Charter of Rights and Responsibilities for Families and Friends.<sup>15</sup>

---

\* Updated data is not yet available from the 2009 SDAC.



Greater consideration of this issue should be included in the final report of the Inquiry, with recommendations or proposals included to ensure that caring relationships and carers are supported and sustained not only in the community context but also in residential aged care facilities.

**Recommendation 9:** The Commission should make recommendations or proposals to ensure that carers and care relationships are supported in residential aged care facilities.

#### **5.4 Need for post-care support**

The impacts of caring are often long-term, and extend beyond the end of the caring role. Even caring for a short time can have impacts that are life-long. For example, a 2009 report on mature age workers with elder care responsibilities shows that carers who leave employment because of their caring responsibilities often do not re-enter the labour force once their caring role ends.<sup>16</sup> Caring for just one year has a negative impact on earnings, and can have sustained effects over the carer's lifetime.<sup>17</sup> Other impacts such as the significant effects that can be felt on physical, mental and social health and wellbeing are also likely to be felt for some time after the caring role ends. In some cases these impacts are felt for the rest of the carer's life.

It is important that the Commission explicitly supports the right of carers to continue receiving the services and supports that they require after the caring role has ended, regardless of whether the older person has or continues to receive services. Carers are individuals with their own needs separate to those of the care recipient. If the older person has died, for example, their care needs have clearly ended, but that does not necessarily mean that the needs of the carer have also ended. Carers' right to support should not be contingent upon the needs of the care recipient, as discussed previously. (See section 5.2.)

In national consultations coordinated by Carers Australia in 2010 with carers, service providers and peak organisations to discuss the development of the National Carer Strategy there were strong views expressed about the inadequate support for, and often, unacceptable circumstances faced by carers once their caring role ceased. The report of these consultations is with the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs for consideration and has not yet been released publicly.

**Recommendation 10:** The Commission should recommend support for carers' access to services and supports beyond the end of the caring role.

#### **5.5 Respite**

The Commission needs to expand its focus not only relating to the diversity of carers, but also regarding the diversity of services and supports that are required. The draft report has correctly identified some of the significant issues that exist regarding access to respite services, but a broader definition and understanding of respite is needed in the final report. More consideration should also be given to different approaches to respite, and to the other services and supports that enable the provision of care to be shared, so that carers are better able to balance work and life responsibilities with their caring role.

Greater consideration must be given to formal care services in the community including day care programs, particularly affordable day care programs with extended

and/or flexible hours to cater for working carers. These and other substitute care arrangements must be accessible to carers to enable them to have real choice regarding their caring role, so that they are able to choose how much care and support they can provide. Services are needed not just to provide carers with a break when required, but also to facilitate the sharing of care provision between the carer and formal services on an on-going basis. (See section 7.5 for more detail.)

More thought must also be given to other ways of enabling or providing flexible and effective respite options, such as a family support entitlement which suit the needs of both the carer, the older person and the caring situation

We are aware that there is some discussion currently occurring regarding the desirability of cashing out respite entitlements. This could be one way of ensuring that carers are able to access respite that suits their needs. Some carers, for example, would use the funds to cover travels costs for a family member or friend to stay in their home with the older person while the carer takes a holiday.

We would support the cashing out of respite as an option for carers, provided certain conditions were met. There would need to be controls in place to ensure probity, and the achievement of good outcomes for the carer and the older person. It may also be important for the payment of respite funds to be staggered, for example, to be paid in two six-monthly payments rather than an annual lump sum. This is one option to ensure that the carer has respite when needed, throughout the year. The parallel Inquiry into Disability Care and Support provides analysis on these issues, which may provide direction to this Inquiry.

**Recommendation 11:** The Commission should give careful consideration to calls for the option to cash out respite entitlements.

The Commission may be expecting that the forthcoming National Carer Strategy will include more direction regarding carers, carer support, respite, and substitute care arrangements. As the National Carer Strategy may not be released until after the Commission's report is finalised, the Commission needs to comprehensively and holistically address these issues in the context of the aged care system.

## **5.6 Care coordination and case management**

Case management is an important component of the care and support model proposed by the Commission. Good case management is an important support for carers and the people they support, particularly when facing challenging changes and transitions. It is vital that those older Australians and carers who need case management services are able to access them when they are first needed and for as long as they are required. Older parent carers, in particular, often need case management services due to the complexity and intensity of their needs. Unfortunately, it is our experience that access to such services is very limited. Too many of the services that are available are short-term which in many cases is inappropriate and unrealistic.

The draft report does not contain a detailed proposal regarding the nature of the case management services which would be provided, but does cite the Community Options program as an example of how such services could be provided by independent agents. Case management services provided under the new aged care system must include long-term and intensive case management services for those who require them. Although the Community Options program may provide a model for how case management services can be provided in the community, other

elements of the program should not be retained, such as the focus on short-term case management, and the restrictive eligibility criteria, which currently limit access considerably for people requiring assistance, including older parent carers.

Care coordination and case management should be available for all caring situations at key life transitions, particularly on the carers' transition into the caring role, caring for an older person with a deteriorating condition, and the transition when an older person moves into residential care.

**Recommendation 12:** The Commission should strongly recommend that long-term case management services are provided where required.

## 5.7 Education and training opportunities

The draft report acknowledges the need for more training and education opportunities for carers, who are often unprepared when taking on caring responsibilities. The Commission notes various organisations that currently provide education, training and resources to assist carers to manage their caring role, and the stresses associated with caring and other aspects of life.

It is vital that the wealth of expertise and resources that currently exists in this field are preserved and built upon in the reformed system. The significant expertise and considerable resources of the carers associations in this area needs to be recognised. The associations provide a range of education and training to carers, service providers who work with carers and employers who may have employees who are carers. Training for carers provided by the carers associations includes specialised sessions and resources for different caring groups and situations, such as working carers, young carers and carers of older Australians. The Commission must ensure that the expertise and resources of the carers associations, and other peak organisations that specialise, for example, in particular conditions or population groups, are not ignored in the reform process.

The Commission should also give consideration to the potential need for funding for carers to access training which meets their unique situations and needs. For example, the demands of their caring role or their situation may be better served through participation in education or training which may not be targeted at carers, or delivered by a carer organisation. This has been recognised in the Disability Care and Support Inquiry draft report which proposes that funding be able to be used for this purpose when appropriate.

**Recommendation 13:** The Commission should ensure that existing expertise and resources in carer education and training, for example through the carers associations, are recognised and utilised in the reformed age care system.

## 5.8 Carer identifier in care records

Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.

(Principle 7 from the *Statement for Australia's Carers*)

The Commission has proposed the use of linked electronic records to avoid the need for older people to repeat the same basic information to multiple sources. According to the draft report, an initial questionnaire would provide the base information for further assessments, and protocols would exist regarding the updating of information.

To ensure that carers are recognised, included and supported in the reformed system it is important that electronic records include a carer identifier. This will ensure the inclusion of carers throughout the older person's journey through aged care, and the continued consideration of and response to their own needs as carers. The initial questionnaire must include a question or questions to ascertain the existence of a carer to ensure that this identifier is effectively and consistently used.

The flagging of a care relationship on electronic records will improve the on-going recognition and inclusion of carers in assessment processes and in care provision. It will also contribute to improved general awareness across the aged care system of the importance of recognising, supporting and including carers.

**Recommendation 14:** The Commission should recommend that a carer identifier be included in the proposed electronic care records.

The draft report does not make clear the relationship between the linked electronic records proposed for aged care, and the national e-health agenda currently being progressed by the National E-Health Transition Authority (NEHTA). The Commission should be looking in detail at the relationship between electronic records in the aged care industry and in other sectors such as health. Consideration must be given to how these systems would interact, or if the same system would serve the aged care, health and other relevant sectors. Whatever the outcome, the Commission should recommend that electronic records include a carer identifier, and flag the existence of a carer.

## **5.9 Consumer directed care**

The model of care and support proposed by the Commission is intended to enhance the choice and control available to older Australians. The degree of consumer choice or direction in the Commission's model is relatively limited, particularly when compared to the 'self-directed' model proposed in the draft report of the Disability Care and Support Inquiry.

Although the degree of consumer direction and choice is limited, it is important that there are supports in place to ensure that older Australians and their carers are not further burdened or disadvantaged by the choice and decision making which will arise in the shift towards consumer directed care. We strongly support the provision of supports outlined in the draft report, such as additional assistance to navigate and plan care needs, including case coordination and management (as discussed above), and the provision of care advocates to represent the interests of the consumer.

Although these supports are vital, to be effective they and the assessment and care planning processes must be informed by an understanding of the carer as a consumer, and take both a person-centred and family-centred approach.

Carers must be involved, and have their opinions and preferences taken into account in 'consumer driven' care planning, especially if the carer is to play a significant role in the care plan. Care plans made without the involvement of carers are likely to be ill considered and unfair, and are unlikely to address the needs of the carer, nor support and sustain the caring relationship. In addition to including carers in 'consumer driven' planning, carers should also be given access to support and advocacy services, as is further discussed below. (See section 7.6.)

**Recommendation 15:** The Commission should incorporate a person and family centred approach in its development of a consumer directed care model for aged care.

Carers right to choice must be built into any consumer directed care model. The Commission must ensure that carers have the right to choose if they take on or continue caring, and that it is the carer who determines how much responsibility they are able to take on and the circumstances in which they are willing to do this. Carers must have a say in decisions which impact upon them, and this will need to be carefully balanced with the right of the older Australian to choice and control of the care and support they receive.

**Recommendation 16:** The Commission must ensure that the carer's right to choice is built into and protected in the consumer directed care model they develop.

### 5.10 Block funding

The Commission is right to recognise that some services or supports, particularly community oriented services, will require block funding. While Carers Australia strongly supports the Commission's acknowledgement that block funding is an element of support for older Australians, we propose that the word "only" is deleted in draft recommendation 8.4 so that it states that direct block funding should continue where "there is a demonstrated need to do so based on a detailed consideration of scale economies, generic service need and community involvement." The consequences of inappropriately removing block funding would be catastrophic for some services, and the individuals they support.

The Commission needs to provide greater analysis in its final report of which services would require such funding, and what the consequences would be if services who need block funding do not receive it. We have serious concerns regarding the services, service providers and associated capacity and expertise which may be lost if Governments do not understand the need for block funding in some cases. The examples listed by the Commission, such as community transport programs, meal delivery, services in rural and remote areas and pilots of innovative services are all valid examples, but it would be helpful for the Commission to provide a more extensive list.

We have particular concerns for services such as day programs or day activity centres, many of which would need block funding or at least an operational subsidy to ensure their continued operation in the reformed aged care system. The Network also recommends the inclusion of a national program for employed carers be included in block funding and that this is coordinated by the Carer Support Centres. The importance of these services to the people who benefit from them cannot be underestimated.

Another area of concern is the provision of carer counselling by Carers Australia and state and territory carers associations under the NRCP. If block funding is not provided, it is unlikely that the provision of this service could continue. Although other counselling services would fill the gap, these are not specialist services, and the expertise developed by the carers associations would be lost. (See section 5.1 for more information.)

The Commission must ensure this issue is given due consideration and analysis, so that these and other vital services continue to be accessible to older Australians and their carers, that access is not compromised by the shift away from block funding.

**Recommendation 17:** The Commission should strengthen its discussion and recommendations relating to the need for block funding for some services.

## **6. Catering for diversity – caring for special needs groups**

### **6.1 Gay, lesbian, bisexual, transgender and intersex people**

It is pleasing that the Commission has acknowledged the experiences of gay, lesbian, bi-sexual, transgender and intersex (GLBTI) people in the aged care system. In its submission to the Inquiry Carers NSW highlighted the need for culturally appropriate services and supports which respect and respond to the needs and choices of GLBTI older people and carers. Although we are pleased to see that this issue has been recognised in the draft report, there are some concerns regarding the way in which it has been addressed.

Firstly the description of GLBTI people as ‘culturally and linguistically diverse’ is very problematic. Culturally and linguistically diverse (CALD) is a term which is commonly understood to refer to non-Indigenous ethnic groups other than the English speaking Anglo-Saxon majority.<sup>18</sup> CALD was introduced to replace “non-English speaking background” by the Ministerial Council of Immigration and Multicultural Affairs in 1996. CALD remains the term currently in common usage despite its limitations.<sup>19</sup> CALD should not be used to capture other individuals and groups who have different needs or experiences to the mainstream population, such as GLBTI people, as it is a term specifically relating to ethnic diversity.

Care must also be taken with language when discussing GLBTI people, or any other group. Referring to “GLBTIs” (as appears on page 281 of the draft report) is inappropriate, and presumably an error. The Commission should take care to always refer to people as people, and be consistent in the use of “GLBTI people” and “GLBTI seniors” as appears elsewhere in the report.

In the draft report the Commission supports “further initiatives between DOHA and peak bodies to help create an aged care system that can better cater for and respond to the needs and preferences of GLBTI older people.” We note that this was not a recommendation of the draft report, nor were there any other recommendations relating to the needs and experiences of GLBTI people.

**Recommendation 18:** The Commission must review its discussion of the issues experienced by gay, lesbian, bisexual, transgender and intersex people and make an appropriate recommendation.

### **6.2 People from culturally and linguistically diverse backgrounds**

We are pleased to see that the draft report includes recommendations relating to the needs of people from culturally and linguistically diverse backgrounds. However, as with the section devoted to GLBTI people, there is some problematic use of language evident.

As indicated in the preceding section, culturally and linguistically diverse is a term which is commonly understood to refer to all non-Indigenous ethnic groups other than

the English speaking Anglo-Saxon majority,<sup>20</sup> and it has replaced the term “non-English speaking background”. We appreciate that “non-English Speaking Background” is terminology used in the *Aged Care Act 1997*, but suggest that the Commission should use the term ‘culturally and linguistically diverse’, as used in the various submissions to the Inquiry quoted in this section.

The Commission must also frame its recommendations so they ensure that all support for the older person, the carer and their family is appropriate to their cultural needs.

**Recommendation 19:** The Commission should:

- a) review its discussion and expression of the issues experienced by people from culturally and linguistically diverse backgrounds
- b) frame its recommendations to ensure that support for the older person, the carer and their family is appropriate to their cultural needs.

### **6.3 Aboriginal and Torres Strait Islander people**

Similarly, it is pleasing that recommendations have been made relating to the needs of Aboriginal and Torres Strait Islander people. It is promising that the Commission has picked up on some of the most significant issues, such as the need to better attract and retain Aboriginal and Torres Strait Islander workers, and the importance of using culturally appropriate assessment tools and enhancing service capacity. Consideration should be given to making the Commission’s comments regarding flexibility in employing Aboriginal and Torres Strait Islander people a recommendation, as warranted by the significance of this issue.

**Recommendation 20:** The Commission should ensure that it strongly emphasises the importance of its recommendations relating to Aboriginal and Torres Strait Islander people.

### **6.4 Socially and financially disadvantaged people**

We welcome the Commission’s acknowledgement of socially and financially disadvantaged people. This is of particular relevance to carers, many of whom are both financially disadvantaged and socially isolated by the impacts of their caring role.

Evidence presented at the Carers NSW 2011 Biennial Conference indicated that carers experience lower life satisfaction than non carers. For carers to experience life satisfaction parity this would equate to an additional \$325 per week.<sup>21</sup> Similarly, earlier research by Deakin University for Carers Australia indicated a significantly lower health and wellbeing index than non carers. This could also be alleviated by an increase in a carer’s income.<sup>22</sup>

We recognise the Commission’s inclusion of these individuals in its proposed model for an aged care system, but remain concerned that the Commission does not demonstrate a full understanding of disadvantage, and put emphasis on wealth in its discussions of older Australians, as discussed in part one of this submission.

### **6.5 People with younger onset dementia as a special needs group**

The draft report fails to give due consideration to the needs of people with younger onset dementia and their carers. Currently there are 15,000 Australians with younger onset dementia.<sup>23</sup> It is disappointing that the needs of these individuals are not

discussed or responded to, despite the Commission's acknowledgement of other issues relating to dementia, and of other special needs groups.

In 2007, Alzheimer's Australia prepared a report for the Australian Government Department of Health and Ageing, *Exploring the Needs of Younger People with Dementia*. According to this report, people with younger onset dementia and their carers have unique needs, and may face different issues to older people with dementia, including:

- difficulty and/or delays in getting an accurate diagnosis
- family responsibilities including still actively raising a family
- currently working or being only recently retired
- having significant financial commitments based on previous earnings
- needing to revise their expectations of everyday life, such as work, finances and living arrangements
- social and sexual relationships, and independence and responsibility for others
- future plans that are affected at an earlier stage in life
- being more likely to have a rarer form of dementia than Alzheimer's disease or a genetically-based cause
- experiencing difficulty in accessing appropriate services, particularly as younger people with dementia are often otherwise physically strong and healthy.<sup>24</sup>

In a submission to the Inquiry, Alzheimer's Australia described people with younger onset dementia as a 'special population' and made recommendations relating to the need for seamless service, and access to age appropriate care services from the aged care system (for those who have not previously received support from disability services).<sup>25</sup>

We strongly suggest that the Commission give greater consideration to the needs of these individuals in the final report, and to ensure that the need for improved diagnosis and age-appropriate care services is addressed. The Commission must also ensure that people with younger onset dementia and their carers are not shifted between the disability and aged care sectors.

**Recommendation 21:** The Commission should give greater consideration to the special needs of people with younger onset dementia and their carers.

## 7. Delivering care to the aged – workforce issues

The valuable social and economic contribution that carers make to society should be recognised and supported.

(Principle 3 from the *Statement for Australia's Carers*)

### 7.1 Carers are a unique stakeholder in aged care – not a subset of the paid workforce

The inclusion of carers in the chapter of the draft report relating to workforce issues is extremely disappointing. Carers Australia's submission to the Inquiry clearly stated that the inclusion of the central discussion on carers in the workforce section of the



Issues Paper was problematic.<sup>26</sup> This issue has also been raised by us and state and territory carers associations in subsequent meetings with the Commission.

Carers are a unique stakeholder in the aged care system. They are the main provider of care in the community, and have been described by the National Health and Hospital Reform Commission (NHHRC) as the 'invisible workforce'.<sup>27</sup> However, there are significant and overwhelming differences between carers and the paid workforce which renders their inclusion within the workforce inappropriate and problematic. These differences include:

- **Remuneration.** The aged care workforce are paid to provide care, carers are not. On the contrary, carers are often forced to sacrifice paid work in order to provide care.
- **Support.** The aged care workforce has entitlements to training and professional development, and other supports from their employer and colleagues.
- **A safe working environment.** Unlike the paid workforce, carers have no workplace protections, regulation or legislation to protect them from injury or ill health arising from their occupation, nor do they receive any support if injury/ill health does occur.
- **Rest and recreation.** Carers do not have finite shifts, the hours they work are not limited, nor do they receive personal or annual leave. Access to respite does not equate to employee benefits.
- **Retirement.** Whilst employers of the paid workforce contribute to their superannuation savings, carers often experience a reverse savings effect as a result of the financial and opportunity costs that caring entails.

As emphasised in Carers Australia's first submission to the Inquiry,<sup>28</sup> the needs of carers and their place in the aged care system are more closely aligned with the needs of consumers than with the workforce. Carers often become decision makers on formal care provision, and advocates for themselves and for the older person. Carers have their own needs for services and support separate to the needs of the person they support. Carers, the older person, and the caring relationship need to be supported and sustained.

**Recommendation 22:** Carers' issues should not be discussed in the chapter on the workforce, but rather a separate chapter should be dedicated to carers in the final report.

## 7.2 Proposals needed to improve carer 'conditions'

Despite including carers with the workforce in the draft report, the Commission has failed to make any proposals to improve the 'conditions' they are exposed to in their provision of care. The Commission should look to some of the issues addressed in the preceding section, such as the need for safer, more sustainable practices in informal care provision, and better protection of carers' rights such as the right to rest and retirement. For example, the Commission must consider improving protections for carers' physical health in their caring role. Proposals are needed to ensure that caring does not result in physical injury to the carer. For those carers who are injured while providing care, compensation, support and substitute care services are required.

The Commission should also consider more seriously the financial situation of carers, and the need for better income support or remuneration for the work they currently provide unpaid. The draft report notes that:

Some carers are not able to participate fully in the workforce as a direct result of their caring responsibilities. The Australian Government recognises this and offers income support through the Carer Payment. The Australian Government also offers ... a Carer Allowance to assist in covering some of the costs incurred as part of their caring activities. (p 353)

It is disappointing that the Commission made this observation without providing any comment on the adequacy of the income support provided. There is no recognition of the significant and long-term financial impacts of caring, nor of the need to prevent these impacts. (See also section 5.4.)

The financial disadvantage associated with caring is well established. Carers are likely to have low income, high dependence on government financial assistance, little or no capacity to save for retirement and experience high financial stress due to the combination of low income and high caring costs.<sup>29</sup> The *2008 Community Care Census* indicates that of the carers of older people accessing the National Respite for Carers Program around 23 per cent were reported to be experiencing 'financial hardship'.<sup>30</sup> Ninety-eight per cent of respondents to the *Carers NSW 2010 Carer Survey* had additional financial costs as a result of their caring role. Among the most commonly experienced costs were medicines (72 per cent of respondents), travel costs (62 per cent) and respite (55 per cent). Fifty-eight per cent of respondents had to borrow money as a result of their caring role.<sup>31</sup>

**Recommendation 23:** The Commission should make recommendations about addressing the significant financial disadvantage that many carers experience as a result of their provision of care.

The Commission should also examine the need for superannuation for carers to alleviate some of the long term financial disadvantage of caring, as advocated for by Carers Australia, as well as the Human Rights and Equal Opportunity Commission (HREOC) in its report, *It's About Time: women, men, work and family*.<sup>32</sup> Due to their low workforce participation, many carers have little opportunity to accumulate superannuation savings, as identified by the National Centre for Social and Economic Modelling in the *Women Carers in Financial Stress Report*. Carers have a right to save for their future retirement and this right must be supported in the reformed aged care system.

**Recommendation 24:** The Commission should consider the need for a superannuation scheme for carers.

### 7.3 Transport services

The consideration given to the transport needs of older Australians is disappointing. Although the issue is mentioned at various points throughout the draft report, it is not given significant consideration. It is promising, however, that the Commission has identified transport as one of the services which will continue to require block funding.

The United Kingdom Social Exclusion Unit describes transport disadvantage as 'the problems with transport and the location of services that contribute to social exclusion by preventing people from participating in work or learning, or accessing healthcare, food shopping and other local activities'.<sup>33</sup>

Aside from the significant implications of transport disadvantage for older people, including negative health outcomes, transport disadvantage has a serious flow-on effect to families and carers. A lack of transport options particularly impacts upon working carers who are often forced to provide transport during working hours, and upon carers from lower socio-economic backgrounds, who may be less likely to have access to private transport. It is for these reasons that transport and carers requires greater discussion than one paragraph under 'Other support services'.

Carers NSW has already provided the Commission with information on the significant need for transport services. It is known, for example, that transport assistance was the second largest area of need for Aged Care Assessment Team clients in 2006-07.<sup>34</sup> According to SDAC 2003,<sup>†</sup> 43 per cent of people in NSW over the age of 60 years needed assistance with transport. Assistance to these individuals was overwhelmingly provided by carers.<sup>35</sup>

Community transport services are currently under significant strain and are forced to refuse requests for transport. For example, it is estimated that in NSW, Community Transport providers are forced to refuse approximately 90,000 requests for transport to health treatment per year. The significant burden of health transport met by Community Transport (680,000 trips to health services are provided by community transport in NSW each year, only ten per cent of which are funded by NSW Health)<sup>36</sup> reduces access to community transport for the social and recreational purposes it was originally established for.

Unmet need for transport can only increase, as there will be a significant increase in the number of older people who will not be able to drive. According to the NRMA, in NSW alone there are nearly 900,000 drivers aged over 60 years old who will have future mobility needs.<sup>37</sup> An NRMA survey conducted in 2010 showed that 23 per cent of drivers who require assistance with their mobility have difficulty accessing public transport in their local area and 42 per cent don't use public transport. It is likely that this situation exists Australia-wide.<sup>38</sup>

An issue of such significance demands greater consideration than it currently receives in the draft report. Transport disadvantage is a very significant and fundamental challenge facing older Australians, their carers, and the aged care and health systems.

**Recommendation 25:** The Commission should give more attention to the transport needs of older Australians.

#### 7.4 Assistive technology

Assistive technology receives relatively little consideration in the draft report despite the strong evidence of its benefits which include:

- improved safety and reduced falls
- reduced hospitalisation
- improved independence, mobility and physical function
- improved wellbeing and quality of life
- an enhanced sense of safety, for the older person and the carer
- increased opportunities to continue living at home.<sup>39</sup>

<sup>†</sup> Updated data is not yet available from the 2009 SDAC.

Assistive technologies also deliver considerable cost savings. As the United Kingdom Audit Commission stated in a national report on aids and equipment for older people and people with a disability:

If a drug was discovered with a similar cost-profile, it would be hailed as the wonder-drug of the age.<sup>40</sup>

The Commission should give greater consideration to the improved provision of assistive technologies in the reformed aged care system, in light of their very significant benefits, and the major barriers that currently exist to their take up, such as a lack of clear information and access points, a lack of follow-up home-based training and basic maintenance, and their lack of affordability.<sup>41</sup> Although the reformed aged care system may address the lack of information and access points, the cost barrier is yet to be addressed. Issues relating to abandonment and waste must also be considered in order to ensure an efficient system.

Addressing the cost issue must be a priority. Currently, considerable out-of-pocket costs are borne by older people and their families and carers. Estimates from the Australian Institute of Health and Welfare *Australia's Health Expenditure 2007-2008*, indicate that almost 73 per cent of the \$3.1 billion of expenditure on health-related aids and appliances is private out-of-pocket expenditure.<sup>42</sup> This is the highest proportion of private expenditure for any health-related expense subsidised by government in Australia. It is particularly concerning given the financial disadvantage already experienced by many carers and older Australians, for whom such additional costs can reduce and prevent access to the aids and equipment they require.

The Commission should give consideration to mechanisms to reduce abandonment. According to a 2003 report by the AIHW, *Disability: the use of aids and the role of the environment*, abandonment rates of aids vary widely from 8 to 75 per cent.<sup>43</sup> Abandonment is concerning not only due to the 'wastage' of equipment, but also due to the lost benefit for the consumer.<sup>44</sup> There are a variety of reasons for abandonment including poor original decision, the inability to test/tryout, changed needs and priorities, performance issues and the level of consumer involvement in selection.<sup>45</sup>

Another priority relating to aids and equipment is the need to facilitate reuse and recycling where appropriate. Older people in particular are likely to use aids and equipment for relatively short periods of time, before requiring different aids or equipment, or no longer requiring the aid or equipment. Schemes in New Zealand and the United Kingdom successfully reissue equipment.<sup>46</sup> Enable New Zealand,<sup>47</sup> which supplies equipment for the Accident Compensation Corporation has recorded savings of around \$NZ20 million over two years through the return, refurbishment and reissue of around 31,000 pieces of equipment.<sup>48</sup> The experiences of these programs may be instructive to the Commission.

**Recommendation 26:** The Commission should make recommendations regarding the provision of aids and equipment which address the need to improve affordability, reduce wastage, and increase reuse and recycling.

#### 7.4.1 Telehealthcare

According to a study of the use of assistive technology by frail older people living in the community prepared for the Australian Government Department of Health and Ageing,<sup>49</sup> telecare and smart technologies are one of the three most effective

assistive technologies (alongside aids, devices and equipment and environmental adaptations). While the latter two are discussed in the report, telecare or telehealthcare is overlooked.

The neglect of telecare and telehealthcare initiatives in the draft report is surprising, given the otherwise forward-looking nature of the report. Carers NSW highlighted the potential applications and benefits of telecare initiatives in the Australian aged care system in its first submission to this Inquiry. As was cited in that submission, evidence from the United Kingdom indicates that telecare initiatives have significant benefits for older people, carers and the aged care system, and according to international evidence can:

- enable people to stay in their homes for longer
- reduce the need for acute home care
- delay admissions to residential care
- reduce the number of unplanned hospital admissions
- reduce the number of delayed discharges from hospital.<sup>50</sup>

Thus it was disappointing that the Commission provided so little analysis on the need to better utilise existing technology in the provision of care to older Australians, despite the significant changes brought about across other industries and in the personal lives of many Australians through the application of information and communication technologies (ICT).

It is the ideal time to be progressing telehealthcare services, considering the current reforms in e-health, the roll-out of the National Broadband Network and the significant take up of other ICT by so many Australians, including older Australians. Respondents to the *Carers NSW 2010 Carer Survey* showed a more marked engagement with ICT, despite the average age of survey recipients being 58 (with 34 per cent aged over 65). Although 76 per cent of respondents had access to the internet and 84 per cent had a mobile phone, only five per cent of respondents were currently using telehealthcare services.<sup>51</sup>

The Commission needs to broaden its approach to the applications of technology to aged care, and look not only to physical aids and equipment, but also to the initiatives and devices included under the telehealthcare umbrella, including:

- movement, flood, gas, smoke or fall detectors
- safe walking systems
- lifestyle monitoring
- health/vital sign monitoring
- tele-consultations.

Although the potential of telehealthcare is particularly relevant to regional and rural carers, its benefits could be felt by all older Australians and their carers. The Commission should address the need to mainstream telehealthcare into the Australian aged care system, to improve the sustainability of ageing at home, and enhance the choice and control enjoyed by older Australians and their carers.

**Recommendation 27:** The Commission's proposed age care system should include telehealthcare as a mainstream and accessible component.

## 7.5 Working arrangements for carers

The difficulty of balancing paid employment with caring responsibilities is well established, as are the significant benefits that arise from carers maintaining their connection to the workforce. Carers of older Australians are particularly disadvantaged in relation to their working arrangements. A parent or 'carer' of a child under school age is entitled to greater workplace flexibility under the *Fair Work Act 2009* and can claim a subsidy from the Australian Government for care costs. These provisions are not available to working carers of an older person or an adult person with a disability.

Carers Australia, with the Taskforce on Care Costs (TOCC), has undertaken research on employed and unemployed carers and 'carers' of younger children, and provided reports to the Australian Government on this inequity and the implications for working carers, particularly those who care for, or will be caring for, an older Australian.

In its three-year body of research TOCC found that there is a clear relationship between work and the cost of care. Findings included:

- 1 in 4 employees with caring responsibilities is likely to leave the workforce because the cost of care is too high.
- 1 in 4 employees with caring responsibilities has already reduced their hours of work because the cost of care is too high. (NB: This applies equally to carers of older people, and carers of people with a disability.)
- In 2006 the cost of care influenced the departure of 64 per cent of unemployed carers from the workforce.
- employees with caring responsibilities want real choices
- 35 per cent of employees with caring responsibilities would increase their hours of work if care was more affordable.
- 60 per cent of unemployed carers would re-enter the workforce if care was more affordable.
- 52 per cent of part-time employees would increase their hours of work if alternative care was more affordable.<sup>52</sup>

The Commission should address this issue on two fronts. Firstly the Commission must reconsider its stance on amending the *Fair Work Act 2009*. In the draft report the Commission notes the numerous submissions from organisations representing carers, governments and consumers that argue for greater work place flexibility for carers. Carers Australia, Carers Victoria and Carers NSW were among the organisations that called for amendments to the *Fair Work Act 2009*, as recommended in the *Who Cares...? Report on the inquiry into better support for carers*.<sup>53</sup>

The Commission's current response to this issue is disappointing in light of its significance to carers and to the aged care system. Despite the number and variety of organisations that have raised this issue, the only response in the draft report is to note that the Australian Government did not accept the recommendation to amend the *Fair Work Act 2009* and a statement to the effect that workplace flexibility will improve as employers face an "increasingly constrained labour environment".

The fact that the Australian Government has previously rejected the recommendation to amend the *Fair Work Act 2009* does not mean that the Commission cannot or should not repeat it. The experience of many carers to date indicates that neither the existing provisions in the Act nor the "increasingly constrained labour environment" have created anywhere near the flexibility, recognition or understanding that is

required for carers to continue in the workforce. The Commission must be prepared to consider the aged care system in context and make recommendations that touch upon areas which may appear to lie outside of this sector, but have a critical impact upon it.

**Recommendation 28:** The Commission should recommend that the provisions for flexible working hours in the *Fair Work Act 2009* be extended to all carers, regardless of the age of the care recipient or the relationship between carer and care recipient.

The Commission must also address the inequity relating to the care services available for children compared to those available for older people and people with disabilities.

This issue goes to the heart of making caring and therefore the aged care system sustainable. As the Commission acknowledges, the availability of carers is expected to decline. National modelling conducted by the National Centre for Social and Economic Modelling (NATSEM) in 2006 estimated that the caretaker ratio (i.e. the number of people most likely to provide care in relation to the number of people needing care) was expected to fall steadily from 2.5:1 to 1.5:1 over the next 20 years, and to 1:1 over the next 35 years.<sup>54</sup>

Taking into account this expected fall in the number of people available to be carers, and the TOCC research that indicated that many carers (including of older people) wanted to re-enter or continue in the workforce, the implications are clear. The Commission needs to recommend that the Australian Government implements significant reform to address these issues. This includes urgent consideration of the need to provide affordable care services for older people and people with a disability, as is currently available for children. An option is for a national employed carer support program (care service) to be coordinated through the Carer Support Centres.

**Recommendation 29:** The Commission should strongly recommend that affordable care services are provided to enable carers to participate in employment and education.

## 7.6 Advocacy for carers

Carers should be treated with dignity and respect.

(Principle 8 from the *Statement for Australia's Carers*)

The Commission correctly identifies the need for independent consumer advocacy services, recommending that “an expanded system of aged care consumer advocacy services” be funded. The Commission has also acknowledged the need for advocacy services for carers, listing advocacy as one of the functions of the proposed Carer Support Centres.

The need for carer and family advocacy services has previously been identified in the report of the *Who Cares...? Inquiry*, which recommended that the National Disability Advocacy be extended to provide formal advocacy for carers in their own right when this is required, and to provide family advocacy services which better recognise the role of carers providing individual advocacy on behalf of, and with, care receivers.<sup>55</sup>

We strongly support the provision of independent carer and family advocacy services in the reformed aged care system. The Commission should clarify whether carers are considered consumers of aged care and would access the aged care consumer

advocacy services, or whether carer advocacy services would be delivered separately. We recommend that clear provisions are made for carer and family advocacy services. This service could be delivered by Carers Australia and the carers associations through block funding as specialist agencies to provide individual advocacy for carers. Another option is that this could be delivered by the same service that provides advocacy services to consumers, or by an independent section of the Carer Support Centres. If provided by Carer Support Centres, this advocacy service must not be limited to the aged care system but provide services to all carers, regardless of the age of the care recipient, or whether they are engaged in the aged care system.

We also provide systemic advocacy for carers relating to their caring situation across the diverse caring roles, e.g. whether caring for an older person, a person with a disability, or a mental illness, and carer populations that experience particular disadvantage through their policy advice.

**Recommendation 30:** The Commission should make clear and strong recommendations relating to the provision of advocacy services to carers.



## Summary of recommendations

A summary of the recommendations included in the submission is provided here with references to the principles of the *Statement of Australia's Carers* that each recommendation supports.

1. The Commission's final report and recommendations must be informed by and be consistent with the principles contained in the *Statement for Australia's Carers* included in the *Carer Recognition Act 2010*.

2. The Commission must strengthen its understanding and recognition of carers as individuals with their own rights and needs, separate to those of the care recipient.. (Principles 1, 4 and 5)

3. The Commission should review the assumption of wealth in its draft report and recommendations and consider the full impact of these recommendations on carers and other family members who may co-reside with the older Australian entering a residential facility. (Principles 1 and 9)

4. The Commission's model for paying for aged care must retain current protections of the family home from the assets test and remove the requirement for Centrelink to review the assets test after two years where there are carers or adult sons/daughters with a disability continuing to reside in the family home. (Principles 1 and 9)

5. The Commission should incorporate safeguards to ensure older Australians can remain in their local areas, regardless of their capacity to pay for services. (Principle 1)

6. The Commission must ensure that the proposed Carer Support Centres are adequately funded and resourced to provide a broad range of services and supports to all carers. (Principles 1, 4, 5, 9 and 10)

7. The Commission must ensure that the proposed Carer Support Centres are aligned with and incorporated into other reforms currently underway in the health, disability and mental health sectors. (Principle 10)

8.

The Commission should provide greater detail regarding carer assessment, and clarify that:

- e) individuals who are assessed as being able to care will not be obliged to do so
  - f) carers' access to assessment, services and support is not contingent on the position of the care recipient
  - g) carer assessment can and will occur when required, for example, pre-discharge
  - h) carer assessment will consider the capacity of carers across their life course.
- (Principles 4 and 5)

9. The Commission should make recommendations or proposals to ensure that carers and care relationships are supported in residential aged care facilities. (Principles 6 and 7)

10. The Commission should recommend support for carers' access to services and supports beyond the end of the caring role. (Principles 1 and 10)

11. The Commission should give careful consideration to calls for the option to cash out respite entitlements. (Principle 10)
12. The Commission should strongly recommend that long-term case management services are provided where required. (Principles 4, 5 and 10)
13.  
The Commission should ensure that existing expertise and resources in carer education and training, for example through the carers associations, are recognised and utilised in the reformed age care system.  
(Principle 10)
14. The Commission should recommend that a carer identifier be included in the proposed electronic care records. (Principles 6 and 7)
15. The Commission should incorporate a person and family centred approach in its development of a consumer directed care model for aged care. (Principles 5, 6 and 7)
16. The Commission must ensure that the carer's right to choice is built into and protected in the consumer directed care model they develop. (Principles 1, 4 and 5)
17. The Commission should strengthen its discussion and recommendations relating to the need for block funding for some services. (Principle 10)
18. The Commission must review its discussion of the issues experienced by gay, lesbian, bisexual, transgender and intersex people and make an appropriate recommendation. (Principle 1)
19.  
The Commission should:
- a) review its discussion and expression of the issues experienced by people from culturally and linguistically diverse backgrounds
  - b) frame its recommendations to ensure that support for the older person, the carer and their family is appropriate to their cultural needs. (Principle 1)
20. The Commission should ensure that it strongly emphasises the importance of its recommendations relating to Aboriginal and Torres Strait Islander people. (Principle 1)
21. The Commission should give greater consideration to the special needs of people with younger onset dementia and their carers. (Principles 1 and 10)
22.  
Carers' issues should not be discussed in the chapter on the workforce, but rather a separate chapter should be dedicated to carers in the final report.  
. (Principles 1, 3, 4, 5, 6, 7, 8, and 9)
23.  
The Commission should make recommendations about addressing the significant financial disadvantage that many carers experience as a result of their provision of care.  
. (Principles 1, 4 and 9)

24. The Commission should consider the need for a superannuation scheme for carers. (Principles 3, 4 and 9)
25. The Commission should give more attention to the transport needs of older Australians. (Principle 10)
26. The Commission should make recommendations regarding the provision of aids and equipment which address the need to improve affordability, reduce wastage, and increase reuse and recycling. (Principle 10)
27. The Commission's proposed age care system should include telehealthcare as a mainstream and accessible component. (Principle 10)
28. The Commission should recommend that the provisions for flexible working hours in the *Fair Work Act 2009* be extended to all carers, regardless of the age of the care recipient or the relationship between carer and care recipient. (Principles 1, 3, 4 and 9)
29. The Commission should strongly recommend that affordable care services are provided to enable carers to participate in employment and education. (Principles 1, 4, 9 and 10)
30. The Commission should make clear and strong recommendations relating to the provision of advocacy services to carers. (Principles 1, 8 and 10)

## **Conclusion**

Carers Australia and the state and territory carers associations are pleased to be contributing to the Inquiry into Caring for Older Australians. We hope that the Commission will act upon the comments and recommendations made in this submission, and that a more equitable and sustainable aged care system is the result.

We look forward to the creation of an aged care system in which caring is a shared responsibility, and in which all older Australians and their carers have access to the services and supports that they need, when they need them.

We have also noted our concern in this submission about the uncertainty of support for carers of people with a mental illness, or a chronic condition in the Commission's two draft reports and who may experience increased difficulties in accessing appropriate support for their caring role due to this uncertainty.

We would be pleased to provide the Commission with further information or advice as required, and look forward to the final report and recommendations.

## References

- <sup>1</sup> Australian Bureau of Statistics, *Disability, Ageing and Carers Australia: Summary of findings, 2009*, Canberra, 2011.
- <sup>2</sup> Ibid
- <sup>3</sup> Productivity Commission, *Caring for Older Australians*, Draft Inquiry Report, Canberra, 2010.
- <sup>4</sup> Australian Bureau of Statistics, 2003 Survey of Disability, Ageing and Carers: Summary of Findings, Australia, Canberra, 2004.
- <sup>5</sup> Australian Unity Wellbeing Index, *The Wellbeing of Australians – Carer Health and Wellbeing*, Survey 17.1, Deakin University, Melbourne, 2007.
- <sup>6</sup> Thomson C, Hill, T, Griffiths M, and Bittman, M, *Negotiating caring and employment*. Final report for the Australian Research Council Linkage Grant Program, UNSW, Sydney, 2008.
- <sup>7</sup> Australian Government Department of Health and Ageing, 'Aged Care Forms' [Online] Available at: <http://www.health.gov.au/internet/main/publishing.nsf/content/ageing-rescare-aaform.htm>, Accessed: March 14, 2011.
- <sup>8</sup> Carers NSW 2011 Biennial Conference, Presentations by Commissioner Robert Fitzgerald and Associate Commissioner John Walsh, and discussion that followed, Sydney, March 2011.
- <sup>9</sup> House of Representatives Standing Committee on Family, Community, Housing and Youth, *Who Cares...? Report on the inquiry into better support for carers*, Canberra, 2009.
- <sup>10</sup> Carers Queensland, *Wanting to be Heard and Included: Carers' Experiences of Hospitals, Health Issues Centre*, edition 90, Victoria, 2007.
- <sup>11</sup> Carers Australia, *Imagine a health system without family carers* Submission to the National Health and Hospitals Reform Commission, Canberra, 2008.
- <sup>12</sup> Productivity Commission, *Caring for Older Australians*, Draft Inquiry Report, Canberra, 2010.
- <sup>13</sup> Australian Bureau of Statistics, *Disability, Ageing and Carers Australia: Summary of findings, 2009*, Canberra, 2011.
- <sup>14</sup> Australian Bureau of Statistics, *Survey of Disability, Ageing and Carers Summary of findings 2003, 2004*.
- <sup>15</sup> Carers Victoria, *Partners in Care* Submission to the Productivity Commission Inquiry Caring for Older Australians, Melbourne, 2010.
- <sup>16</sup> Page A, Baird M, Heron A and Whelan J, *Taking Care: Mature age workers with elder care responsibilities*, University of Sydney, Sydney, 2009.
- <sup>17</sup> Thomson C, Hill, T, Griffiths M, and Bittman, M, *Negotiating caring and employment*. Final report for the Australian Research Council Linkage Grant Program, UNSW, Sydney, 2008.
- <sup>18</sup> Pooja Sawrikar and Ilan Katz, *How useful is the term 'Culturally and Linguistically Diverse' (CALD) in Australian research, practice and policy discourse?* [Online] Social Policy Research Centre, University of NSW, Available at: <http://www.sprc.unsw.edu.au/media/File/Paper276.pdf>, 2009.
- <sup>19</sup> Ibid
- <sup>20</sup> Pooja Sawrikar and Ilan Katz, *How useful is the term 'Culturally and Linguistically Diverse' (CALD) in Australian research, practice and policy discourse?*, University of NSW, 2009.
- <sup>21</sup> Carers NSW 2011 Biennial Conference, *Research to Practice – the cost of care, informal carers and the implications for governments and service providers*, Professor Jane Hall, Centre for Health Economics Research and Evaluation, University of Technology, Sydney, March 2011.
- <sup>22</sup> Cummins R et al, *Special Report 17.1: The wellbeing of Australians – Carer health and wellbeing*, Melbourne, October 2007.
- <sup>23</sup> Alzheimer's Australia, *Exploring the Needs of Younger People with Dementia in Australia*, report to the Australian Government Department of Health and Ageing, Canberra, 2007.
- <sup>24</sup> Ibid
- <sup>25</sup> Alzheimer's Australia, 'Submission to the Productivity Commission Inquiry: Caring for Older Australians', Canberra, July 2010.
- <sup>26</sup> Carers Australia, *The true nature of aged care in Australia* Submission to the Productivity Commission Inquiry into Caring for Older Australians, Canberra, 2010.
- <sup>27</sup> National Health and Hospitals Reform Commission, *A Healthier Future For All Australians: Final Report of the National Health and Hospitals Reform Commission*, Canberra, 2009.
- <sup>28</sup> Carers Australia, 'The true nature of aged care in Australia', 2010.
- <sup>29</sup> Australian Bureau of Statistics, *Survey of Disability, Ageing and Carers 2003, 2004*.

- 
- <sup>30</sup> Australian Government Department of Health and Ageing, *The 2008 Community Care Census*, Canberra, 2010.
- <sup>31</sup> Carers NSW, *Carers NSW 2010 Carer Survey*, Sydney, 2010.
- <sup>32</sup> Human Rights and Equal Opportunity Commission, *It's About Time: women, men, work and family*, Sydney, 2010.
- <sup>33</sup> Social Exclusion Unit, *Making the Connections* Final report on transport and social exclusion, London, 2003.
- <sup>34</sup> Australian Institute of Health and Welfare, *Australia's Welfare 2009* series no. 9.Cat.no.AUS 117, Canberra, 2009.
- <sup>35</sup> Australian Bureau of Statistics, *Survey of Disability, Ageing and Carers 2003, 2004*.
- <sup>36</sup> TCCNSW, NCOSS and NSW CTO, *No Transport, No Treatment: Community transport to health services in NSW*, Sydney, 2010.
- <sup>37</sup> NRMA, *Transport and Mobility Needs of Ageing Australians*, Discussion Paper, Sydney, October 2010.
- <sup>38</sup> Ibid
- <sup>39</sup> Connell J, Grealy C, Olver, K and Power J, *Comprehensive scoping study on the use of assistive technology by frail older people living in the community*, prepared by Urbis for the Department of Health and Ageing, 2008.
- <sup>40</sup> Audit Commission, *Fully Equipped: The Provision of equipment to older or disabled people by the NHS and social services in England and Wales*, Promoting Independence 2, The Audit Commission, London, 2000, p 64.
- <sup>41</sup> Connell J, Grealy C, Olver, K and Power J, *Comprehensive scoping study on the use of assistive technology by frail older people living in the community*, prepared by Urbis for the Department of Health and Ageing, 2008.
- <sup>42</sup> Australian Institute of Health and Welfare, *Australia's Health Expenditure 2007-2008*, 2009.
- <sup>43</sup> Australian Institute of Health and Welfare, *Disability: the use of aids and the role of the environment*, Cat. No. DIS 32, Canberra, 2003.
- <sup>44</sup> Summers Michael, *National Aids and Equipment Reform Agenda Background Paper*, Preliminary Draft (unpublished) MS Australia, 2010.
- <sup>45</sup> Ibid
- <sup>46</sup> Ibid
- <sup>47</sup> Enable New Zealand, 'About us' [Online] Available at: <http://www.enable.co.nz/>, Accessed: March 14 2011.
- <sup>48</sup> Summers Michael, *National Aids and Equipment Reform Agenda Background Paper*, Preliminary Draft (unpublished) MS Australia, 2010.
- <sup>49</sup> Ibid
- <sup>50</sup> Carers Scotland, 'A weight off my mind' *Exploring the impact and potential benefits of telecare for unpaid carers in Scotland*, Edinburgh, 2009.
- <sup>51</sup> Carers NSW, *Carers NSW 2010 Carer Survey*, Sydney, 2010.
- <sup>52</sup> Taskforce on Care Costs, *The hidden face of care: Combining work and caring responsibilities for the aged and people with disabilities*, Sydney, 2007.
- <sup>53</sup> House of Representatives Standing Committee on Family, Community, Housing and Youth, *Who Cares...? Report on the inquiry into better support for carers*, Canberra, 2009.
- <sup>54</sup> AMP.NATSEM, *Who Cares? The cost of caring in Australia 2002 to 2005: Income and Wealth Report Issue 13 May 2006*, Canberra, 2006.
- <sup>55</sup> House of Representatives Standing Committee on Family, Community, Housing and Youth, *Who Cares...? Report on the inquiry into better support for carers*, Canberra, 2009.