

## A National and Strategic Approach to Carer Recognition and Policy

- 3.1 This chapter examines the role and contribution of carers to society and identifies the need for greater formal recognition. The chapter will:
- provide information on the caring role and consideration of the contribution that carers make to society;
  - consider the importance of carer recognition and strategies to promote improved carer recognition through:
    - ⇒ initiatives to increase community awareness of carers and promote a better understanding of their needs;
    - ⇒ review of existing legislation and policies that impact on carers; and
    - ⇒ the introduction of national carer recognition legislative and policy frameworks.

### The Role and Contribution of Carers

- 3.2 Each caring situation has unique aspects reflecting the circumstances of the carer, the care receiver and the family. The association between carers and care receivers covers the spectrum of family relationships and friendships. Carers provide care for children and adults with a wide range of health and mental health conditions, disabilities and the frail aged. For some, the caring experience may span months or years, for others it spans decades and may involve providing care for one or more care receivers at various times.
- 3.3 Through written submissions and verbal statements to the Inquiry, over 1200 carers have shared their experiences, often describing the range of

tasks that they are required to undertake on a daily or regular basis, and the challenges that they encounter in providing care.<sup>1</sup> While some carers have described the rewards associated with providing care<sup>2</sup>, many have indicated that providing care, even for a loved one, is frequently demanding. The caring role is often a 24 hour a day, seven days a week responsibility.<sup>3</sup> Ms Sheralyn Hughes who cares for her 20 year old son with a severe autism spectrum disorder described her role in the following stark terms:

Endless, thankless, poor, a no win situation, desperate, extremely depressing and very bleak.<sup>4</sup>

- 3.4 Another carer, Ms Michela Cardamone, who cares for a family member with a mental illness described her role as follows:

Terrifying, traumatic, overwhelming, confusing, stressful, isolating, lonely, undervalued, under resourced, not understood, unsupported, unheard, invisible, frustrating, depressing, emotionally draining, physically exhausting.<sup>5</sup>

- 3.5 While it is clear that no two caring situations are the same, the excerpts below illustrate the breadth and intensity of the caring role.

**Ms Joy Roze - carer for her son with autism spectrum disorder**

Carers have a diverse role to play in their caring position dependant on the type of disability involved. There can be heavy lifting or restraint management involved, sleep deprivation, endless appointments to attend, medication to collect and administer, behavioural management to implement, adjust and uphold, extra home duty chores such as more frequent changing of bed linen, cleaning, specialised food preparation and extra laundry.

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- 1 See for example: Ms S Menegatos, Submission No 63, p 1; Ms S Hand, Submission No 322, p 1; Ms M Wright, Submission No 330, p 1; Ms J Schroeter, Submission No 838, p 1; Ms J-A Beattie, Submission No 1045, p 1.
- 2 See for example: Ms A Bellchambers, Submission No 349, p 1; Ms T Hayes, Submission No 933, p 2.
- 3 See for example: Ms T Camilleri, Submission No 48.1, p1; Ms K Stanley, Submission No 51, p 1; Ms S Hughes, Submission No 158, p 1; Ms P Bastow, Submission No 161, p 1; Ms J Thorburn, Submission No 170, p 1; Ms L Brown, Submission No 325, p 1; Ms R May, Submission No 351, p 1; Ms J Gutteridge, Submission No 708, p 1; Mr T Stroud, Transcript of Evidence, 12 August 2008, p 50.
- 4 Ms S Hughes, Submission No 158, p 1.
- 5 Ms M Cardamone, Submission No 799, p 1.

The Carer's role is constant. The Carer is on call 24 hours per day, seven days per week with most of us receiving little or no relief from our caring role.<sup>6</sup>

**Ms Kerryn McDonall – carer for her two daughters with disabilities**

To care for all my daughters' personal care, medical care, equipment needs, as well as cooking, cleaning, washing, shopping etc etc. These needs are for a lifetime, my eldest daughter is 25 and I am still changing nappies, cleaning up the mess she has made, trying to work out what she wants, putting things away so she doesn't break them, as well as bathing, dressing, cutting up her food, cleaning teeth, doing her hair, putting her shoes on again and again, putting on music in the hope she may stay still for a few minutes.

My 16 year old has a physical disability so I do most of the same for her but with more lifting. Then there are appointments with doctors, specialist, dentists, physios, schools, case workers (who keep changing), to arrange and attend.

Another role is to advocate for my daughters and to find services that meet their needs this takes a lot of emotional energy and time often with very limited results.<sup>7</sup>

**Ms Careen Dew – young person assisting with care for her 9 year old brother with multiple disabilities**

I am 21 years old and, together with my mum and my 18 year old brother, I care for my younger nine-year-old brother, Alec, who suffers from multiple disabilities which have left him unable to speak, eat, walk and even smile. My caring role for him is quite endless. It also extends to caring for his twin brother who is not disabled but, because Alec has had over 150 hospital admissions and with my mum by his side, I am pretty much the second parent of the house who looks after everything else whilst also trying to work part-time and study law down here in Sydney.<sup>8</sup>

**Mr Francis Horgan – carer for his wife with diabetes**

As a Carer, I feel that my role is important in facilitating the health and happiness of my wife who is eighty years old: has Type 2 Diabetes for more than ten years: as well as heart/blood pressure problems: loss of balance occasionally and suffers from shortness of breath. I assist my wife in her daily living activities; outside shopping; driving activities and

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6 Ms J Roze, Submission No 485, p 2.

7 Ms K McDonall, Submission No 518, pp 1-2.

8 Ms Careen Dew, Transcript of Evidence, 6 August 2008, p 45.

companionship; twenty four hours per day. This support allows my wife to enjoy an independent lifestyle in her own home.<sup>9</sup>

3.6 Despite the diversity of caring situations many carers also share common experiences. In drawing a broader picture of common experiences, Ms Deirdre Croft identified the following four dimensions of the caring role:

- **Physical dimensions of caring** (e.g. lifting, bathing, feeding, managing medication, hygiene requirements, behavioural management etc).
- **Practical dimensions of caring** (e.g. financial and administrative requirements, providing transport, assistance with shopping, domestic maintenance etc).
- **Emotional dimensions of caring** (e.g. based on a personal relationship, concern for, and commitment to, the wellbeing of the person with disability, advocating for and representing their needs etc).
- **Moral/ethical dimensions of caring** (e.g. as a way of living life compassionately with concern and practical consideration for the needs and vulnerabilities of others).<sup>10</sup>

3.7 In considering the contribution that carers make to society, many carers firstly describe the direct benefits for the care receivers. Carers emphasised the importance of being able to provide the best possible quality of life for the care receiver and helping to maintain a level of independence thereby preventing early or inappropriate entry into institutional or residential care.<sup>11</sup> Many carers also noted that by providing unpaid informal care in their own homes, they are saving governments significant amounts of money.<sup>12</sup> For example, as explained by Ms Saara Arnoldy, a carer of over 30 years for her son with multiple disabilities:

I have been called a hero! I never wanted to be one. I never wanted to be a divorced mother to a child with disabilities. I love my son, so there is only one thing to do, to look after him the best I can. The contribution I have made towards my son's welfare is immeasurable. The contribution I have made to society in monetary form can be calculated in very large figures.<sup>13</sup>

9 Mr F Horgan, Submission No 513, p 1.

10 Ms D Croft, Submission No 1219, p 4.

11 See for example: Ms M Loyer, Submission No 61, p 1; Mr K Matthias & Ms M Matthias, Submission No 710, p 1; Ms M Ross, Submission No 713, p 1; Ms L Dowd, Submission No 848, p 2; Ms J Steepe, Submission No 1023, p 6.

12 See for example: Ms B Kelly, Submission No 12, p 1; Mr N Faint, Submission No 20, p 1; Ms L Baker, Submission No 807, p 9; Mr G Bateson, Submission No 906, p 1; Ms N Jensen, Submission No 1052, p 1; Ms C Gray, Submission No 1133, p 1.

13 Ms S Arnoldy, Submission No 774, p 1.

3.8 There have been several estimates of the imputed economic value of the informal care provided by carers. In 2005, Access Economics estimated the value of the opportunity cost, that is the income forgone by carers spending time providing care rather than undertaking paid work, to be \$4.9 billion for that year.<sup>14</sup> Using the replacement valuation method, that is the cost of buying the equivalent number of hours of care from the formal care sector, Access Economics estimated that the economic value of informal care to be \$30.5 billion for that year.<sup>15</sup> The Australian Institute of Health and Welfare provides another estimate of the economic value of unpaid care (2005-06) for people with disabilities, including those who need assistance because of old age as \$27.4 billion.<sup>16</sup>

3.9 Although the estimates vary to some degree, the conclusion is that the current mix of informal and formal care arrangements results in significant savings for governments. However, these savings to governments have come at a cost to carers and their families. As noted by ANGLICARE (Sydney):

Informal care combined with some community-based care costs society far less than institutionalised care. It is the informal care component that reduces the cost of care, however this is the form of care that is least subsidised. Government benefits to informal carers were estimated at 35% of the opportunity cost to carers in 2005.<sup>17</sup>

3.10 Importantly, as indicated by many submissions the contribution of carers to Australian society can not be measured in purely monetary terms. More broadly carers also contribute by:

- building and maintaining family life and relationships;
- promoting social inclusion for people with disabilities, mental illness, serious medical conditions and for the frail aged; and
- supporting community cohesion.

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14 Access Economics (2005), *The Economic Value of Informal Care*, p 13.

15 Access Economics (2005), *The Economic Value of Informal Care*, p 15.

16 Australian Institute of Health and Welfare, Submission No 1033, p 4.

17 ANGLICARE Sydney, Submission No 769, p 15.

## Carer Recognition

- 3.11 Despite their significant contribution to society, many carers have stated that they feel their role is still not fully understood or appreciated by governments or by the wider community, including professional groups that have significant and frequent interaction with carers (e.g. health professionals, community service providers). As a consequence, many consider that the contribution of carers continues to be undervalued.<sup>18</sup> As observed by the Carers Support Network of South Australia:

Generally speaking, there is an appalling level of awareness within our society of the impact of caring. The financial, social, medical impacts are often profound and result in poverty, social isolation and poor health of the carer. Doctors, teachers, health workers, and above all - Centrelink workers, have poor understanding of what a day in the life of a carer looks like.<sup>19</sup>

- 3.12 Also describing a general lack of recognition and appreciation, the National Carers Coalition stated:

There can be little doubt that the role and contribution of family carers is undervalued, taken for granted, exploited and clearly sidelined by our governments and our society; by all those who should care.<sup>20</sup>

- 3.13 As one carer observed, for her and for many other carers, caring is effectively a 'hidden' activity, with even family, friends and neighbours failing to fully appreciate the demands associated with the caring role:

It is a hidden life because most of it occurs behind closed doors. Nobody, apart from my husband and children - not my extended family or even my closest friends and definitely not my neighbours - know what I do and how hard I work.<sup>21</sup>

- 3.14 Time and time again carers have specified the best way to recognise carers and to demonstrate that their contribution is genuinely valued, is through adequate provision of practical supports and services both for carers and
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18 See for example: Palliative Care Australia, Submission No 688, p 1; Name withheld, Submission No 1038, pp 1-2; Ms L P Dryburgh, Submission No 1048, p 1; Ms H Johnson, Transcript of Evidence, 12 August 2008, p 60; Ms W L Cheung, Transcript of Evidence, 12 August 2008, p 41.

19 Carers Support Network of South Australia, Submission No 675, p 5.

20 National Carers Coalition, Submission No 571, p 10.

21 Name withheld, Submission No 1248, p 1. See also: Ms C Alliston, Transcript of Evidence, 13 August 2008, p 50.

care receivers.<sup>22</sup> Specifically, carers have frequently called for increased levels of income support, greater assistance with meeting the additional costs of disability and care, greater access to community care services, particularly suitable respite, and for improved access to services for care receivers, including a range of supported accommodation options. The importance of demonstrating carer recognition through the provision of adequate supports and services is illustrated by the following statements:

**Ms Deborah Edwards - carer for her severely disabled adult son**

We work day in and day out, but we're not seen as workers. We save society a 'bucket load' of money, but are never thanked for that. We are the hidden army, as we have neither the time and energy nor the money to participate in society to any great extent, so we are unnoticed and easily ignored. ... a change in attitude towards Carers at a Government level is needed. Total reform of the way financial and physical support is delivered to us so that we are no longer 'welfare recipients' with all the stigma that is attached to that, but partners who carry out critical work for Government in a cost-effective way. Until then I don't believe we will truly feel that we are valued members of society at large.<sup>23</sup>

**Ms Narelle Hughes - carer for her adult daughter with profound intellectual and physical disabilities**

We have all heard the wonderful words spoken by many and varied people about the great contribution carers make in society and I am pleased that there is some recognition of my seemingly never-ending role. However, words do not put food on the table, or compensate carers for the loss of earnings they may have made, or help to accumulate savings for the future, or fund a retirement which is unlikely to come anyway. We are feted during Carers Week and given a 'bonus' in the Budget if we fight for it. Carers of working age need to be paid a wage commensurate with the work they do. Carers need to be recognised as workers who are providing a vital service which would otherwise need to be provided by the Government.<sup>24</sup>

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22 See for example: Ms L Belsham, Submission No 96, p 1; Ms J Cheal, Submission No 116, p 2; Mr I Morris, Submission No 162, p 1; Ms C Agnew, Submission No 166, p 1; National Carers Coalition, Submission No 571, pp 15-17; Ms J Bourke, Submission No 981, p 6; Name withheld, Submission No 1038, pp 1-2; Ms A-M Newbold, Submission No 1042, p 1; Ms D Currow, Submission No 1180, pp 1-3.

23 Ms D Edwards, Submission No 159, pp 1-2.

24 Ms N Hughes, Submission No 830, p 3.

3.15 The Committee has become only too aware of the significant social and economic contribution that carers make to Australian society. Clearly, given the considerable financial and personal costs for carers themselves, the importance of adequately recognising their contribution is fundamental. Many carers have identified the critical importance of practical measures which recognise the contribution of carers by providing adequate supports and services to meet the needs of carers, care receivers and their families. Detailed consideration of the issues associated with supports and services for carers is presented later in the report. However, the remainder of this chapter considers other options for enhancing carer recognition. These are:

- initiatives to increase community awareness;
- review of existing legislation and policy;
- the introduction of national carer recognition legislation and policy; and
- a review of arrangements for systemic carer advocacy.

## Increased Community Awareness

3.16 A number of submissions have referred to recent media exposure that has raised the profile of carers, highlighting their plight and the critical role that they play in society.<sup>25</sup> However, some carers and organisations have identified that there is still a need for further awareness raising through a national publicity campaign and community education.<sup>26</sup> For example, the Carers Support Network of South Australia indicated its support for:

Public awareness campaigns about:

- the financial contribution that Carers make to our society (billions of dollars per year);
- the role of Carers and what they do - legitimise their role by providing information throughout public media about their levels of skills and knowledge.<sup>27</sup>

25 See for example: Ms P Bodegraven, Submission No 509, p 2; Ms L Baker, Submission No 807, p 7; Ms D Etherington, Submission No 1204, p 4.

26 See for example: Name withheld, Submission No 22.1, p 1; Taskforce on Carer Costs, Submission No 23 (Attachment 1), *The Hidden Face of Care: Combining work and caring responsibilities for the aged and people with a disability*, p 36; Ms P Bodegraven, Submission No 509, p 2; Carers Support Network of South Australia, Submission No 675, p 5; Carers SA, Submission No 684, p 11; National Seniors Australia, Submission No 686, p 4; Brotherhood of St Laurence, Submission No 694, p 2; Sir Roden Cutler Charities, Submission No 700, p 2; Ms K McCann, Submission No 751, p 7; Name withheld, Submission No 1044, pp 1-2; Ms C Masolin, Submission No 1190, p 1; Ms H Johnson, Transcript of Evidence, 12 August 2008, p 60.

27 Carers Support Network of South Australia, Submission No 675, p 5.



3.17 Similarly, Anglicare Canberra and Goulburn also recommended a national community awareness campaign to raise the profile of carers using electronic and print media, billboards and community events. In making this recommendation, Anglicare Canberra Goulburn suggested that increased community awareness might 'mobilise' enhanced community support for carers, saying:

The Australian community, in general has demonstrated a great generosity of spirit towards people who experience misfortune and those who are disadvantaged. Specific education campaigns to help raise awareness of the circumstances carers find themselves in, will be likely to mobilise members of the community to show their support in practical ways.<sup>28</sup>

3.18 Carers Tasmania identified the following possible benefits of increased community education on the role of carers and their contribution to society:

Greater community education is needed to help people understand more about caring. This will have a two-fold effect: firstly, to assist people to self-identify and self-refer to services if they have support needs; and, secondly, to increase wider community awareness of caring needs and promote inclusion.<sup>29</sup>

3.19 In addition to raising awareness in the wider community, evidence has also identified the need for initiatives that target specific professional groups. For example, the submission from the Queensland Government recommended:

Development and delivery of programs to raise awareness of and responsiveness to carer's needs and issues within services, government agencies, businesses, and educational institutions.<sup>30</sup>

## A National Community Education Campaign

3.20 The Committee agrees that a national community education campaign to raise the profile of carers is needed to enhance carer recognition and promote a greater appreciation of the valuable contribution that carers make to society. As well as validating the role of carers, a better appreciation of the challenges associated with providing care, and a better

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28 Anglicare Canberra and Goulburn, Submission No 724, p 9.

29 Carers Tasmania, Submission No 671, p 8.

30 Queensland Government, Department of Premier and Cabinet, Submission No 1203, p 9.

understanding of the specific needs of carers should promote a more inclusive and supportive society.

- 3.21 In addition to raising the profile of carers in the community more broadly, the Committee agrees that there is also a need for education that specifically targets particular sectors and professional groups. For example, a campaign could specifically target employees in the health and community services, education and private sectors.
- 3.22 As noted in chapter 2, a national community education campaign should also seek to target those carers who may not readily self-identify as such, and to address the concerns of those carers who may be reluctant to disclose their role to others. Importantly the campaign should advise these carers of the government services available to them.
- 3.23 An effective national education campaign will need to be tailored to the different target groups, taking into account strategies to reach new carers, young carers, carers from culturally and linguistically diverse (CALD) and indigenous backgrounds. Similarly, publicity targeting specific sectors or professional groups will need to be delivered in different ways.
- 3.24 Although the Committee considers that a national community education campaign is warranted, it also acknowledges that there is limited value in raising community awareness in the absence of other measures which increase access to supports and services for carers and care receivers. Therefore, the Committee emphasises that its support for a national community education campaign should be viewed as part of a proposed broader suite of reforms to recognise carers through practical measures.

## Recommendation 2

3.25 That the Australian Government, through the Department of Families, Housing, Community Services and Indigenous Affairs and the Department of Health and Ageing support a national community education campaign to promote a better understanding of the role and needs of carers, and an appreciation of the contribution that carers make to society.

The campaign should also include components to promote increased awareness of their role among 'hidden' carers who may not readily self-identify and to address the concerns of carers who may be reluctant to disclose their role to others.

## Carer Recognition through Legislation and Policy

3.26 Evidence from individuals and from organisations have emphasised the importance of developing robust legislative and policy frameworks to raise the profile of carers and to uphold carer rights. Several submissions have referred to frameworks of carer legislation and policy in other countries, such as the United Kingdom, Ireland, New Zealand, Canada and Sweden.<sup>31</sup>

3.27 For example, Ms Mary Lou Carter notes that the United Kingdom has enacted three pieces of carer specific legislation.<sup>32</sup> Between them these confer a number of rights for carers including:

- an assessment of the carer's ability to provide care;
- an assessment of the carer's own needs; and
- access to services and information.<sup>33</sup>

3.28 To complement this legislation in June 2008 the United Kingdom Government released its carer strategy *Carers at the heart of 21<sup>st</sup> century families and communities*. The strategy sets out the short-term agenda to be

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31 See for example: National Carers Coalition, Submission No 571, p 14; Carers Australia, Submission No 699, pp 31-32; Ms N Brown, Submission No 951, p 7; Ms M L Carter, Submission No 1291, pp 4-5; Ms A Ashton, Transcript of Evidence, 26 September 2008, p 5.

32 These are: *The Carers (Recognition and Services) Act, 1995*; *The Carers and Disabled Children Act 2000*; and *The Carers (Equal Opportunities) Act, 2004*.

33 Ms M L Carter, Submission No 1291, pp 4-5. See also: Ms N Brown, Submission No 951, p 7.

achieved by 2011 and a long-term vision for the future support of carers to be achieved by 2018.<sup>34</sup> The essence of the strategy is embedded in its vision statement:

Our vision is that by 2018, carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals' needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, while enabling the person they support to be a full and equal citizen.<sup>35</sup>

3.29 Arguing the case for a legislative basis to support carer rights in Australia, and to provide a legislative foundation for the implementation of carer policy, Carers ACT stated:

Legislation is a critical component of social structure. It provides a foundation of support which underpins policy development and service provision. It outlines the rights and responsibilities of all people affected, and it ensures their due protection under the law. Carers may feel more secure when their rights and responsibilities are clearly set out in such a charter.<sup>36</sup>

3.30 In also providing its support for carer legislation and national strategic carer policy, Carers Australia observed:

Carer legislation, carer policies and/or action plans have been introduced in all states and territories and some overseas countries. This action is a vehicle for enhancing and embedding recognition of carers and in some cases conferring rights or provisions within existing legislation.<sup>37</sup>

3.31 With regard to the preferred legislative model Carers Australia noted that carer recognition legislation may require reform to existing legislation, the introduction of new legislation or a combination of both, stating:

Whether it is one act or more and/or reform to existing legislation is a question about the best form of legislation. However to

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34 United Kingdom Government, Department of Health website, *Carers at the heart of 21<sup>st</sup> century families and communities* (2008), viewed 25 February 2009 at [www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/DH\\_085345](http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/DH_085345).

35 United Kingdom Government, Department of Health website, *Carers at the heart of 21<sup>st</sup> century families and communities: a caring system* (2008), p 9, viewed 25 February 2009 at [www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/DH\\_085345](http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/DH_085345).

36 Carers ACT, Submission No 702, p 13.

37 Carers Australia, Submission No 699, p 9.

demonstrate true recognition for the role and contribution of carers, national carer legislation is needed.<sup>38</sup>

## The Framework of Existing Legislation and Policy

3.32 The scope of existing legislation and policy which directly or indirectly impacts on carers is broad. As shown in Table 3.1 some states and territories, have already introduced specific carer recognition legislation. Some states and territories, either in addition to carer specific legislation or as an alternative to carer specific legislation, have carer policies in the form of carer strategies or action plans. Through these strategies and action plans governments articulate their commitments to carers.

Table 3.1 State and Territory Specific Carer Recognition Legislation, Strategies and Action Plans

State / Territory	Specific Carer Recognition Legislation <sup>39</sup>	Carer Strategy / Action Plan
Australian Capital Territory	No	Caring for Carers Policy 2003 Carers Action Plan 2004-08
New South Wales	No	Carers Action Plan 2007-12
Northern Territory	<i>Carers Recognition Act 2006</i>	Carers Charter
Queensland	<i>Carers Recognition Act 2008</i>	Carers Recognition Policy 2003 Carers Action Plan 2006-10
South Australia	<i>Carers Recognition Act 2005</i>	SA Carers Policy Carers Charter
Tasmania	No	No
Victoria	No	Caring Together: a Carer Participation Action Plan 2003-08
Western Australia	<i>Carers Recognition Act 2004</i>	Carers Plan for Western Australia 2004-07

Source: Parliament of Australia, Parliamentary Library 2009.

38 Carers Australia, Submission No 699, p 10.

39 Table 3.1 lists specific carer recognition legislation introduced by states and territories. The table does not include reference to Acts introduced to increase carer recognition through amendments to existing legislation as introduced in NSW, ACT or Victoria.

3.33 Evidence to the Inquiry indicates that the carer recognition legislation and policies that have been introduced by the states and territories are generally viewed favourably. For example, Carers Tasmania outlined the potential benefits of carer recognition legislation as follows:

Carer charters, such as those in operation in Western Australia and in the Northern Territory have proved that legislated minimum standards are the surest way of beginning a process of consistent compliance across whole of government and related services. These standards set clear and achievable guidelines for carer access to information, consultation in care processes, and provision of information. They also provide for strategic consultation, representation and participation in all planning matters related to carers.<sup>40</sup>

3.34 Emphasising the importance of state and territory based carer specific legislation to support carer rights and reinforce carer policy, Ms Dianne McCarthy of the Association for Children with a Disability observed:

I would like to say that a [carers] charter basically means little or nothing unless there is legislation to back it up. There are already some charters that currently exist and there are some efforts in this state [Victoria] to introduce a carers charter as well. But that is not backed by legislation. That is the essence of it. One thing complements the other.<sup>41</sup>

3.35 In addition to the state and territory based carer recognition legislation, carers are potentially affected by other legislation, including human rights, equal opportunities and anti-discrimination legislation which may be international, national, or state and territory based.<sup>42</sup>

3.36 Therefore, rather than introducing carer recognition legislation, some states and territories have elected to increase carer recognition and rights through amendments to existing legislation. For example, the *NSW Anti-Discrimination Amendment (Carers Responsibilities) ACT 2000 (NSW)* amended the *Anti-Discrimination Act 1977 (NSW)* to include a provision prohibiting unlawful discrimination on the grounds of caring

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40 Carers Tasmania, Submission No 671, p 14.

41 Ms D McCarthy, Transcript of Evidence, 12 August 2008, pp 94-95.

42 See for example: Carers South Australia, Submission No 684, p 10; ACT Government, Submission No 1000, p 2.

responsibilities.<sup>43</sup> More recently through the *Carer Recognition Legislation Amendment Act 2006 (ACT)* the ACT Legislative Assembly introduced amendments to the *Discrimination Act 1991 (ACT)*, *Guardianship and Management of Property Act 1991 (ACT)* and to *Human Rights Commission Act 2005 (ACT)* to strengthen a number of provisions relating to carer recognition.<sup>44</sup>

3.37 The introduction of state and territory based carer recognition legislation and amendments to broader human rights and anti-discrimination legislation suggest that recognition of carers is increasing. However, inconsistencies between jurisdictions have prompted calls from carers and organisations for a legislative framework that is both more robust and consistent between the jurisdictions.<sup>45</sup>

3.38 In addition to concerns regarding the lack of consistency in carer recognition legislation, an issue that has frequently been raised relates to the limitations of some legislative and policy frameworks in terms of acknowledging carers across all government portfolio area. For example, finance, housing, employment, education and transport. The importance of acknowledging carers across the full range of services was emphasised by the Disability Support Commission which noted that:

Access to other [mainstream] essential services – especially housing, transport, education and health – is a constant struggle for many carers.<sup>46</sup>

3.39 Although WA was the first state to introduce carer recognition legislation and policy, Mr Paul Coates of Carers WA told the Committee that there is a need to broaden the existing legislation:

We are looking for joined-up thinking in government. By that I mean not just focusing on carers programs but looking at all areas of policy. For example, in the area of affordable housing we

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43 Parliament of New South Wales website, viewed 26 February 2009 at [www.parliament.nsw.gov.au/prod/PARLMENT/NSWBills.nsf/0/A62946D1E1E60DFECA2568D3001C3E30?Open&shownotes](http://www.parliament.nsw.gov.au/prod/PARLMENT/NSWBills.nsf/0/A62946D1E1E60DFECA2568D3001C3E30?Open&shownotes).

44 ACT Government, ACT Legislation Register website, viewed 26 February 2008 at [www.legislation.act.gov.au/a/2006-47/default.asp](http://www.legislation.act.gov.au/a/2006-47/default.asp).

45 See for example: Ms M Trewhella, Submission No 154, p 5; Ms J Harrison, Submission No 301, p 1; National Carers Coalition, Submission No 571, p 3; Carers NSW, Submission No 661, pp 9-10; Carers South Australia, Submission No 684, p 10; Ms T Hayes, Submission No 933, p 3; Ms E Walker, Submission No 973, p 2; Mr K Wood, Submission No 1007, p 3; Disability Services Commission, Submission No 1039, p 3; Ms J-A Beattie, Submission No 1045, p 3; Ms C Masolin, Submission No 1190, p 3; Ms M Ryan, Submission No 1155.1, p 22.

46 Disability Support Commission, Submission No 1039, p 5.

believe that carers should be taken account of in policy and service delivery. Carers could be included as one of the priority groups in the allocations of affordable housing policy, rental policy and arrears operational policies to take account of carers' needs there. In education, we believe that awareness and recognition of carers should be endemic throughout the whole education system, particularly regarding young carers. In the school and education system, for example, teachers need to be made aware of the issues of young carers and the fact that they may have young carers in their class so that there is more flexibility in the delivery of education. We believe the transport policy and system need to take account of carers in allowing access, which is particularly important in regional and remote areas.<sup>47</sup>

### **The Need for Review of Existing Carer Legislation and Policy**

- 3.40 The Committee agrees that a robust legislative and policy framework will enhance carer recognition and provide the basis to develop policy, programs and services that better meet the needs of carers. To date the approach to increasing carer recognition has been on a state by state basis with some states and territories introducing specific carer recognition legislation and/or policies, while others have amended broader non-carer specific legislation. As a consequence, the extent to which existing legislative and policy frameworks address the needs of carers varies between jurisdictions.
- 3.41 To reduce these inconsistencies the Committee concludes that a systematic review of existing legislation and policy, in particular in relation to health and community care, is warranted in order to ensure carers are adequately recognised. Given the need to achieve harmonisation across jurisdictions, the Committee believes that consideration by the Council of Australian Governments (COAG), through the Health Community and Disability Services Ministerial Council (HCDSMC) is required.
- 3.42 However, given the breadth of legislation and associated policy that may impact on carers, the Committee is also cognisant that some relevant items will be outside the scope for consideration by the HCDSMC. The Committee suggests that a review of broader legislation that impacts on carers may also need to be considered, possibly under the auspices of COAG.

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47 Mr P Coates, Transcript of Evidence, 23 July 2008, pp 2-3.



### Recommendation 3

3.43 **That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing propose to the Health, Community and Disability Services Ministerial Council (HCDSMC) that the Australian Government and each jurisdiction review existing legislation and policy relating to health and community care to ensure that carers are adequately recognised.**

**If legislation affecting carers falls beyond the jurisdiction of HCDSMC then it should be referred to the appropriate ministerial council for review.**

### A National and Whole of Government Approach to Carer Legislation and Policy

3.44 To address concerns regarding the inconsistency of carer recognition legislation and policy between states and territories, and to achieve greater cross portfolio consideration of carer issues, the Committee has received evidence which suggests that there is a need for a national and whole of government approach to carer recognition legislation and policy.<sup>48</sup>

3.45 Providing her support for the introduction of national carer legislation, Ms Valerie Simpson, a carer for over 30 years for her son with high support needs, as well as for her two other adult children also with disabilities, stated:

I strongly believe there should be Uniform Carer Legislation in place throughout Australia, in this way Carers will be recognised by governments.<sup>49</sup>

3.46 Another long term carer living in WA and providing care for her husband with a degenerative neurological condition, also argued the case for national legislation, saying:

In this state [Western Australia] we have the Carer Recognition Act 2004 which seeks to acknowledge the valuable role of carers and bring them into the decision making processes via

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48 See for example: Name withheld, Submission No 559, p 4; Ms K McCann, Submission No 751, p 5; Name withheld, Submission No 853, p 3; Families Australia, Submission No 1088, p 18; Ms C McDiarmid, Transcript of Evidence, 20 August 2008, p 48; Mr D Herd, Transcript of Evidence, 6 August 2008, p 63; Ms R Warmington & Mr P Saunders, Transcript of Evidence, 13 August 2008, pp 10-11.

49 Ms V Simpson, Submission No 260, p 5.

consultation with them on both service provision and strategic direction of health and disability services.

This is a useful first stage of valuing carers and one that the Federal government could follow to ensure that across all sections of government, attention was paid to make relevant decisions considering people with disabilities, chronic illness and frailty and the needs of their carers. Federal legislation could bring parity across the states.

Federal legislation could set the stage for national leadership on a wide range of decision making levels and policies such as: planning infrastructure of public resources and venues which address access issues, this equates to adequate Australian building codes provisions.<sup>50</sup>

- 3.47 The Ethnic Disability Advocacy Centre, while acknowledging state and territory legislative advances in carer recognition, argued for national legislation and associated policy, saying:

Each of the State governments through their Carer Recognition Acts and policies is demonstrating a desire to support carers. However there is still a need for a national carer's legislation with targeted strategies and action plans for supporting carers - especially with integration of shared responsibilities between state and commonwealth governments, families and communities.<sup>51</sup>

- 3.48 Carers NSW raised the importance of national carer recognition legislation that complements state and territory legislation, stating:

Carers NSW believes national overarching legislation is important to recognise, protect and provide equal opportunity to carers across Australia. The key to effective national carer legislation will be to ensure its compatibility to state and territory legislation so that one does not negate the other.<sup>52</sup>

- 3.49 Mr Dougie Herd from the Office of the Disability Council of New South Wales called for the Australian Government to take the lead in developing national carer legislation and policy, saying:

We need the Parliament of Australia, the Government, to give a lead that brings together the different stakeholder interests of

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50 Name withheld, Submission No 853, p 3.

51 Ethnic Disability Advocacy Centre, Submission No 787, p 9.

52 Carers NSW, Submission No 661, p 9.

people with disability and their family members, friends and others. It brings to some kind of resolution the problems that have existed ... between states and territories. Unless we get the balance between the states and federal system right we will continually have a problem of people not knowing where the lead should come from and therefore what they should expect from different arms of government.<sup>53</sup>

- 3.50 Ms Tania Hayes, a full time carer for her husband for the past 11 years also noted the challenges for carers that arise as a consequence of the involvement of multiple government agencies representing various portfolio interests, noting:

Currently carer issues cross many government programs. No single Australian Government agency has responsibility for coordinating carer support policies. Each of these agencies has their own priorities that often take precedence over the interests of carers. There needs to be a co-ordinated approach to ensure policies work together to address the range of carer needs in a way that allows flexibility and options for individual carers and their families.<sup>54</sup>

- 3.51 Summarising information provided by a number of Defence Force family carers in relation to the importance of national carer policy, the submission from the Defence Special Needs Support Group reported:

... carers felt that they were not valued nor recognised for the contribution that they make in society. Some expressed concern that there was no National Carers Strategy or Policy at a Federal level to recognise their caring role. They felt that this would assist with job security, support and appropriate service provision and provide recognition at a high level.<sup>55</sup>

- 3.52 To guide the implementation of legislated carer rights and to monitor outcomes, evidence has also highlighted the importance of developing an adequately resourced national carer strategy or action plan. Commenting on the complementarity of national carer legislation and a national carer action plan, Ms Annemarie Ashton of Carers ACT said:

To have one without the other, you would miss out on some essential components. Having an action plan without the

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53 Mr D Herd, Transcript of Evidence, 6 August 2008, p 58.

54 Ms T Hayes, Submission No 933, p 3.

55 Defence Special Needs Support Group, Submission No 695, p 2.

legislation would make it too easy for everything to just get shelved if there was a change of government.<sup>56</sup>

3.53 As also explained by Ms Joan Hughes, Chief Executive Officer of Carers Australia:

Carers keep saying, 'Why don't people value and acknowledge what we do?' We believe that you can do that within legislation, but you also have to have a strategy; you have to be able to monitor whether that is having an impact on carers' lives.<sup>57</sup>

### Elements of National Carer Legislation and Policy

3.54 In considering the potential elements of national carer legislation and policy, evidence to the Inquiry has suggested the following components:

- increased recognition of carers by:
  - ⇒ the wider community to support an enhanced awareness of the challenges carers face and the needs of carers<sup>58</sup>;
  - ⇒ governments to promote carer involvement through consultation and ongoing engagement in the development of carer legislation, policy and service planning<sup>59</sup>; and
  - ⇒ professionals working in the health system and community care system to acknowledge the involvement of carers as partners in care.<sup>60</sup>
- the right of carers to receive an assessment of their health and welfare needs, their information and skills development needs, and their needs for supports and services to assist them in their role;
- access to supports and services to assist carers to provide sustainable care and/or which allow the carer to access life choices beyond their caring role; and
- support for carer participation in education and/or employment, including carer rights in the workplace.<sup>61</sup>

56 Ms A Ashton, Transcript of Evidence, 26 September 2008, p 7.

57 Ms J Hughes, Transcript of Evidence, 28 November 2008, p 13.

58 See for example: Carers SA, Submission No 684, p 28;

59 Queensland Government, Department of Premier and Cabinet, Submission No 1203, p 9.

60 See for example: Carers Victoria, Submission No 652, p 32; Ms M Wells, Submission No 1034, p 3.

61 See for example: National Carers Coalition, Submission No 571, p 40; Carers Victoria, Submission No 652, p 32; Disability Council of NSW, Submission No 662, p 9; Carers

- 3.55 Advocates for national carer legislation and policy also argue that it should acknowledge the diverse needs of different carer populations, including young carers, CALD carers and Indigenous carers.<sup>62</sup>
- 3.56 The importance of including processes for assessing the impact of a national care legislation and policy, for monitoring compliance and providing a mechanism for carers to raise grievances or complaints has also been emphasised.<sup>63</sup> With regard to establishing a suitable grievance process, Carers Australia suggest that the following models are worthy of consideration:
- a dedicated Commissioner within the Human Rights and Equal Opportunity Commission;
  - an independent Carer Commissioner established under specific carer legislation, along the line of Children's Commissioners at the state level; or
  - a Carer Ombudsman position within the Commonwealth Ombudsman's Office.<sup>64</sup>
- 3.57 Several submissions have also noted the importance of providing adequate funding and resources to support the implementation and effective operation of a national carer legislative and policy framework.<sup>65</sup> In relation to this, Ms Annemarie Ashton of Carers ACT stated:
- It is very important that the [national carer recognition] charter also has provision to resource an education program. Having the best charter in the world is not any good if nobody in public or in government knows it is there, how to use it and what it means. We would like an obligation that all carers are informed of their rights and responsibilities under any such charter and that service providers have that information as well so they fully understand rights and responsibilities of carers and also of the health profession.
- We would like to see an element of compliance in the charter. If you do not actually put a compliance mechanism within the

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Australia, Submission No 699, pp 9-11; Ms M Wells, Submission No 1034, p 3; Ms M L Carter, Submission No 1291, p 11; Ms A Ashton, Transcript of Evidence, 26 September 2008, p 5.

62 See for example: Carers NSW, Submission No 661, p 33; Carers SA, Submission No 684, p 28; Ethnic Disability Advocacy Centre, Submission No 787, p 19; Queensland Government, Department of Premier and Cabinet, Submission No 1203, p 10.

63 See for example: Carers Australia, Submission No 699, p 12; Ms A Ashton, Transcript of Evidence, 26 September 2008, pp 5-6.

64 Carers Australia, Submission No 699, p 12.

65 See for example: Australian Association of Families of Children with a Disability, Submission No 581, p 2; Carers ACT, Submission No 702, p 14.

charter, government departments and agencies will not address and achieve that systemic reform.

The establishment of an appropriate federal body is essential to review the implementation of such a charter, to receive and review reporting on compliance, to receive complaints from carers on non-compliance and to have sufficient power to take proper action to redress evident non-compliance.<sup>66</sup>

## Support for National Carer Legislation and Policy

- 3.58 The Committee acknowledges the weight of evidence urging an improvement in carer recognition and carer rights through specific carer recognition legislation and associated policy. While recognising that most states and territories already have carer recognition legislation and/or carer strategies or action plans, the Committee believes that a national approach to establish consistent and minimum acceptable standards is justified. Therefore, the Committee supports the introduction of overarching national carer legislation to complement existing state and territory legislation.
- 3.59 The Committee also believes that national carer legislation will need to be complemented by national carer policy which details precisely how and when governments will meet their commitments to carers. Although the Committee sought advice from several sources on the essential elements for inclusion in a national carer recognition framework, it is clear that further detailed consideration and consultation with key groups, including with carers themselves, is required. Importantly, national carer policy, as with national carer legislation, will need to build on and complement existing state and territory frameworks.

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66 Ms A Ashton, Transcript of Evidence, 26 September 2008, pp 5-6.

## Recommendation 4

3.60 **That the Minister for Families, Housing, Community Services and Indigenous Affairs seek the Health, Community and Disability Services Ministerial Council to develop a nationally consistent carer recognition framework, comprising:**

- **national carer recognition legislation, which complements state and territory carer legislation; and**
- **a national carer strategy which builds on and complements state and territory carer policies.**

3.61 Importantly, once established the effective implementation and operation of a national carer recognition framework will require adequate resourcing to support an education program to inform carers, governments, community care service providers, health professionals and others of their rights and responsibilities under the framework. The framework will also need to possess mechanisms for monitoring compliance, for assessing outcomes for carers and for addressing any grievances that may arise.

## A National Coordination Mechanism or Office for Carers

3.62 In addition to calls for the introduction of a national carer recognition framework, submissions from some carers and organisations have identified the need for a mechanism or entity to oversee the development of carer legislation, policy, programs and services that are nationally coordinated, effectively linked across all tiers of government and across portfolios. To achieve coordination across the various tiers of government, Carers SA proposed:

That strategic partnerships be developed between national and state jurisdictions similar to the Commonwealth State and Territories Disability/Council of Australian Governments Agreements be explored as avenues for a national/state strategic nexus for carer support.<sup>67</sup>

3.63 Based on her own experiences of providing care both for her elderly father and for her son with profound and severe disabilities, Ms Helen Johnson

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<sup>67</sup> Carers SA, Submission No 684, p 7.

highlighted apparent inequities in the levels of support available to the frail aged and their carers in comparison to younger people with disabilities and their carers, noting:

... there is so much more funding available to those who are ageing and support for their Carers in comparison to parents and/or Carers who are caring for children and young adults with a disability for a greater length of time.<sup>68</sup>

- 3.64 To address this inequity Ms Johnson proposed that responsibility for the provision of supports and services for the frail aged, for people with disabilities and for their carers could be assumed by a single Australian Government portfolio, suggesting:

Perhaps the whole portfolio needs to be called 'Health, Ageing, Disability and Carers (HADC) portfolio. This will bring responsibility at a Commonwealth level and hopefully a positive outcome for some of the most vulnerable members of the Australian community.<sup>69</sup>

- 3.65 Ms Mary Walsh, who has also provided long term care for more than one care receiver with differing care needs, highlighted the inefficiencies for the Australian Government and for carers arising as a consequence of separated portfolio responsibilities, explaining:

... having Health and Ageing (Aged care and HACC) in one department, and Disability (FaHCSIA) in a separate department are internal barriers which create inefficiencies for Government and additional barriers for carers irrespective of the type of carer. Many carers of people with lifetime disability are now also carers for their ageing parents, so they have to deal with two separate departments - as well as Centrelink and the medical fraternity.<sup>70</sup>

- 3.66 To effectively administer and coordinate carer legislation, policy, programs and services, some submissions have suggested that there is a need for the establishment of a single national government entity.<sup>71</sup> For example, Palliative Care Australia (PCA) explained:

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68 Ms H Johnson, Submission No 1178, p 2.

69 Ms H Johnson, Submission No 1178, p 3.

70 Ms M Walsh, Submission No 752, p 4.

71 See for example: Name withheld, Submission No 500, p 26; Carer Support and Respite Centre, Submission No 585, p 3; Carers Support Network of South Australia, Submission No 675, p 4; National Seniors Australia, Submission No 686, p 5; Australian Association of Gerontology, Submission No 915, p 1.



To date there has been little coordination of service funding and service provision across federal, state and local government areas and limited co-ordination between voluntary agencies, leading to unequal social and geographical distribution of services. PCA believes a key contribution of an 'Office for Carers' could be to support better outcomes through greater coordination.<sup>72</sup>

3.67 Advocating for the establishment of a 'National Office for Carers', Carers Australia observed:

Carer issues and policies sit across many government portfolios. There is currently no framework to assist departments achieve coherence across policy and program initiatives. Also there is no vehicle for coordinating a broad national carer strategy or action plan. This is a perpetual challenge for governments.<sup>73</sup>

3.68 Carers Australia proceeded to make the following suggestions in relation to a possible location for a National Office for Carers:

The optimal location of this office is with the Department of Prime Minister and Cabinet in line with its strategic influence and coordinating role across government.

The Federal Government has established an Office of Work and Family and one option is that the Office for Carers be located within this structure. However the Government is also in the process of developing its social inclusion agenda and strategy and it may be that a future Social Inclusion Unit is established. This may be an alternative structure within which an Office for Carers could be situated.<sup>74</sup>

## Support for Increased Coordination

3.69 Given the need to achieve a national framework of carer legislation and policy that is effectively linked across all levels of government and portfolio, the Committee agrees that there is a need to establish a coordinating mechanism or entity. Rather than seeking to establish a new entity, the Committee considers that there is merit in the suggestion to embed the functions of a national office for carers in an existing Australian Government department.

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72 Palliative Care Australia, Submission No 688, p 8.

73 Carers Australia, Submission No 699, p 10.

74 Carers Australia, Submission No 699, p 10.

- 3.70 Given its role in coordinating the administration of legislation and policy across Australian Government departments and in supporting intergovernmental relations with state and territory governments, the Department of Prime Minister and Cabinet (PM&C) might be an appropriate location for a national office for carers.<sup>75</sup> It is unclear however, whether the role of an office for carers could be assumed by the Office of Work and Family that already exists within PM&C, or whether a new office will need to be established within this Department to support the role.

### **Recommendation 5**

- 3.71 **That the Department of Prime Minister and Cabinet establish a national office for carers, either within the Office of Work and Family or as a new office within the Department.**

**That the Australian Government nominate a lead Minister to be responsible for overseeing the development of nationally coordinated carer legislation, policy, programs and services so that these are effectively linked across all levels of government and portfolios.**

- 3.72 Specifically with regard to the coordination and streamlining of policy, programs and services provided by the Australian Government, the joint submission from the Australian Government departments (FaHCSIA, DoHA & DVA) themselves recognise problems for carers and care receivers arising as a consequence of the involvement of different portfolios in providing programs and services, stating:

The Australian Government recognises the difficulties [the involvement of various portfolios and levels of government] poses for carers and their families and the complexities they face in navigating the service delivery system.<sup>76</sup>

- 3.73 Although the joint submission from the Australian Government departments (FaHCSIA, DoHA & DVA) proceeds to indicate that the various Australian Government departments with portfolio responsibility for carers and for care receivers are working together on options for

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<sup>75</sup> Australian Government, Department of Prime Minister and Cabinet, *Annual Report 2007-08*, p 8.

<sup>76</sup> Australian Government Departments (FaHSCIA, DoHA & DVA), Submission No 1109, p 43.

structural reform to simplify and streamline programs and services, the Committee understands that this is likely to be a challenging and time consuming process. An alternative approach to achieving greater coordination and streamlining of carer policy and programs at the level of the Australian Government would be for a single Australian Government department to assume portfolio responsibility for people with disabilities, people with mental illness, the frail aged and their carers.

### **Recommendation 6**

- 3.74 **That the Australian Government consider consolidating portfolio responsibility for people with disabilities, people with mental illness, the frail aged and their carers into a single Australian Government department.**

