

## Information, Skills and Capacity Building

- 4.1 This chapter looks at the increasing demands placed on carers to provide quality care in diverse caring situations, and the breadth of knowledge and diversity skills required to fulfil the caring role. The chapter will examine carers' needs for:
- information;
  - peer support networks;
  - training and skills development;
  - coordination of services or case management; and
  - advocacy support, both for themselves and on behalf of the care receiver.
- 4.2 The chapter also looks at the need to increase recognition of carers by health professionals and community service providers as partners in the care team. The final section briefly explores existing legal mechanisms relating to substitute decision making.

### **Diversity of Information Needs**

- 4.3 Changes in health, mental health, disability and age care policies have supported shifts from institutional care to care at home. Carers are increasingly required to manage complex health and care needs of people with serious medical conditions, disability, mental illness and terminal illness. Current policies rely not only on the availability and willingness of people to provide care, but also on their ability, their competence and capacity to provide care.

4.4 However, as the Ethnic Disability Advocacy Centre explained:

... family carers generally find themselves taking on this role 24/7 with little preparation, knowledge or support for the task at hand. They are expected to do it with professionalism and frequently need to juggle the numerous other roles within their usual daily routine. Family carers take on many of the skills of 'professional' roles such as health care nursing, life coaches/counsellors and educators, social facilitators, negotiators and advocates, care managers, futures planners, etc.<sup>1</sup>

4.5 Many carers reported feeling ill-equipped to carry out the many facets of the caring role. Throughout the evidence, carers and organisations have pointed out the need for carers to be given increased access to relevant information, education, training, family and carer advocacy, case management and care coordination services. Many are, in fact, calling on public policy makers, healthcare professionals and community care service providers to recognise carers as members of the care team providing a service to meet the needs of the care receiver.

4.6 Understandably, the information carers find useful will vary according to their situation. Ms Lee-Ann Heron, from the organisation Special Kidz Special Needs, described some of the questions she was concerned about at the commencement of her caring role:

When I first found out my daughter has special needs I had so many questions, like: What services and supports are available? Where do I find information on her condition? What are her therapy options? What are her equipment options? What are our childcare & respite options? What are her education options? What are my career options? ... It took a long time to find the answers to these questions ... time that is precious to carers like me. <sup>2</sup>

4.7 On the other hand, for many carers, including older carers considering their own future and that of the care receiver, information on legal and financial issues, alternative accommodation and care options may be a priority.<sup>3</sup> As Ms Dulcie Sullivan explained:

I have cared for Paul for his entire life ... In 2007 due to my increasing age I applied to VCAT [Victorian Civil and

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1 Ethnic Disability Advocacy Centre, Submission No 787, pp 5-6.

2 Special Kidz Special Needs, Submission No 567, p 12.

3 See for example: Huntington's Victoria, Submission No 670.2, pp 5-6; Prof J Wilson, A-Prof C Tilse & Prof L Rosenman, Submission No 698, pp 1-3; Ms M Robbins, Submission No 1139, p 2.

Administrative Tribunal] to appoint a Public Trustee to manage his financial affairs ... I also applied to VCAT to appoint a Public Advocate for guardianship of his medical, dental and housing requirements ... The E. W. Tipping foundation have been assisting with some 'Home skills Training' for when Paul finally goes to live without me. This transitional period is not easy for me due to lack of knowledge of choices available.<sup>4</sup>

4.8 The information needs of carers are as diverse as their care situations. However, evidence has suggested that there are common subject areas that carers want information about. These include information on:

- the care receiver's medical condition or disability, and options for treatment, therapy, aids and equipment;
- the practical aspects of providing care, including nursing care, personal care and behavioural management;
- services and supports;
- self care; and
- legal and financial issues, including guardianship and substitute decision making, mental health legislation, social security, financial and future planning.

## Barriers to Information Access

4.9 As noted previously, health and community care service systems are complex and fragmented. Currently there is no single access point for carers to seek information. Carers WA presented the following picture:

There remains a multiplicity of agencies and services that provide information which can present a confusing, off-putting and impenetrable process for carers.<sup>5</sup>

4.10 The impact on carers is explained by the Yarrawonga Mulwala Carers Support Group:

Many carers report difficulty accessing appropriate information throughout their caring life. There is a broad range of information available for carers however dissemination of this information is

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4 Ms D Sullivan, Submission No 126, p 3.

5 Carers WA, Submission No 566, p 20.

very fragmented - often what carers find out depends on which agency they have been referred to. Many carers report 'stumbling on information' which would have been useful to them much earlier on.<sup>6</sup>

- 4.11 The result is confusion and frustration for many carers. The following comments from carers provide examples of how carers experience barriers to accessing information:

**Mr Rolf Regal – carer for his wife who has multiple sclerosis**

Assistance for people with disabilities and their carers is already available from many different sources, e.g. from each of the three levels of government, as well as from charitable organisations and other private bodies. It is delivered in a multitude of different ways, and eligibility criteria are many and varied. Initially, when carers first take on their caring role, after a fresh diagnosis or an accident, most carers know nothing about any of this. One of the most frequently expressed frustrations which carers have is, that they do not know what assistance is available and what they may be entitled to i.e. we have a communications problem.<sup>7</sup>

**Mr Henry Thomas - carer for his wife who has dementia and who is now in residential care**

It was a little complex in that I did not know where the care services were. I started ringing up the shires and eventually got talking to the Towong shire where I actually live. They provided HACC [Home and Community Care] services but they also told me that I should get an ACAT [Aged Care Assessment Team] assessment, which I did. That then put me into a package which was taken over by an agency in Wodonga. So I was never really able to get a grasp on where funding was coming from between the various agencies, and because I was then on a package which the agency in Wodonga was looking after, they were talking to the Towong shire and then to me. So I was never properly in the loop. Initially, even before I had the ACAT assessment, things were

6 YNH Services Inc and Yarrawonga Mulwala Carers Support Group, Submission No 678, p 4. See also: Ms W Smith-Squires, Submission No 263, p 2; Committed About Securing Accommodation for People with Disabilities, Submission No 577, p 5; Ms J Gutteridge, Submission No 708, p 2; Mr R King & Ms M King, Submission No 817, pp 1-2; Name withheld, Submission No 904, p 3; Ms F Tountzis, Submission No 1140, p 2; Ms M Edwards, Submission 1147, pp 4-5; Ms C Atkinson, Submission No 1158, p 1; Ms M Major, Submission No 1163, pp 2-3; Ms A Arnold, Submission No 1166, p 2; Ms J Cooper, Submission No 1194, p 1.

7 Mr R Regal, Submission No 335, p 4.

being done, services were being provided, but when I asked, 'Who is paying for this? Where is the money coming for this and that?' I was told, 'Well, there are various buckets of money,' and that is as far as it really got. So I did not understand what the system was and, over the four to six years, I only started to find out more through groups ... where I could speak to other carers, find out what they had been given in services and then compare my situation with theirs.<sup>8</sup>

**Name Withheld - an employed carer who has been caring for her elderly mother for 20 years**

Difficult and time consuming to obtain the information as service providers are not forthcoming with such information until they have secured a package ...

I have found it extremely difficult and time consuming to obtain information on care and what is available. I appreciate that there are associations like Carers Queensland who handle respite and they have been helpful but the situation became difficult when I then tried to put their information into practice. I started to hit brick walls especially as far as respite and in home care were concerned.<sup>9</sup>

- 4.12 The evidence suggests that carers expend energy, time and resources which they often do not have, exploring various options to find information and services that they require for themselves or for the care receiver. Carers report that they feel that the onus is on them to ask the right questions to the right agency to elicit relevant information. As one carer explained:

It is also very difficult to access information - you ring one Department and get passed to another Department or get told it is State or Federal or vice versa. In the end, you give up trying because, as a carer, you just don't have time to keep following things up or to do the amount of paperwork involved.<sup>10</sup>

- 4.13 The barriers to accessing information for carers from culturally and linguistically diverse (CALD) backgrounds are even greater. Ms Au Yeong, a carer in Perth, pointed out several of the significant barriers confronting carers from CALD backgrounds and certain strategies which,

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8 Mr H Thomas, Transcript of Evidence, 1 October 2008, p 8.

9 Name withheld, Submission No 904, p 1.

10 Ms M Cochrane, Submission No 824, p 2. See also: Ms M Robbins, Submission No 1139, pp 2-3.

in her view, could help overcome certain barriers:

[Migrant carers] do not know they have rights or they think: 'As a migrant I shouldn't be saying that I want this and that, because I need it. I'll be grateful for what I receive and therefore I do not ask for help.' Secondly, they do not know what help to ask for. The system is a nightmare. It is so complex for people who have good English comprehension. A migrant or a refugee recently arrived would not know how to navigate the system or what to ask for. So that empowerment and that self-advocacy is one issue. Also, you need to look at providing sufficient interpreting and translation. The mainstream services should be aware and take note of where to disseminate that information and whether it needs to be translated into different languages ... Perhaps through the ethnic communities themselves – through ethnic radio perhaps. There are a couple of avenues that mainstream services need to look at in getting the information out.<sup>11</sup>

- 4.14 Although the vast majority of carers have contact with health services, evidence indicates that many are not provided with basic information on services and supports. One such carer, Ms J Burke, commented:

I care for my husband with an ABI [Acquired Brain Injury] and I have breast cancer. I wasn't aware of 63 days respite for carers until 3 years into my husband's stroke. Why don't medical facilities, medical personnel tell you about these things from the start?<sup>12</sup>

- 4.15 For some carers the need for information is urgent and critical. In its submission, the National Network of Adolescent and Adult Children who have a Mentally Ill Parent (NNAAMI) quoted one of the organisation's members as saying:

'I was on the verge of attempting suicide, giving up, packing it all in, finishing it all, no more, had it all planned out, until I saw the NNAAMI [web]site by accident. I now know I'm not alone. I cried and cried! The whole time reading those stories, not much different to my own'<sup>13</sup>

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11 Ms J Au Yeong, Transcript of Evidence, 23 July 2008, p 65.

12 Ms J Burke, Submission No 99, p 1. See also: Ms J Lehmann, Submission No 1258, pp 5-6; Mr R Sinclair, Transcript of Evidence, 13 August 2008, pp 2, 4; Ms R Warminton, Transcript of Evidence, 13 August 2008, p 17; Ms H McDougall, Transcript of Evidence, 1 October 2008, p 9.

13 National Network of Adolescent and Adult Children who have a Mentally Ill Parent, Submission No 1243, p 5.

- 4.16 A number of submissions commented on the lack of availability of information about financial assistance available to carers through Centrelink. One such submission, provided by Mr Peter Casey, observed:

... one member of our circle had absolutely no idea that there was such a thing as a carers allowance or payment available from Centrelink. This poor woman had been performing the task of carer alone and unassisted for years and my heart really went out to her. Being the sceptic that I am I can see how such a situation might come about because Centrelink is remarkably reticent in advertising allowances and other facilities available to carers and they should bear at least some of the blame for such a regrettable oversight.<sup>14</sup>

- 4.17 Another submission, from Huntington's Victoria, highlighted difficulties with Centrelink services, which some carers experience:

There are many issues with incorrect information being given from Centrelink staff to clients, in addition to extremely distressing incidents of poor service provision. The one issue that makes our clients cry is when they talk about Centrelink.<sup>15</sup>

- 4.18 The Commonwealth Ombudsman also raised concerns about the difficulties carers face accessing and understanding information about social security entitlements:

Our experience has been that complainants are not aware of the difference between carer payment and carer allowance. Nor are they aware of other supplementary payments such as mobility allowance and pensioner education supplement that might be payable to the person who was receiving the care (the care receiver).

In most cases that we investigate, particularly those where the level of care required is high, the carer has taken on responsibility for managing the financial, as well as physical needs of the care receiver. They do not have time to research what payments or services might be available for them, whether online, or by phone enquiries or visits to Centrelink.<sup>16</sup>

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14 Mr P Casey, Submission No 3, p 5. See also: Ms J Dajic, Submission No 56, pp 1-2; Name withheld, Submission No 484, p 1; Ms F Tountzis, Submission No 1140, p 2.

15 Huntington's Victoria, Submission No 670.2, p 4. See also: Ms J Nicholas, Submission No 1149, pp 2-3; Mr D Nicholas, Transcript of Evidence, 13 August 2008, p 23.

16 Commonwealth Ombudsman, Submission No 511, p 3.

- 4.19 Centrelink uses a 'life events' model which aims to match customers or potential customers with all the correct payments and services applicable to their situation or combination of circumstances.<sup>17</sup> However, the Ombudsman's investigations have shown that, in practice, the life events model used by Centrelink does not always ensure that customers are advised of the full range of services which their situation entitles them to.<sup>18</sup>
- 4.20 The evidence clearly suggests that carers want clear, accessible and relevant information on financial and non-financial services and supports which are available. As one carer summed up:
- ... it is essential that all carers, and in particular new carers, are aware of what help is available. That help, even now, is considerable but many people flounder around, unaware of what is available. This may be the fault of the medicos who make the diagnoses not being *au fait* with the system - but I believe that it is at that point that the carer should be allocated a case manager, introduced to Carers Australia and any other source of information necessary to their efficient functioning as a carer. This could save a lot of heartache.<sup>19</sup>

## National Networks Providing Information

- 4.21 There are three key national networks which can provide carers with information and support:
- Commonwealth Respite and Carelink Centres;
  - Carers Australia and the state and territory network of Carer Associations; and
  - Centrelink.
- 4.22 There is a national network of 54 Commonwealth Respite and Carelink Centres across the country. The joint submission from the Australian Government departments (Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), Department of Health and Ageing (DoHA) and Department of Veterans' Affairs (DVA)) explained that the Centres:
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17 Commonwealth Ombudsman, Submission No 511, p 2.

18 Commonwealth Ombudsman, Submission No 511, p 2.

19 Mr R Smeaton, Submission No 69, p 3. See also: Ms W Smith-Squires, Submission No 263, p 2.



- provide information for carers, the aged and other members of the community seeking free and confidential advice on community care, aged, disability and other support services available in local regions;
- provide information about costs for services, assessment processes and eligibility criteria and maintain an extensive database of services; and
- network with Aged Care Assessment Teams (ACATs), general practitioners, allied health providers and community organisations.<sup>20</sup>

4.23 Nevertheless, a number of carers and organisations have been critical of the Commonwealth Respite and Carelink Centres' capacity to meet the needs of carers. For example, Carers WA suggested that the Centres cannot adequately address the information needs of carers because they have to provide services to a wide range of clients.<sup>21</sup> The issue of Commonwealth Respite and Carelink Centres having insufficient local knowledge has also been raised:

Setting up services that cover such a large geographic area [that] they have no 'real' knowledge of the area is counter productive [and] causes a high level of frustration with other services and client's. In Macarthur, the Commonwealth Information service that is meant to cover our area is not based locally. A local provider reported one of their clients had said 'oh I rang them, first I had to spell the name of the town I lived in, then they just read me stuff off a database'. That same person through a local service provider was referred to another agency, informed of a local unfunded support group that had commenced recently and was invited to attend a consultation regarding their needs.<sup>22</sup>

4.24 Others are more complimentary. One carer described the service as:

... a wonderful and crucial service to families/carers with children/adults with highly specialised care needs.<sup>23</sup>

4.25 The information services provided by the Commonwealth Respite and Carelink Centres are bolstered by information services provided by Carers Australia and the national network of state and territory Carers Associations. The Carers Associations are funded through several

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20 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, p 26. See also: Mr K Tracey-Patte, Transcript of Evidence, 28 November 2008, p 25.

21 Carers WA, Submission No 566, p 20.

22 The Macarthur Aged & Disability Forum, Submission No 749, pp 3-4. See also: Ms C Morka, Transcript of Evidence, 12 August 2008, p 66.

23 Ms J Tams, Submission No 908, p 7.

Australian Government programs<sup>24</sup> to deliver a range of information products, specialist information and advice services to carers, including young carers, and to service providers.<sup>25</sup>

4.26 In the view of Carers Australia, the two national networks comprising Carer Respite and Carelink Centres and the Carers Associations, provide a sound national structure for the provision of information and support to carers.<sup>26</sup>

4.27 Centrelink is also a national network which provides information and advice on social security and financial issues for, among many other client groups, carers and care receivers. For some, Centrelink is ideally placed to disseminate broader information to carers.<sup>27</sup> Ms Susan Pringle from the Cooina Family Support Group, commented:

Information provision is random and may be around at a time when it has little significance and so is overlooked when required. Centrelink is the ideal avenue of forwarding relevant information to carers on a regular basis.<sup>28</sup>

4.28 The three national networks all provide advice to carers and/or care receivers, but each has a slightly different focus. In addition, there are also state and territory and local government agencies, not-for-profit and for-profit organisations delivering health and community care services and supports to carers and care receivers, including information services of different kinds. What many carers have called for is a 'one-stop-shop' or 'single access point' to bring together advice on all the services available for carers and care receivers.<sup>29</sup>

24 For example through the Carer Information and Support Program, the National Carer Counselling Program, and the Respite and Information Services for Young Carers.

25 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, pp 26-32.

26 Ms J Hughes, Transcript of Evidence, 28 November 2008, p 16.

27 See for example: YNH Services & Yarrowonga Mulwala Carer Support Group, Submission No 678, p 4.

28 Ms S Pringle, Transcript of Evidence, 1 October 2008, p 39.

29 See for example: Mr F De Rosa, Submission No 63, p 2; Mr W de Goede, Submission No 366, p 1; YNH Services Inc and the Yarrowonga Mulwala Carers Support Group, Submission No 678, p 4; Mr G Jarvis, Submission No 767, p 2; Ms M-L May, Submission No 891, p 3; Name withheld, Submission No 904, p 3; Ms V Wood, Submission No 1164, p 1; Mr J Halford, Transcript of Evidence, 12 August 2008, p 43; Ms M Anderson, Transcript of Evidence, 12 August 2008, p 44; Mr R Sinclair, Transcript of Evidence, 13 August 2008, p 8.

## A Single Access Point for Carers

- 4.29 A typical example of the calls for a one-stop-shop was made by Ms Colleen Atkinson who commented:

... within my home file I have information on the following agencies - Commonwealth Carers Respite Centres; Commonwealth Carelink Centres; Carers SA; Carer Support & Respite Centre Inc; Commonwealth Carer Resource Centre; HACC; local government; plus a number of NGO's offering respite. Where do I start? ... Consider a review of the above-mentioned agencies (vis-a-vis respite), and establishment of a 'one-stop shop' central agency which can provide straight forward but comprehensive information about services to carers - and which is widely advertised so it is easy for carers to access.<sup>30</sup>

- 4.30 The case for a one-stop-shop to respond to carers' information needs was also argued by Carers WA in the following terms:

The need for information can be best met in the form of a one stop shop dedicated to carers in which the multiplicity of service providers, health professionals and others can be linked. In addition many carers do not respond well to call centres and phone services only and would prefer a person centred face to face model of service delivery. The location of information centres for carers has to be addressed as it is not meeting carer's needs. The information needs of carers would be best met in a variety of central settings such as information centre for family carers in every teaching hospital, local community centre and Centrelink offices.<sup>31</sup>

- 4.31 DoHA and state and territory governments are currently piloting Access Point Demonstration Projects in at least 11 locations across the country.<sup>32</sup> The Access Points are designed to provide one-stop-shops to make access to community care services easier for carers and care receivers by:

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30 Ms C Atkinson, Submission No 1158, p 1.

31 Carers WA, Submission No 566, p 20. See also: Brotherhood of St Lawrence, Submission No 694, p 5; Mr R Haines, Mr P Sparrow and Mr G Vogt, Transcript of Evidence, 13 August 2008, pp 69-74.

32 Australian Government, Department of Health and Ageing website, viewed 12 March 2009 at [www.health.gov.au/internet/main/publishing.nsf/Content/ageing-twf-access-status.htm](http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-twf-access-status.htm). See also: Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109.1 pp 4-6; Name withheld, Submission No 1304, p 1.

- providing information about community care services;
  - providing advice on eligibility for services;
  - conducting a broad assessment of needs, including the carer needs; and
  - facilitating referrals to community care service providers or for a more comprehensive assessment.<sup>33</sup>
- 4.32 Each Access Point Demonstration Project will operate for about 12 months and be evaluated at three levels: project, jurisdictional and national. The evaluations will inform decisions about potential broader rollout of Access Points in the future.<sup>34</sup>
- 4.33 The Committee considers that the Access Point Demonstration Projects have merit as they are an attempt to make access to community care easier by bringing together Australian Government, and state and territory services in a consistent way. However, for Access Points to fully meet the needs of carers for a one-stop-shop, they will need to have the capacity to assist all carers in diverse caring situations. This will require Access Points to provide carers with information and advice, assessment and referral to services across the fragmented community care system. This includes aged care services, disability services and community mental health services as required by the carer and care receiver.
- 4.34 It is unclear what linkages, if any, will exist between the assessment and referrals provided through Access Points with other programs delivered by state and territory governments, for example the Aged Care Assessment Program and disability programs.<sup>35</sup> Even if the single access model is deemed a success, it is also not clear whether Access Points would replace or complement the Commonwealth Respite and Carelink Centres. The risk is that yet another layer of program orientated and ultimately narrowly focussed reform will perversely lead to more complexity and confusion for carers rather than less.

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33 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109.1, pp 4-6.

34 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109.1, pp 4-6.

35 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, p 28.

## Recommendation 7

- 4.35 **That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing, seek agreement through the Health, Community and Disability Services Ministerial Council to extend the Access Points Demonstration Projects to include disability services and community mental health services.**
- 4.36 The reality is that it may never be practical to have a genuine one-stop-shop to help carers and care recipients given the range of their needs and because they are also likely to need to use Centrelink for financial services. In that case and certainly in the short term, there appears scope to improve the links between the existing networks (as well as with state and territory information services). Without wishing to make a specific recommendation, the Committee encourages the Health, Community and Disability Services Ministerial Council to improve the coordination between agencies so that they can provide seamless and consistent advice across programs and jurisdictions to carers and care receivers.

## Peer Support Groups

- 4.37 Carers and organisations consistently reported that peer support groups and networks are an extremely valuable source of information and empowerment for carers.<sup>36</sup> Peer support groups for carers function in different locations across Australia providing carers with information, advice, support and social opportunities as well as providing a means for advocating for supports and services. Many of these groups are unfunded and are not legal entities in their own right. Other support groups, such as Coinda Family Support Group based in Albury/Wodonga, have evolved into incorporated bodies funded by government to provide support services to carers and care receivers.<sup>37</sup>

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36 See for example: Ms J Cheal, Submission No 116, p 2; Mr J Davis, Submission No 368, p 1; Ms S Jalanski, Submission No 446, p 2; Ms A Atkins, Submission No 771, p 1; Mr G Ingram & Ms K Ingram, Submission No 865, p 1; Ms J Rafferty, Submission No 1183, p 1; Mr H Thomas, Transcript of Evidence, 1 October 2008, p 8.

37 Coinda Family Support Group, Submission No 693, p 1.

4.38 Some peer support groups are affiliated and supported by state and territory Carers Associations. For example, Carers Queensland provides support to over 100 carer groups throughout the state which provide opportunities for carers to meet and share experiences on a regular basis.<sup>38</sup> Other support groups have been established under the auspices of particular programs. For example, the Dementia Respite Options program in Albury NSW provides dementia specific services including carer support groups to people in the region.<sup>39</sup>

4.39 Another support group from Albury NSW, Daughters in Demand, was formed over ten years ago by a group of nurses caring for elderly parents who wanted emotional and other support to balance the demands in their lives.<sup>40</sup> This and many similar groups exist through the generosity of carers and former carers who come together to support each other, share experiences and knowledge and volunteer their time, a resource which is often extremely limited.<sup>41</sup>

4.40 Some unfunded carer support groups, such as the Kiewa Valley Carer Support Group in Victoria, have concerns about their sustainability and capacity to meet the needs of local carers.<sup>42</sup> Occasionally, there appears to be some limited possibilities for funding from state and territory governments. As indicated by the Myrtleford Carer Support Group:

Just recently, we applied to DHS [Victorian Department of Human Services] for some non-recurrent funding around running some activity days to better support carers. We ran a music therapy day one month, and then last week we ran a Humour in Caring day.<sup>43</sup>

4.41 Many carers believe that the support offered by a peer support network is extremely beneficial. One such carer, Ms Michiko Parnell, explained how beneficial she believed peer support would have been to her and her husband at the time of their child's diagnosis:

We were told of our child's diagnosis and left the paediatrician's office to face the unknown and the grief on our own. It would have been very helpful for the paediatrician to give us a number to

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38 Carers Queensland, Submission No 703, p 12.

39 Ms H McDougal, Transcript of Evidence, 1 October 2008, p 6. See also: Mr P Sparrow, Transcript of Evidence, 13 August 2008, pp 68-69.

40 Ms M Campbell, Transcript of Evidence, 1 October 2008, p 14.

41 See for example: Ms G Esson, Submission No 647, p 2; St Helens Support Group, Submission No 798, pp 1-2.

42 Mr G Lindsey, Transcript of Evidence, 1 October 2008, p 26.

43 Ms C Sanderson, Transcript of Evidence, 1 October 2008, p 32.

call, that we could get a home visit or just have another parent WHO HAS BEEN THROUGH THIS, to act as a bit of a 'peer support' role. Even a national support line (like Lifeline) so that I could talk to someone who has lived the experience, would have been enormously helpful. Looking back, five years later, what would have helped my mental health more than anything is the HOPE that we would enjoy our lives after the catastrophe of the diagnosis and in spite of the workload of the care and barriers we face in everyday life.<sup>44</sup>

4.42 As another carer explained in her submission:

... I am on antidepressants and need to talk to others on how they cope and get advice [on] how they cope ... Getting advice and help [on] how to handle certain situations like alcohol abuse, money issues and general advice ... Providing more information on what help is available.<sup>45</sup>

4.43 Given the importance to carers of peer support, many carers and organisations have recommended the expansion of informal peer support networks. One such recommendation was made by ANGLICARE Sydney:

Carer Peer Support programs be funded to encourage networking, social interaction and further support for advocacy. Carer Support programs also need to run in the evenings and weekends to ensure that working carers can access them.<sup>46</sup>

4.44 The valuable contribution made by the non-government and voluntary sectors using peer support, self help and consumer or group advocacy models was also commented on by the Royal Australian and New Zealand College of Psychiatrists in respect of people with mental illness and their carers.<sup>47</sup> The College recommended:

... more support should be given to the development and expansion of non government organisations to assist carers access meaningful supports, and promote self help and consumer advocacy ...<sup>48</sup>

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44 Ms M Parnell, Submission No 849, p 1.

45 Ms C Cornish, Submission No 1150, pp 1-2. See also: Ms J Davis, Submission No 1167, p 2.

46 ANGLICARE Sydney, Submission No 769, p 19. See also: Ms S Durkin, Submission No 329, p 2; Submission No 855, p 2; Australian Association of Gerontology Inc, Submission No 915, p 2; Mr R Taylor, Submission No 923, pp 1-2.

47 The Royal Australian and New Zealand College of Psychiatrists, Submission No 672, p 3.

48 The Royal Australian and New Zealand College of Psychiatrists, Submission No 672, p 3.

- 4.45 There is no doubt of the value of peer support groups for providing carers with information, support, social contact and, at times, advocacy. The Committee believes that there is further potential for government to encourage the development and geographical coverage of such groups. One way this could be accomplished is through the provision of small grants to assist groups with expenses. Access to small grants programs for carer peer support groups would need to take into account that some groups will not be incorporated bodies nor be affiliated with an incorporated body such as a Carer Association.

### Recommendation 8

- 4.46 **That the Australian Government make locally based peer support carer groups a priority within existing community grants programs available across portfolios.**

- 4.47 In addition to the informal peer support groups considered above, there is a national network of peer support groups for carers of young children (i.e. under school age) with a disability. This is funded by the FaHCSIA. The MyTime Peer Support Groups give carers the chance to socialise and share ideas with others who understand the rewards and challenges of the caring role. The groups also provide an opportunity for carers to access information about available community support services and parenting information. The MyTime Peer Support Program commenced in February 2007 and has established 175 peer support groups.<sup>49</sup>

- 4.48 The submission from Uniting Care Remote Family Services in Bairnsdale, Victoria, endorsed the support offered to parents of young children through the MyTime Peer Support Groups. The submission strongly advocates for the expansion of the Program in terms of its coverage of regional and remote areas as well as the level of assistance provided to individual MyTime Peer Support Groups:

Our group commenced in February this year and we have found MyTime funding hopelessly inadequate and are desperately looking for more funding so as to more adequately support these families.<sup>50</sup>

49 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109.2, p 9.

50 Uniting Care Remote Family Services, Submission No 656, p 2.



4.49 The Committee sees the value of a national network of MyTime Peer Support Groups to provide support to parents caring for young children with disability. The Committee notes that FaHCSIA is trialling a small number of MyTime Peer Support Groups for parents of school age children with disability. Assuming this proves successful, the Committee supports an expansion of the Program to include this group of carers and their children. In addition, the Committee believes the benefits of the Program for carers warrants further expansion to increase geographical coverage, particularly in regional and remote locations.

### **Recommendation 9**

- 4.50 **That the Minister for the Department of Families, Housing, Community Services and Indigenous Affairs fund the expansion of the MyTime Peer Support Program to:**
- include parents of school aged children with disability; and
  - increase geographical coverage.

## **Skills Development and Capacity Building**

4.51 As previously mentioned, the health and community care service systems rely heavily on carers continuing to provide care in their own homes for care receivers and increasingly, to care for those with high support needs who have been discharged from formal health services into community settings.<sup>51</sup> As stated simply by one carer:

Carers ... relieve the stretched resources of hospitals, aged care facilities by keeping their caree at home.<sup>52</sup>

4.52 As a result, Carers WA explained:

... [carers] are significantly involved in the clinical processes including recovery and rehabilitation as well as the ongoing care of people with long term and, in some cases terminal, health issues.<sup>53</sup>

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51 Carers SA, Submission No 684, p 24.

52 Ms A M MacArthur, Submission No 871, p 1.

53 Carers WA, Submission No 566, p 22.

- 4.53 However, the majority of carers commence their caring role with little or no warning, as Carers Australia reported:

Carers can come into their caring responsibilities at any stage throughout their life. This could be with the birth of a child with a disability, an accident, the onset of mental illness, the diagnosis of a terminal illness or with an ageing parent becoming frail.<sup>54</sup>

- 4.54 It is clear from the evidence that many carers over time develop a high level of skill in a wide range of areas. A carer who has cared for her husband who has a degenerative neurological condition commented:

Over the past 29 years I have become my husband's physiotherapist as necessary to keep his muscles from total atrophy, podiatrist and manicurist as due to poor balance he cannot manage such tasks, his wound nurse, as wheelchair living is an occupational hazard for tissue tearing; pressure care specialist, as the body loses muscle the pressure areas on the bottom and the feet become susceptible to pressure sores; case manager for keeping track of care workers who come to the home to carry out personal care routines and this means filling in when they don't arrive, educating ... on the new or re instituted treatments; negotiator for access to care or respite care. Overnight care includes re positioning due to pain in my husband's legs, assisting with bladder/bowel functions as necessary ...

I act therefore as a para-professional, with a wider range of skills than they, as I have to act in such a wide variety of roles whereas their skills are compartmentalised.<sup>55</sup>

- 4.55 However, understandably, at the outset of caring most carers are unprepared for the role. As Carers WA observed:

Most carers are not trained in basic nursing care when taking the care recipient home ... and basic training is required in order to support carers adequately and therefore provide the care recipient with the best quality of life possible<sup>56</sup>

- 4.56 The comments from the state and territory Carer Associations are supported by many individual carers who reported that at the
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54 Carers Australia, Submission No 699, p 45.

55 Name withheld, Submission No 853, pp 1-2. See also: Ms A Arnold, Submission No 1166, p 1; Ms E Fudge, Transcript of Evidence, 13 August 2008, p 54.

56 Carers WA, Submission No 566, p 22. See also, Mr R Sinclair, Transcript of Evidence, 13 August 2008, p 2.

commencement of their caring role they felt ill equipped and believed they lacked the skills, knowledge or capacity to cope effectively with the practical and emotional aspects of providing care. Some typical comments from carers are presented below:

**Ms Judith Small - an employed carer who cares for her husband**

My role as a carer commenced in December 1993 when my husband, Bob, was diagnosed with a very large Brain Tumour and subsequently had surgery for its removal. These events left him paralysed from the waist down and unable to speak. He was hospitalised for 2 months after which he was discharged into my care, on the grounds that medical staff felt Bob was making better progress when I took him home on weekends. There was no consideration as to my capacity to cope.<sup>57</sup>

**Ms Claire Hill - carer for her 95 year old father**

I struggle with my father's care - I am not a nurse and often find it hard to know how to proceed with things like, for example, wound care.<sup>58</sup>

**Ms Julie Witts - carer for her daughter**

I don't have any formal training and feel there is less importance put on my role than that of paid carers who assist my daughter ... As a carer, I need help with training to deal with the specific needs of the person I care for.<sup>59</sup>

**Perth Carers Forum Group - a group of 42 carers from diverse caring situations**

... carers reported that they could be providing significant care in the line of nursing care, with very little training or skills. It is just assumed that they would have to somehow learn and undertake complex care tasks. Carers felt that the burden and strain placed on them needed to be recognised and that relevant, trained support should be provided to ensure that they are skilled and prepared for their caring role from the outset.<sup>60</sup>

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57 Ms J Small, Submission No 110, p 1.

58 Ms C Hill, Submission No 1117, p 1.

59 Ms J Witts, Submission No 326, p 2.

60 Perth Carers Forum Group, Submission No 883, p 4.

4.57 Many carers are asking governments to provide formal training to equip them for the caring role.<sup>61</sup> There are some opportunities available across the community care system to receive skills development in relation to the caring role. For example, Alzheimer's Australia described its role in providing training for carers under the Dementia Caring Project which was funded in 2006 by the DoHA:

Alzheimer's Australia partnered with 52 Commonwealth Carer Respite Centres who contacted carers and families of persons with dementia to develop a menu of skills enhancement activities that consumers desired. The project enabled over 900 individuals to take part in various learning and skills enhancement sessions.<sup>62</sup>

4.58 Alzheimer's Australia reported that there was a positive uptake of the training by carers, with the following skill areas being the most sought after:

- Accessing legal information;
- Understanding dementia;
- Advocacy;
- Self care strategies;
- Managing behaviours of concern;
- Continence management;
- Health and well being;
- Communication;
- Accessing information to support decision making, for example, information on residential care, Centrelink, and support services;
- Home maintenance;
- Personal care;
- Role reversal related practical tasks such as car maintenance and cooking; and
- Use of computers and the internet including internet banking, online shopping and e-mail.<sup>63</sup>

4.59 However, it appears that formal training available to carers is largely *ad hoc* and often limited in scope and duration.<sup>64</sup> In response, carers and

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61 See for example: Ms D Stewart, Transcript of Evidence, 13 August 2008, p 27.

62 Alzheimer's Australia, Submission No 1002, p 16. See also: NSW Government, Submission No 1278, p 13.

63 Alzheimer's Australia, Submission No 1002, p 16.

64 Carers SA, Submission No 684, p 25. See also: Ms M Alford, Transcript of Evidence, 13 August 2008, p 4.

organisations have recommended the expansion of training opportunities for carers to support them in their caring roles.<sup>65</sup> Carers SA summed up the training and skill development needs of carers as follows:

Training is required across a range of topics such as the carer's roles and responsibilities; disabilities and illnesses; manual handling; carer personal care and health and well being; communication and relationships; negotiation and advocacy, including making complaints; the health and community services system ... and managing the relationship with paid care support workers.<sup>66</sup>

4.60 The training requirements of carers will vary to some degree according to their stage of life and the needs of the care receiver. For some carers the dominant need may be for skills in relation to accessing and understanding information on legal and financial issues, for other carers acquiring skills to manage complex care needs may be required, while for others developing skills in relation to safety issues and managing concerning behaviour is of the utmost importance.<sup>67</sup> A parent of three children, two of whom have an autism spectrum disorder, explained she urgently required skills to manage:

Constant behaviour issues. Constant safety issues. Constant violence; threats; damage. I need help with teaching; safety; behaviours ... I need someone to show me how to teach my kids.<sup>68</sup>

4.61 In her submission, Ms Michela Cardamone who is a carer for a family member with a mental health condition and employed as a carer consultant, points out that carers constantly need to advocate for themselves and the care receiver and often don't have the skills to negotiate with mental health professionals. She commented that there was a need for carers to have:

Education about the privacy act, and how this impacts on caring for a person with mental illness. How to negotiate with clinicians around issues concerning confidentiality. It is important for family members to be able to get information about what is happening to their loved ones. This is particularly the case when it is clear that

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65 Carers WA, Submission No 566, p 6. See also: Ms J Coulter, Submission No 1151, p 2.

66 Carers SA, Submission No 684, p 25.

67 Huntington's Victoria, Submission No 670.2, pp 5-6. See also: Mr R Sinclair, Transcript of Evidence, 13 August 2008, p 3.

68 Ms M McIlroy, Submission No 108, p 1.

after treatment most mentally ill people will be returned to their families.<sup>69</sup>

- 4.62 The Committee accepts that the training and skills development needs of carers are currently not being fully met. The challenge, however, is to provide appropriate and accessible training that reflects the diverse situations of carers. In these circumstances training should not be developed in an *ad hoc* manner and the Committee sees benefit in a national training and skills development strategy for carers. This may very well be built on existing educational and training programs.
- 4.63 The Committee also suggests that such a training strategy for carers examines the use of flexible approaches and delivery mechanisms, including use of e-learning and video conference media.<sup>70</sup>
- 4.64 The Committee has targeted its recommendation below to the Ministers for Families, Housing, Community Services and Indigenous Affairs and Health and Ageing and the states and territories through the Health, Community and Disability Services Ministerial Council. However, the Committee would expect the Department of Education, Employment and Workplace Relations and its state equivalents, at least, to be involved in planning and implementing a national training and skills strategy for carers.

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### **Recommendation 10**

- 4.65 **That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing request that the Health, Community and Disability Services Ministerial Council develop a national strategy to address the training and skills development needs of carers.**

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69 Ms M Cardamone, Submission No 799, p 3.

70 See for example: Carers WA, Submission No 566, p 22; Carers SA, Submission No 684, p 25.

## Coordination and Representation

### Case Management/Care Coordination/Carer Support Planning

- 4.66 Carers often seek the support of a case manager or coordinator to advise them and help them access services for themselves and for the care receiver. Most carers welcome these services but argue that they are inadequate.
- 4.67 There are a number of Australian Government, state and territory funded case management, care coordination or carer support planning programs to help carers to find and arrange services for care receivers. At the Australian Government level, the National Respite for Carers Program, Australian Government Aged Care Packages<sup>71</sup> and Home and Community Care (HACC) all provide some level of care coordination and/or case management services to carers and care receivers.<sup>72</sup>
- 4.68 Under the first of these, the National Respite for Carers Program, the Carer Associations in each state and territory provide specialised advice, support and referrals including ‘guided referrals’ to carers. A guided referral is generally a one-off process, provided when a carer is assessed as lacking the skill, time and capacity to access services which are urgently required, for example a counselling service.<sup>73</sup> Also, under the National Respite for Carers Program, Commonwealth Respite and Carelink Centres offer information, service coordination, carer support planning and referral.<sup>74</sup> However:
- ... there is a clear distinction between ‘coordination’ and ‘case management’. For the [Commonwealth Respite and Carelink] Centres to become involved in ‘case management’ would require substantial additional funding as it is a resource intensive activity.<sup>75</sup>

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71 These are Community Aged Care Packages (CACP), Extended Aged Care at Home (EACH) Packages and Extended Aged Care at Home Dementia (EACHD) Packages.

72 Australian Government Packages offer subsidised packages of care for older, frail people with complex care needs. Home and Community Care (HACC) is a joint program of the Australian, state and territory governments.

73 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109.1, pp 4-5.

74 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109.1, pp 4-5.

75 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109.1, p 5.

4.69 As mentioned, Australian Government Aged Care Packages offer subsidised packages of care for older, frail people with complex care needs. The packages comprise the Community Aged Care Packages (CACP), Extended Aged Care at Home (EACH) packages and Extended Aged Care at Home Dementia Packages (EACHD). Under these packages, approved providers may use a case management approach to arrange and coordinate services for the care receiver. A significant number of older frail people who receive an Australian Government Aged Care Package, are also supported by carers. In these situations the carers may participate in the case management offered through the package, as explained by the Australian Government departments below:

In administering the package (and at the care recipient's request), the approved provider is required to recognise the role of the carer and reflect the importance of both clients and carers in the planning, provision, and review of the package of service.<sup>76</sup>

4.70 Case management services for carers and care receivers are also available through HACC for its clients. The service:

... comprises active assistance received by a HACC client from a formally identified agency worker who coordinates the planning and delivery of a suite of HACC services to the individual client.

In 2007-08, some 7 percent, or around 58,000, of HACC clients received case management services through the Program.<sup>77</sup>

4.71 Finally, case management and coordination services are also provided through various state and territory government disability and community services programs. However, the complaints to the Committee about the lack of case management and coordination services available for care receivers and their carer, suggest that the existing services are inadequate.

### Carers Want More Case Management

4.72 Both new and experienced carers report that they often require additional assistance to navigate the service system, access information and coordinate services for the person for whom they are caring.<sup>78</sup> A typical comment was made by Ms Megan Major:

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<sup>76</sup> Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109.1, p 5.

<sup>77</sup> Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109.1, p 5.

<sup>78</sup> See for example: Ms M Nazzari, Submission No 100, pp 1-2; The Partners of Veterans Association of Australia Inc, Submission No 566, p 5; Ms S Matheson, Submission No 587, p 6; St George Migrant Resource Centre, Submission No 746, p 10; ANGLICARE Sydney, Submission No 769, p 6; Ms L Baker, Submission No 807, p 16; Name withheld, Submission No



When my husband had his stroke, the hospital social worker helped me apply for carers allowance, obtain an 'Advice for Carers Package', organised a 'Post Acute Care Program', and gave me information about 'Home and Community Care Services'. A month after my husband came home I was drowning in paperwork and information and going round in circles trying to find out who actually did what!

I got lost in 'the maze' as I tried to work out who to contact for various types of support. I had to deal with: District Nursing Service and Cognitive Dementia and Memory Service - West Gippsland Health Care Group, Gippsland Regional Aged Care Assessment Service - Latrobe Community Health Services, Carers Victoria, Baw Baw Home and Community Care, Commonwealth Carer Respite Centre and Commonwealth Carer Resource Centre, Centrelink, plus GPs, physician and Neurologist.

I found this very stressful. I believe if I had been able to continue with the support of the hospital social worker and if the local healthcare group co-ordinated the services I would not have 'fallen in such a big heap'.

- 4.73 The evidence provides many examples of challenging caring experiences which could have been alleviated to some extent had the carer been assisted to access and coordinate appropriate support services. Some typical comments from carers include:

**Mr Martin Hengeveld - carer for his 60 year old partner who has Alzheimer's disease**

My biggest challenge has been, and still is, to come to grips with who does what. There are 9 agencies who all have a finger in the pie, of which none stand out as truly supportive. When all this started I would have loved to have a 'case manager', who would have been my constant source of reference throughout my caring time, some one who might even ring up occasionally to check on how we are going.<sup>79</sup>

**Ms Giovanna Walker - an employed carer, caring for her elderly father**

Getting access to services is a challenge. I work full time, and between the national helpline and local council it involved many

860, p 1; Mr R Hart & Ms M Hart, Submission No 1174, p 2; Ms M Anderson, Transcript of Evidence, 12 August 2008, pp 44-45.

79 Mr M Hengeveld, Submission No 29, p 1.

phone calls, I didn't know where to go. I felt helpless, no one would take responsibility.<sup>80</sup>

**Name withheld – carer of a young child who was born with Trisomy 13, a condition which causes severe developmental delay**

After a year of struggling, my daughter had been admitted into the Sunshine Hospital and whilst she was in hospital the nurses were shocked to find out that I wasn't receiving any home help and organised the social worker to come and see me.

Consequently I received some home help and respite and my daughter was put on waiting lists for early intervention services, which is now receives.<sup>81</sup>

**Name withheld a carer for two daughters who use mental health services**

As soon as a family member is thought to have a mental illness, the prospective carer should be able to discuss the situation with a social worker (free of charge) to help the carer start off on the path to accessing help - medical, counselling, financial. If a caseworker were assigned from the start, the carer would be more competent and over time require less help from government. It would prevent subsequent problems, and facilitate people re-joining society.<sup>82</sup>

**Mr Robert McEachern and Ms Grace McEachern – carers for their 38 year old son who has a severe life long disability, living in rural NSW**

A support network/caseworker who can supply information on what is of assistance eg aids, respite, financial.

At the moment there seems to be many different organizations who have brokered for money to help...Finding these organizations seems to be by word of mouth... For us also is the looming decision of the day we can no longer look after our son Will we be able to obtain long term care when we make that decision? Will that care be available locally so he can still be a part of our lives and possibly spend day visits with us? What will

80 Ms G Walker, Submission No 266, p 1.

81 Name withheld, Submission 852, p 1.

82 Submission No 855, p 3.

happen when we can no longer drive? Being in our local country community will be important for our son's well being<sup>83</sup>

- 4.74 Many carers want case management/coordination services to work with them in partnership to address whole of life planning for the care receiver. Mr Kevin Hewitt, a Victorian carer, raised these issues in the following terms:

... what I need is a good working partnership where we can plan for the future for a better life and more productive life for my daughter. In this process we would have planned timelines and available resources guaranteed ... Get out of the crisis needs controlling system ... there needs to be more face to face case management – need to develop working partnerships with families ...<sup>84</sup>

- 4.75 Similarly, carers also seek partnerships with a range of service providers to jointly plan for and provide the best quality of life possible for the care receiver. As a carer, Mr Arthur Skimin, explained to the Committee in Canberra:

We are frustrated by the fact that the carer of the patient is not recognised by the professional care providers. This is frustrating because we feel that we are out of the loop. We are also frustrated by the case management processes. Many carers are aged and once you are in your mid to late 70s you can drop off the twig any day. What happens to that individual then? How do they keep their quality of life and self-esteem as the years roll on?<sup>85</sup>

- 4.76 The need for more case management services is supported by organisations and governments. ANGLICARE Sydney, which operates the Commonwealth Respite and Carelink Centres in the Nepean and South West Sydney Regions, argued that these could be funded to expand their services to offer case management for care receivers and their carers.<sup>86</sup>

- 4.77 In particular, as young carers may be especially vulnerable, service providers are calling for the need for case management support for this group. The Queensland Government emphasised the need to help these younger people:

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83 Mr R McEachern & Ms G McEachern, Submission No 1171, p 4.

84 Mr K Hewitt, Submission No 328, p 2. See also: Sunnyfield Independence, Submission No 663, pp 2-4; Perth Carers Forum Group, Submission No 983, p 4.

85 Mr A Skimin, Transcript of Evidence, 26 September 2008, p 14.

86 ANGLICARE Sydney, Submission No 769, pp 8-9.

The key transition points and different developmental stages experienced through adolescence would require review and adjustment of interventions, resources and supports needed by the young carer. Consequently, engaging in a regular process of case review and management involving care recipient, care provider and support agencies would be required (Adequate resourcing would need to be available to support this kind of response to young carers).<sup>87</sup>

### Case Management Dissipating Funds?

4.78 A number of carers and organisations note however, the costs of diverting already scarce resources to case management or brokerage. For example, the Friends of EACH Action Group, is critical of the case management model used by Aged Care Packages as a 'leakage of funds' away from direct care and respite, saying:

The Case management model ... is jammed packed with Case management costs, administration costs and outsourcing costs. These costs accumulate and the end result is that between 70 and 80 percent of the package is dissipated in costs and is not utilized to purchase hours of support that is required to assist the person being cared for and as indicated earlier the provision of respite for the Carer. There is very little scope for the assessment or consideration of the quality of care provided and support provided by this model to the person being care for and for the caregiver.<sup>88</sup>

4.79 Ms Helen Johnson, who cares for her son who is profoundly and severely disabled noted the reduction of funds available directly for care:

Currently the Victorian State Government is kind enough to provide us with a 'Linkages funding Package' where after brokerage dollars (as this package must have a case manager attached to it) we receive approximately \$6.5K.<sup>89</sup>

4.80 Despite these concerns, the Committee believes the argument for case management is clear. The fact that carers are concerned that funding case

87 Queensland Government, Department of Premier and Cabinet, Submission No 1203, p 15. See also: Carers NSW, Submission No 661, p 29; ANGLICARE Sydney, Submission No 769, pp 8-9.

88 Friends of EACH Action Group, Submission No 1279, p 11. See also: Ms G Hawthorne, Submission No 12, p 2; Ms J Killeen, pp 1-2; Ms M-L May, Submission No 891, p 3; Mr T Stroud, Transcript of Evidence, 12 August 2008, p 49.

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

management reduces the amounts left over for care, reflects the overall lack of funding available – a matter that will be discussed in more detail in subsequent chapters. Innovative funding models to be discussed in chapter 6 have the flexibility to allow carers and care receivers to choose whether or not they wish to purchase case management/coordination services.

- 4.81 The Committee understands that carers require easy access to clear and up-to-date information, but at times they also require professional assistance to understand the options for their care receiver and help to liaise with service providers. Carers may also require assistance to consider longer term planning for themselves, the care receiver and other family members. Case management may be particularly relevant for new carers and for those facing transitions in their own lives or in the lives of those for whom they care.

### **Recommendation 11**

- 4.82 **That the Minister for Families, Housing, Community Services and Indigenous Affairs and Minister for Department of Health and Ageing direct their Departments to review the adequacy of case management or care coordination for carers and care receivers using community care, aged care, disability and community mental health services.**

### **Advocacy for Carers**

- 4.83 Advocacy is about speaking out, acting or writing, with minimal conflict of interest, on behalf of a person or a group, in order to promote their best interests. There are a range of different approaches to advocacy described in disability and carer literature. Broadly, however, advocacy can be described at two levels - 'individual' advocacy and 'systemic' advocacy.
- 4.84 Individual advocacy focuses on achieving outcomes for individual carers or care receivers. It can be useful to consider the following types of individual advocacy:
- self-advocacy – when a person raises their concerns themselves with, for example, professionals, media and politicians;
  - informal or family advocacy – when a family member, friend or neighbour advocates on behalf of a family member or friend; and

- formal advocacy (including legal advocacy) – provided by a paid staff member of a service on behalf of an individual.
- 4.85 Systemic advocacy on the other hand, is a form of advocacy provided by organisations or associations representing the rights and interests of a group rather than a particular individual. Systemic advocacy tends to focus on influencing government policy and practices.
- 4.86 A number of submissions to the Inquiry have suggested empowering carers to advocate for themselves and on behalf of those that they care for, and by enhancing carers' capacity to advocate systemically to ensure that carer interests are upheld and to remove policy barriers and discriminatory practices.

### Individual Advocacy

- 4.87 Funding for disability advocacy is provided through the National Disability Agreement and delivered by 63 non-government organisations across Australia. The program is targeted at people with disability under the age of 65 years, to overcome barriers that affect their daily life and their ability to participate fully in the community. One of the models of advocacy funded under the National Disability Advocacy Program (NDAP) is informal or family advocacy which supports family members to advocate with, or on behalf of, a care receiver.<sup>90</sup>
- 4.88 Many carers have commented on the value of formal disability advocacy services for care receivers.<sup>91</sup> However, it is arguable that carers themselves, rather than formal advocacy services, provide most of the advocacy required by care receivers.<sup>92</sup> Carers also report that disability family advocacy services, designed to support them in their informal advocacy role on behalf of a person with a disability, are often difficult to access.<sup>93</sup> In the view of the National Carers Coalition, the extent of informal family advocacy provided by carers themselves on behalf of care receivers, coupled with the apparent lack of formal family advocacy services, should be addressed by the establishment of a new family

90 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109.2, p 2. The National Disability Advocacy Program does provide funding for some systemic advocacy on behalf of people with disability.

91 See for example: Ms H Johnson, Submission No 1178, p 8; Mr R Gow, Transcript of Evidence, 15 October 2008, p 5.

92 See for example: Ms S Harmer, Submission No 430, p 1; Gippsland Carers Association, Submission No 660, p 4; Mr R Gow, Transcript of Evidence, 15 October 2008, p 6.

93 See for example: Ms F Galbraith, Submission No 1089, pp 5-6. See also: National Carers Coalition, Submission No 571, pp 4-6; Gippsland Carers Association, Submission No 660, p 4; A4 Autism Aspergers Advocacy Australia, Submission No 1105, pp 2-3.

advocacy network for carers to be funded by the Australian Government.<sup>94</sup>

- 4.89 Many carers have identified the need for additional training to enhance their own capacity to advocate on their own behalf and on behalf of care receivers. The importance of building the capacity of carers for self advocacy has been mentioned earlier in the chapter.
- 4.90 However, evidence suggests that there is also a pressing need for carers to have access to formal advocacy services for carers in their own right. Carers Queensland reported that carers currently seek advocates to work with them in a range of situations including dealings with employers, guardianship boards and tribunals, government agencies including Centrelink, service providers and health funds.<sup>95</sup> Carers ACT provided further examples of where carers themselves need assistance:

Carers of people with mental health issues and drug or alcohol addiction may face an additional problem when their personal possessions are damaged or stolen by the carer-recipient. These losses are not covered by insurance. It is also difficult to track down where stolen items have been sold and try to claim them back. Carers will not usually take action that leads to criminal charges against the care-recipient. However carers do need access to advocacy and support when dealing with such complex issues to assist with finding ways to resolve issues without putting the carer or care relationship at risk.<sup>96</sup>

- 4.91 Carers themselves have described distressing situations where they were not able to achieve a positive service response or intervention through their own efforts. Ms Carmen Polidano, a carer for her 31 year old son, described her difficult caring situation:

My son has been physically violent and verbally abusive since he was 14 years old. When the violence started, my daughters were very young. As a family, we endured 15 years of domestic violence and verbal abuse. We lived in constant fear. I lost contact with friends, as my son would become violent if I even talked with

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94 See for example: Mr R Gow, Transcript of Evidence, 15 October 2008, pp 4-7. See also: Ms F Anderson, Submission No 979, p 12; Ms A Geach-Bennell, Submission No 1022, p 1; Ms F Galbraith, Submission No 1089, p 5; Ms H Johnson, Submission No 1178, p 8; Ms N Brown, Transcript of Evidence, 6 August 2008, p 48.

95 Carers Queensland, Submission No 703, p 12. See also: Carer Support and Respite Centre Carer Group, Submission No 585, p 4; Carers ACT, Submission No 702, pp 26-28.

96 Carers ACT, Submission No 702, p 20. See also: Mr J Wilkinson, Submission No 1035, p 6.

them on the phone. My daughters could not socialise at home for the same reasons. We became socially isolated and extremely depressed. We lived with this problem daily and did our best to keep it from escalating to the point where we had to call the Police. We were a family unit constantly on the verge of collapse. Family and Police intervention didn't help. The only way the police could help was if I pressed charges. Our only other avenue of help, a support agency for the disabled, Care Connect, advised us to ring 000 - so we continuously went round in circles. There is nowhere a Carer can go to get help or protection from violence. Calling the Police is not the best way to resolve domestic violence involving someone with a disability. This is a medical problem not a criminal problem.<sup>97</sup>

- 4.92 The need to increase formal individual advocacy services for carers is supported by many carers and organisations.<sup>98</sup> Carers Australia, which receives Australian Government funding to provide information and specialist advice to carers, reported that they cannot keep up with the demand from carers for formal advocacy services:

We have not done enough promotion of our services because we cannot meet the demand. A lot of those families want individual advocacy, and that can be very expensive, especially when you get into the legal side of caring ... So there is a need to look at individual carer advocacy.<sup>99</sup>

- 4.93 Not all the evidence to the Inquiry, however, supported an expansion of services targeted at carers. A community based, state-wide disability advocacy agency providing advocacy services for children and adults with a developmental disability in NSW, expressed their concerns:

... at the amount of funding that is being deflected from the disability service system into programs for carers, as often the benefit is aimed at the carer alone, is short lived and creates a demand for more of the same. This is opposed to providing support which is long term, benefits the person with disability

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97 Ms C Polidano, Submission No 259, p 2.

98 See for example: Ms V Simpson, Submission No 260, p 5; Carers NSW, Submission No 661, p 14; Australian Association of Gerontology Inc, Submission No 915, p 3; Ms J O'Connor, Submission No 1003, p 3; Ms F Galbraith, Submission No 1089, pp 5-6; National Ethnic Disability Alliance, Submission No 1110, pp 22-23; Mr G Schlecht, Transcript of Evidence, 20 August 2008, p 34.

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



equally, and builds on, rather than replaces, naturally occurring supports.<sup>100</sup>

- 4.94 As with the arguments above for and against greater funding for case management, arguments against funding carer advocacy reflect the overall lack of resources for care receivers and carers alike.
- 4.95 The Committee notes that the Australian Government has undertaken to improve service delivery and access to advocacy for people with disability, and supports this commitment.<sup>101</sup> The evidence to the Inquiry suggests further work needs to be done to recognise and support the pivotal role carers play in advocating on behalf of care receivers and when required, to provide carers with advocacy services in their right.

## **Recommendation 12**

- 4.96 **That the Minister for Families, Housing, Community Services and Indigenous Affairs extend the National Disability Advocacy Program to:**

- **provide family advocacy services which better recognise the role of carers providing individual advocacy on behalf of, and with, care receivers; and**
- **provide formal advocacy for carers in their own right when this is required.**

- 4.97 The Committee also suggests that the proposed extension to the NDAP be accompanied by a change in program name to encompass both people with disability and their carers, and to more adequately reflect the objective of the National Disability Agreement to support:

People with disability and carers to have an enhanced quality of life and participate as valued members of the community.<sup>102</sup>

## **Systemic Carer Advocacy**

- 4.98 Systemic advocacy for carers is currently considered core business for Carers Australia as the national peak body for carers and for the network

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100 Family Advocacy, Submission No 768, p 1.

101 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109.2, p 2.

102 Council of Australian Governments, National Disability Agreement, p 3.

of state and territory Carer Associations.<sup>103</sup> Specific funding for this is provided by DoHA. Some carers have commented positively in relation to the systemic advocacy provided by the Carer Associations.<sup>104</sup> Others have questioned whether the current arrangements represent the full diversity of carer views.<sup>105</sup> For example, Ms Estelle Shields a long-term carer for her adult son with intellectual disabilities, stated:

[Carers], the workers at the coalface, must have an equal voice with service providers and peak bodies and we must have our own funded advocacy.<sup>106</sup>

4.99 Elaborating on concerns with the existing structures of systemic carer advocacy, Mr Robert Gow a Queensland member of the National Carers Coalition, said:

It is a fact that disability advocates and service provider organisation peaks represent themselves and their constituents – that is, people with disabilities and service providers respectively. It is a fact that their role is not to represent the interests of carers. It is a fact that carer’s advocates and disability advocates do not necessarily share the same concerns. Certainly there are some crossovers, that is true, but it is a fact that the two are not mutually inclusive. Please do not assume that because advocates and peaks raise issues that involve carers that they represent carers.<sup>107</sup>

4.100 Ms Jean Tops, Victorian Liaison for the National Carer Coalition, also proceeded to outline her concerns in relation to the dual role of the carer associations as service providers and as advocates for systemic reform for carers saying:

We want to make it very plain here that the carer associations are in fact service providers. On their own admission, they provide thousands of services to carers every year, and when they do that

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103 Carers Australia website, viewed 11 March 2009 at [www.carersaustralia.com.au/?/national/article/view/via:0:157](http://www.carersaustralia.com.au/?/national/article/view/via:0:157). See also: Australian Government, Department of Families, Housing, Community Services and Indigenous Affairs, viewed 11 March 2009 at [www.facs.gov.au/disability/national\\_disability\\_advocacy/default.htm](http://www.facs.gov.au/disability/national_disability_advocacy/default.htm).

104 See for example: Name withheld, Submission No 244, p 10; Mr J Halford, Transcript of Evidence, 12 August 2008, p 43.

105 See for example: National Carers Coalition, Submission No 571 (Attachment 2), pp 1-14; Ms N Brown, Transcript of Evidence, 6 August 2008, p 47.

106 Ms E Shields, Submission No 35, p 1.

107 Mr R Gow, Transcript of Evidence, 15 October 2008, p 5.

they do an excellent job. It is inappropriate for service providers to also be advocates for carers.<sup>108</sup>

4.101 To address these concerns the National Carers Coalition suggests that there is a need for substantial reform to the current arrangements for systemic carer advocacy, recommending the establishment of a new advocacy model, which represents the interests of carers of people with lifelong dependent disabilities.<sup>109</sup>

4.102 Ms Joan Hughes, Chief Executive Officer of Carers Australia, responded to these concerns by noting:

There is an issue with lots of families who have not been part of a system. They are families who would criticise disability advocacy groups, carer advocacy groups and ageing advocacy groups, because they feel like their voice has not been heard, and that is absolutely valid. We have a role at Carers Australia, as the national peak body, to work with these groups.<sup>110</sup>

4.103 Specifically in relation to the dual role of Carer Associations as service providers as well as providers of systemic carer advocacy, Ms Hughes proceeded to say:

Even though we are providing advice and services to carers, we also have the capacity through our research and evidence to talk with government about some of those strong issues.

... We also started as a grassroots organisation, and a lot of people do not know the history. Seventy-five per cent of board members of carers associations are current or former family carers. When you explain that to people, they say, 'Oh really?' We have mums and dads who are presidents of our associations, but we have not promoted that well enough. ... Carers Australia will continually fight for better support for those families, but we need to bring those other groups in. I am very committed, and so is the board of Carers Australia, to have meetings with some of those national alliances and see how we can work together.<sup>111</sup>

4.104 Mr Andrew Stuart of DoHA, explained that it is not unusual for government to fund organisations to provide both services and systemic advocacy. Mr Stuart expressed that in his opinion:

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108 Ms J Tops, Transcript of Evidence, 15 October 2008, p 10.

109 National Carers Coalition, Submission No 571 (Attachment 2), pp 1-14.

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

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

Carers Australia is a very good and strong advocate that is able to open doors in this House [the Australian Parliament]; I certainly do not have any sense of any reticence because they are also a funded program delivery organisation. I would just put on record that I particularly respect the way that they always bring and give a voice to individual carers at the functions that they manage.<sup>112</sup>

- 4.105 While the Committee acknowledges the concerns expressed by some carers with regard to systemic carer advocacy, it notes that others have commented favourably on the role of the Carer Associations in representing their views and advocating for systemic reform. In view of the conflicting evidence, the Committee does not believe that a compelling case for fundamental reform to existing arrangements for systemic carer advocacy has been demonstrated. The Committee also notes Carers Australia's commitment to represent the full diversity of carers, including groups that have not previously engaged.
- 4.106 Nevertheless, to investigate further the concerns expressed by some carers, the Committee believes that a review of existing arrangements of systemic carer advocacy may be beneficial. Specifically, the Committee recommends that existing arrangements for systemic carer advocacy be examined to determine how arrangements might be extended or reformed to further promote representation and inclusion of the diversity of carers, with particular focus on those that may feel that they are under represented.

### **Recommendation 13**

- 4.107 **That the Minister for Health and Ageing review arrangements for systemic carer advocacy provided through Carers Australia and the network of state and territory Carer Associations.**

**The review should examine the extent to which arrangements for systemic advocacy represent the diversity of carer groups and consider whether these arrangements might need to be extended or reformed.**

### **Carers as Partners in Care**

- 4.108 As discussed in chapter 3, carers and organisations are calling on the Australian Government to formalise the recognition of carers through the

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112 Mr A Stuart, Transcript of Evidence, 28 November 2008, p 38.

adoption of national legislation and a strategic policy framework. One element for consideration is for formal recognition of the essential contribution of carers in the care, treatment and management of people affected by serious medical and mental health conditions. With changes in health, mental health, disability and age care policies supporting shifts from institutional care to care at home, carers are asking for recognition as partners in care by health, mental health, disability and aged care professionals and by service providers.<sup>113</sup>

- 4.109 Carers in many different types of caring situations have commented on the lack of recognition they are given by health professionals.<sup>114</sup> Ms Michela Cardamone, an employed carer who works as a carer consultant in the Psychiatric Disability Rehabilitation Support Sector in Victoria observed:

My own experience has shown me that when strong and trusting relationships developed between my family member, the mental health professionals involved in her care, and myself, a far better outcome was achieved than any of us could have hoped for in caring for or treating her independently. Sadly though, this has not been the experience of the majority of carers I have come in contact with. Many, particularly those involved with the adult mental health sector, describe being shut out, ignored, disempowered and disrespected by the mental health system within which their loved one is treated.<sup>115</sup>

- 4.110 The complexity of the issue, particularly for carers of people with a mental illness, was raised by another Victorian carer, in the following comment:

The Confidentiality Act needs to be reviewed and understood. Too frequently a seriously ill, often deluded family member will be placed in hospital, and will be asked, in that state, if he, she wishes to have carers informed of treatment plans etc. If the consumer does not want the carer involved, the carer is out of the picture.<sup>116</sup>

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113 See for example: Mr W de Goede, Submission No 366, p 1; Ms S Matheson, Submission No 587, p 5; Carers NSW, Submission No 661, pp 10-12; Carers Australia, Submission No 699, p 10; Ms H Johnson, Submission No 1178, p 9; Dr M Leggatt, Transcript of Evidence, 12 August 2008, pp 9-10; Mr P Saunders, Transcript of Evidence, 13 August 2008, p 11; Ms J McMahon, Transcript of Evidence, 13 August 2008, pp 91-92; Ms A Ashton, Transcript of Evidence, 26 September 2008, p 5.

114 See for example: Name withheld, Submission No 503, p 1; Ms J Nicholas, Submission No 1149, 3-4; Ms L Harper, Submission No 1162, p 4.

115 Ms M Cardamone, Submission No 799, p 1.

116 Ms A Burgess, Submission No 127, p 2. See also: Ms C Alliston and Ms C Fudge, Transcript of Evidence, 13 August 2008, pp 56-57.

4.111 The recognition of carers as partners in care would involve carers in assessment, treatment, discharge and care planning and implementation, services delivery, and monitoring.<sup>117</sup> The recognition and involvement of carers as partners in care has a great deal to offer not only the carers but the formal care team and the care receiver, for instance:

- carers can provide valuable information and feedback to health care professionals;
- providing carers with information, education and training and involving them in discharge and care planning can increase compliance with discharge plans, prevent readmissions and improve the quality of care; and
- during hospitalisations, carers can support care receivers and act as quality monitors, alerting staff to potential costly problems before they happen.<sup>118</sup>

4.112 The recognition of carers as partners in care has been included in some state and territory government carer recognition legislation, mental health legislation and health policies.<sup>119</sup> WA was the first jurisdiction to enact carer recognition legislation. As Carers WA explained:

Within Western Australia state legislation, the health and disability departments are expected to include carers as partners of health professionals in care planning and to support carers own needs as a community and family member.<sup>120</sup>

4.113 Carers SA raised the importance of educating service providers in relation to such legislative and policy obligations:

... when it comes to building the participation of carers in service delivery, and a genuine sense of partnership with them, many service providers need guidance ... A comprehensive education and training program for service providers on carers and the caring role is required if services are to have the capacity to respond to developments arising from the State Government's Carers Recognition Act 2005 and SA Carers Policy.<sup>121</sup>

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117 Carers Victoria, Submission No 652, p 32.

118 Carers NSW, Submission No 661, p 11.

119 See for example: Ms R Warmington, Transcript of Evidence, 13 August 2008, p 13.

120 Carers WA, Submission No 566, p 20. See also: Carers NSW Submission No 661, p 9; Carers SA, Submission No 684, p 11.

121 Carers SA, Submission No 684, p 11. See also: Ms R Warmington, Transcript of Evidence, 13 August 2008, pp 13-14.

- 4.114 The issue of recognising carers as partners in care with health and community care service providers raises complex issues about balancing the needs and interests of carers, care receivers and service providers. The submission from the Royal Australian and New Zealand College of Psychiatrists commented on the complexity in the mental health sector:

The involvement of family carers in the care of their family members with severe disability from mental illness is complicated by legal, ethical, bureaucratic processes that are often complex and difficult to navigate and 'cultural' issues. For instance, there may be confusing agendas between traditional ethical notions of confidentiality, privacy principles and legal obligations under the various State mental health acts. It is, however, noted that a duty to inform family is contained within Australian model mental health legislation and further enacted in some Mental Health Acts such as current NT legislation. While privacy is a valued right and needs to be protected it is imperative that other rights and responsibilities that protect the safety and quality of people's lives are also balanced in considerations. This is a complex area, but one that warrants review.<sup>122</sup>

- 4.115 In its submission the Mental Health Council of Australia also called on governments to review policies in relation to confidentiality:

Mental health carers are often excluded from involvement in care due to privacy and confidentiality provisions. There is an urgent need for such policies to be reviewed and for a nationally consistent policy to be developed to clarify, for both service providers and carers, what can and cannot be shared in the absence of patient consent ...<sup>123</sup>

- 4.116 The evidence strongly indicates that the involvement of carers as partners in care with health, mental health and community care service providers, can have positive results for all involved. This benefit needs to be balanced with the right of care receivers if they wish for privacy. The Committee understands that this is a vexed issue, particularly in relation to people who suffer episodic mental illness. However, there is considerable support from mental health professionals for the inclusion of family members who play key roles in the care and support of people with mental illness.

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122 Royal Australian and New Zealand College of Psychiatrists, Submission No 672, p 4. See also: Dr J Freiden & Dr M Leggatt, Transcript of Evidence, 12 August 2008, pp 4-5.

123 Mental Health Council of Australia, Submission No 682, pp 9-10. See also: Ms J Hardy, Transcript of Evidence, 13 August 2008, p 93.

Health information privacy in particular, is a complex issue bound by Australian Government, state and territory legislation and regulation and professional codes of conduct.

### **Recommendation 14**

**4.117 That the Attorney-General, in conjunction with the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing, investigate whether the National Privacy Principles and the Information Privacy Principles, and equivalent provisions in state and territory privacy and mental health legislation, adequately allow carers to be involved in the treatment of the individuals for whom they care.**

**The Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing promote to health and community care providers the importance of involving carers in the treatment and services for those receiving health and community care services.**

### **Substitute Decision Making**

4.118 Under various state and territory legislative regimes, carers, in certain situations, can act as substitute decision makers for care receivers. In instances where a care receiver has a disability which impacts on their decision making ability, carers may seek formal guardianship through state and territory Guardianship Boards and Tribunals. Such powers can provide carers with the authority to make decisions on behalf of the care receiver.

4.119 There are also various provisions under state and territory legislation for a competent adult to appoint an enduring guardian or an enduring power of attorney to make personal decisions and manage financial matters on their behalf if the time comes when they are unable to do so for themselves.<sup>124</sup> However, these arrangements are not straightforward:

... current legal provisions relating to enduring powers of attorney and advance care directives are complex and vary across the jurisdictions; terminologies are confusing and inconsistent and all

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<sup>124</sup> See for example: NSW Guardianship Tribunal, Submission No 659, p 1; Mr T Tregale & Ms H Tregale, Submission No 766.1, pp 1-2.



too often the wishes of the person with dementia are not appropriately followed. Currently the opportunity of advance decision making is underutilised.<sup>125</sup>

- 4.120 There is a lack of awareness in the general community of issues in relation to substitute decision making, including guardianship, enduring powers of attorney and advanced care directives. Alzheimer's Australia points out that:

Research has demonstrated that not all health professionals, including general practitioners are well informed about the enduring powers and advance directives and may lack the time or skills to assist people with this process. Lawyers also vary in their knowledge of the issues confronting people with a recent diagnosis of dementia.<sup>126</sup>

- 4.121 The NSW Guardianship Tribunal's submission suggested:

... it would be beneficial to provide accessible and extensive community education to increase awareness of the legal options available for the appointment of substitute decision makers. Increased community education about enduring guardianship and enduring power of attorneys would be beneficial. It is important that such education also clarifies the duties and obligations of appointed substitute decision makers to always act in the best interests of the person with a disability.<sup>127</sup>

- 4.122 A number of jurisdictions also have legislative processes to govern the use of 'advanced care directives' which enable an individual to make a statement about how they wish to be treated and who they wish to be involved in their treatment at a time in the future should the individual not have the capacity to make health care decisions for themselves. The evidence contained a degree of support for the use and promotion of advanced care directives. The Mental Health Council of Australia stated:

A practical way to overcome the problems associated with protecting the privacy and confidentiality of the person with the mental illness is to develop Advance Directives. Advance Directives allow consumers, when they are well, to plan what they would like to happen to them if they become unwell, and provides

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125 Alzheimer's Australia, Submission No 1002, p 19.

126 Alzheimer's Australia, Submission No 1002, p 19. See also: Ms R Beale, Submission No 741, p 3; Ms M Robbins, Submission No 1139, p 2.

127 NSW Guardianship Tribunal, Submission No 659, p 2.

carers with a clear outline as to what extent they should be involved in treatment and recovery planning. Although Advance Directives may explicitly exclude carers from involvement in a person's care, they are a powerful and practical tool that can easily circumvent current privacy and confidentiality legislation with the prior permission of the person with a mental illness ... An Advance Directive pro-forma, that is legally valid in all states, should be developed so that consumers are able to decide what care they receive and who should be involved. Not only will this clarify the role of mental health carers, it will also lead to improved outcomes for the person with a mental illness as it can be used to guide treatment based on what has worked in the past for a particular person.<sup>128</sup>

- 4.123 For people with dementia and their carers, there can be significant problems when advanced care directives or enduring powers of attorney are not in place. As explained by Alzheimer's Australia:

While informal arrangements can often work well in families, many individuals with dementia and their family carers encounter significant problems when wishes for future care and decision-making are unknown. End-of-life care can also become more difficult in the absence of advance directives. If powers are not in place the guardianship law may have to be utilised.

An increasing number of people with dementia who have not put enduring powers in place are referred to Guardianship Tribunals across Australia. Approximately 50% of all referrals relate to people with dementia.<sup>129</sup>

- 4.124 The Committee is aware of the complexity of issues which confront carers in relation to the area of substitute decision making, including guardianship, enduring powers of attorney and advanced care directives. The evidence provided to the Committee suggests that the use of enduring powers of attorney and advanced care directives can be further utilised and that a uniform national approach is desirable.

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128 Mental Health Council of Australia, Submission No 682, pp 9-10.

129 Alzheimer's Australia, Submission No 1002, p 19.

**Recommendation 15**

- 4.125 That the Attorney-General promote national consistency and mutual recognition governing enduring powers of attorney and advanced care directives to the Standing Committee of Attorneys-General.

**Recommendation 16**

- 4.126 That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing and the Attorney-General fund a national information campaign to raise awareness about the need for, and benefits of, enduring powers of attorney and advanced care directives in the general community and among health and community care professionals.

