

Access to Supports and Services

- 6.1 This chapter considers issues relating to the access and effectiveness or otherwise of current community care services for carers. The chapter will:
- examine issues associated with the availability and accessibility of community care services for carers, including carers living in regional and remote locations and Indigenous carers;
 - examine issues associated with the availability, accessibility, affordability and quality of respite services for carers; and
 - examine issues associated with the availability, accessibility, affordability and quality in-home assistance for carers.
- 6.2 This chapter will also consider the need and options for structural and/or fundamental reform to community care systems.
- 6.3 Finally the chapter will consider the importance for carers of access to adequate community care services for care receivers.

Community Care Services

- 6.4 The broad community care system for carers and care receivers is made up of a number of different service systems, namely:
- community care services;
 - aged care services;
 - specialist disability services;
 - community mental health services; and
 - veterans' care services.

- 6.5 In addition, carers and care receivers using these services may be accessing other services in the health, mental health and palliative care sectors, as well as other services provided through education, employment, housing, transport and income support. The adequacy of all these services, individually and collectively, directly affect the quality of life for carers and care receivers alike.
- 6.6 Community care services have evolved to help improve the capacity of people with a disability, chronic illness, mental illness or frailty to live independently or, in circumstances where informal care is provided by family members or friends, to support the carers to provide adequate and sustainable care. In these circumstances, community care services are either targeted to support:
- care receivers directly, while possibly also indirectly alleviating the caring responsibilities of carers; or
 - carers directly, while also aiming to meet the needs of care receivers.
- 6.7 Based on their experiences, carers have raised a diverse range of issues and concerns relating to community care systems and services for carers and for care receivers. Carers and organisations report that not only is it difficult to discover and access appropriate community care services, but where they are available – and often they are not – they may not be of adequate quality.

The Accessibility and Availability of Community Care Services

Navigating the Service Maze

- 6.8 A common theme from carers is that the current array of community care services is too complex and confusing for those trying to identify and access services.¹ The complexity of community service systems derives from a number of factors, including:
- the linked but different needs of care receivers and carers;

1 See for example: Ms M Anderson, Submission No 331, p 2; Carer ACT, Submission No 702, pp 24, 34; Submission No 855, p 3; Mr R Taylor, Submission No 923, p 2; Ms J Steepe, Submission No 1023, p 6; Ms M Major, Submission No 1163, pp 1-2; Ms C Masolin, Submission No 1090, p 3.

- the multiple portfolio and program areas across all levels of government that are involved in the funding and administration of community care services;
- the separate service systems which provide assistance to carers and care receivers, namely, the community care, aged care, disability, community mental health and veterans' care services; and
- the involvement of government and not-for-profit and for-profit non government organisations in the delivery of services to carers and care receivers.

6.9 The result is that carers may have to identify community care services for themselves or their care receiver from different government departments and agencies, across different levels of government and delivered through a range of community or private sector organisations. These fragmented and complex service systems have resulted in a 'service maze', which is a source of frustration to carers. Furthermore, once services are identified, carers and care receivers are then confronted by varying eligibility requirements and assessment processes to access them.²

6.10 The experiences recounted below are typical of the frustration experienced by many carers trying to navigate community care systems to determine what services are available to support them or their care receiver:

Ms Kerry Ferguson - sole carer for a 22 year old with Cantu Syndrome

I am continually frustrated by the process to procure funding, services, packages, shared supported accommodation, case management and respite. Applications are not always clearly developed or transparent. It is a repetitive process that is impersonal, time consuming, highly frustrating and costly. Upon completion, even if the criteria are met, there is no guarantee of a successful outcome. This is directly due to funding shortfalls. Therefore, families are denied choice and there is no availability or flexibility. You may make several applications, attend requested meetings or make numerous telephone calls, all to no avail. There are few services that will accept applications for support and have established waiting lists.³

2 See for example: Ms K Batram, Submission No 33, p 1.

3 Ms K Ferguson, Transcript of Evidence, 1 October 2008, pp 39-40.

Ms Carey Sebbens and Mr John Doyle - carer for their fourteen year old son with complex care needs

There is an incredible maze of carers services, recreational, respite, post school options, advocacy, specialists, specialist medical experts etc that are very difficult to navigate. Basically the only way you find out about services your family member maybe eligible for is through word of mouth which is extremely frustrating and distressing especially when you learn of a service that may have benefited the person you care for years too late to make any difference.⁴

Ms Anne-Marie MacArthur - carer for her elderly mother

Although services are available to carers trying to access those services is akin to being in an ever increasing maze with illegible signposts so that the carer never really knows where to go or in which direction to take. To add to this mix the carer, in this case myself, is physically exhausted and emotionally spent. Not a happy combination when trying to understand bureaucratic-speak.⁵

Ms Megan Major - provides care for her husband with Parkinson's Disease and Lewy Body Dementia following a stroke

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, Saw Saw Home and Community Care, Commonwealth Carer Respite Centre and Commonwealth Carer Resource Centre, Centrelink, plus GPs, physician and Neurologist.

4 See for example: Ms C Sebbens & Mr J Doyle, Submission No 615, p 2.

5 Ms A-M MacArthur, Submission No 871, p 1.

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'.⁶

- 6.11 Even for carers seeking to access a single type of service, such as respite, the challenges of navigating the maze are still immense as explained in the submission from the Macarthur Aged and Disability Forum:

There are so many services that have been set up for respite but all of them are run by different agencies and have different guidelines. In Macarthur no one service provides the range of respite options carers require. Funding has been made available however the competitive process has resulted in a confusing mish mash of services. Add to this the confusion caused with different guidelines for every State, Federal and State/Federal funded programs and people who work in the sector have difficulty making sense of it all, imagine a carer who is already stressed, tired and at their wits end finally deciding to get some respite and they are faced with the above - giving up is a very practical option.⁷

- 6.12 The problem of finding suitable services is particularly challenging for carers from culturally and linguistically diverse (CALD) backgrounds. The submission from the Centre for Cultural Research, University of Western Sydney, identified the need for 'cultural competence' to successfully navigate and negotiate the community care system:

The capacity of carers to find information, make contact and negotiate services was influenced by what we describe as 'cultural competence'... This encapsulates knowledge of how the system of community and social care works, including the culture of service delivery, language of care provision, and the power structures within and across both government and non-government organizations. The fact that many carers, particularly CALD carers, knocked at the wrong doors, did not know or use the 'right' language, and/or disclosed needs to the wrong person resulted in frustration and led to many participants taking on an excessive burden of care.⁸

6 Ms M Major, Submission No 1163, pp 1-2.

7 The Macarthur Aged and Disability Forum, Submission No 749, p 3. See also: Ms I Stockfeld, Transcript of Evidence, 12 August 2008, p 45.

8 Cardona B, Chalmers S, Neilson B, *Diverse Strategies for Diverse Carers, The Cultural context of Family Carers in NSW* (2006), p 52 (quoted in Submission No 758, p 1).

- 6.13 With such a splintered array of services, carers and care receivers may find that their individual circumstances do not allow them to be pigeonholed neatly into a single support category. This can create difficulties for carers navigating service options in determining, for example, whether the disability or mental health service system is responsible for supporting a care recipient with an intellectual disability and a mental illness.⁹
- 6.14 It is not only carers of people with multiple medical conditions who are faced with the challenges of accessing services across service systems. MND [Motor Neurone Disease] Australia, made the point that care provision for people with neurological conditions also often cross over a number of service systems over time:
- Care provision for people with MND crosses traditional departmental boundaries including; health, disability, aged, chronic disease and palliative care and involves a combination of local, non-government, state and federal funding bodies: it does not fit into a single established funding stream. People with rapidly progressive neurological disease and their carers struggle to navigate this complex system. ... Carers consistently report to MND Associations that they become lost in the service provision maze.¹⁰
- 6.15 To some extent the difficulty facing carers in navigating the complex community care services could be alleviated by the provision of a single access point for information and increased access to case management services. The Committee has acknowledged this, at least partial solution, in recommendations made earlier in the report. Another partial solution is to streamline community care services through improved coordination and structural reform and this is addressed later in this chapter.

Eligibility and Assessments for Accessing Services

- 6.16 A by-product of having many, fragmented and narrowly focussed services is that carers and care receivers are forced to undergo multiple eligibility assessments before they can access services. Carers WA described carers and care receivers experiencing 'assessment fatigue' from the onerous assessment requirements:

The amount of assessments for essentially the same illness/disability and [care] situation is a barrier in itself. Many

9 Ms S Crowe, Transcript of Evidence, 6 August 2008, p 80.

10 MND Australia, Submission No 568, p 9.

carers and care receivers have 'assessment fatigue' from the amount of hoops that they have to jump through - many just do not bother asking for help, knowing that they would have to go through the assessment process again. For some, it may be easier to stay home themselves and provide all of the care, rather than being assessed for a service that may not be available, or at a convenient time, or that is not meaningful for the care recipient.¹¹

- 6.17 While the needs of carers may be considered when the needs of care receivers are being assessed for services, some evidence to the Inquiry has argued that it is important for carers to also have the option of a full assessment of their needs in their own right. For example, Carers SA suggested:

... carers not only have the right to be assessed independently of the care recipient but also should have the results of that assessment taken into account for the provision of services. This would offer a protection to carers to have their needs taken into account at that time.¹²

- 6.18 The reality is that there is no nationally consistent approach to assessing the needs of carers, or even a common language for defining need. In recognition of this, the Department of Health and Ageing (DoHA) in conjunction with the state and territory governments and the community care sector is developing national assessment tools for assessing carer needs including the Australian Community Care Needs Assessment-Revised (ACCNA-R) and the called the Carer Eligibility and Needs Assessment-Revised (CENA-R). The CENA-R is intended to be used for DoHA's carer related programs and services.¹³ Each carer assessment will consider:

- the extent of care hours required to assist the care recipient;
- an estimate of carer health;

11 Carers WA, Submission No 566, p 17.

12 Carers SA, Submission No 684, p 20. See also: Ms S Ruggiero, Transcript of Evidence, 12 August 2008, p 12.

13 ACCNA-R is used to collect and record relevant information about the needs of both the care recipient and carer at a 'broad and shallow' level. It will be used within some of the Access Point Demonstration Projects. CENA-R is a carer-specific assessment which adds to the information about a carer to form a 'deep and narrow' view of the caring relationship and an assessment of a carer's support needs. See also: Australian Government, Department of Health and Ageing website, viewed 20 February 2009 at www.health.gov.au/internet/main/publishing.nsf/Content/ageing-twf-assessment-ncaf.htm.

- the development of a coping profile which notes challenges and supports for the carer, an evaluation of carer burden, and an assessment of carer mental health and well-being; and
- a screen of the physical capabilities of the carer to assess whether they themselves require supports and services.¹⁴

6.19 The Committee supports any initiative to minimise the bureaucratic burden placed on carers and welcomes the CENA-R initiative. The Committee believes that further development and application of the CENA-R should aim to fully utilise the CENA-R as a national assessment tool for carers across all Commonwealth, and state and territory government services and programs. The Committee, however, also recognises that it may be difficult to integrate CENA-R as an assessment tool with the eligibility requirements for payments delivered by Centrelink.

6.20 However, the possibilities of linking the CENA-R to the current development of a single assessment process for Carer Payment and Carer Allowance¹⁵ should be considered in terms of the Committee's previous recommendation in relation to the acceptance of recent supporting documents to verify claims for Care Payment and Carer Allowance.

Recommendation 29

6.21 **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 expand the nationally consistent assessment process based on the Carer Eligibility and Needs Assessment-Revised questionnaire.**

This will need to ensure the inclusion of carers accessing services offered through the Department of Families, Housing, Community Services and Indigenous Affairs and the state and territory governments.

14 Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109, p 50. See also: Australian Government, Department of Health and Ageing website, viewed 20 February 2009 at www.health.gov.au/communitycare_thewayforward.

15 Australian Government Departments, (FaHCSIA, DoHA & DVA), Submission No 1109, p 45.

- 6.22 The ultimate goal should be to reduce the requirement for carers and care receivers to undergo multiple assessments in order to access services within and across sectors.
- 6.23 Some evidence emphasised that carer assessments should take a ‘whole of family’ situational approach to take into account the needs of primary carers and secondary carers who may also support a care recipient.¹⁶ Whatever else, the eligibility criteria for services, funding and other supports needs to be flexible enough to accommodate the diversity of caring roles.¹⁷ The Committee was also reminded by the Disability Council of NSW that any carer assessment needs to be done on the basis that the care recipient also has their support needs assessed.¹⁸ In fact the needs of carers cannot be assessed without taking into account the needs of care receivers.

Community Care Services in Regional and Remote Locations

- 6.24 Evidence to the Inquiry indicates that carers living in regional and remote areas often face particular challenges accessing community care services. Services may simply not be available locally, forcing carers and care receivers to travel sometimes long distances.¹⁹ As Carers Australia explained:

Carers in these areas will often not have access to the internet, will need to travel long distances to access health professionals, information and support programs, will need to rely on other relatives or friends to care for other family members and their place of residence while they are travelling and will have additional costs associated with travelling. This has become particularly difficult with the increases in petrol prices.²⁰

- 6.25 In a specific example, the Horsham Family Advisory Committee, an advisory body to the Ballarat Health Services Psychiatric Service, pointed

16 Carers ACT, Submission No 702, p 22. See also: Carers SA, Submission No 684, p 20; Carers Australia Transcript of Evidence, 28 November 2008, pp 10-11, 15.

17 The Perth Carer Forum Group, Submission No 983, p 3.

18 Disability Council of NSW, Submission No 662, p 9.

19 See for example: Ms J Mort, Submission No 44, p 1; Mr M McDonald & Ms J McDonald, Submission No 589, pp 1-2; Mr C Kellett, Submission No 707, pp 1-3; Mr T Stroud, Transcript of Evidence, 12 August 2008, p 59; Ms R Warmington, Transcript of Evidence, 13 August 2009, pp 14-15; A Prof R Parker, Transcript of Evidence, 26 November 2008, p 4.

20 Carers Australia, Submission No 699, p 37.

out the challenges facing regional and remote area carers of those with a mental illness:

Mental health family and carers need to travel large distances to access specialised services in regional centres or cities and therefore face increased financial costs for travel. As well there is a lack of accessible public transport options in rural areas which adds to the family burden when an individual with [mental illness] becomes so unwell that they cease driving.²¹

- 6.26 Carers Australia suggested delivery of supports and services for carers living in regional and remote areas using a variety of means to suit individual requirements:

Carers in rural and remote areas of Australia need access to support programs, education and training, information and resources to be delivered by a medium that suits their individual needs and requirements. This could be through the internet, DVDs or in-home support by visiting service providers. It is absolutely critical that when addressing the needs of Australia's carers, the Committee has a particular focus on how best to meet the needs of those carers living outside metropolitan and large regional centres.²²

- 6.27 The Committee understands that providing any services in regional and remote areas can be difficult. Later in the chapter the Committee makes recommendations to address the shortages of health and community care services for carers generally. While recognising that these shortages are a national problem, the Committee encourages the Minister for Families, Housing, Community Housing and Indigenous Affairs and the Minister for Health and Ageing to consider the particular difficulties carers and care receivers face accessing services in regional and remote Australia. Later in the chapter, the Committee also examines the potential of individualised funding models to give carers and care receivers greater control over the services they receive. Potentially these models will allow carers in regional and remote areas to make maximum use of existing local resources and infrastructure.

21 The Horsham Family Advisory Committee (Victoria), Submission No 1108, p 5.

22 Carers Australia, Submission No 699, p 37.

Recommendation 30

- 6.28 **That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing address the shortages of health and community care services for people living in regional and remote locations.**

Community Care Services for Indigenous Carers

- 6.29 The Committee received limited evidence from or about Indigenous carers. The fact that Indigenous carers often do not self-identify as such because many see caring as a natural extension of family duty also reduces the likelihood of their seeking any assistance from community care services.²³ This issue of carers not identifying themselves as such is considered earlier in the report.
- 6.30 However, even when assistance is sought it appears that Indigenous carers face particular challenges in accessing appropriate community care services.²⁴ Evidence has emphasised that a mix of Indigenous specific services and culturally sensitive mainstream services for Indigenous carers and care receivers is important.²⁵ One Indigenous carer who did contribute to the Inquiry suggested that Indigenous carers and care receivers would make greater use of mainstream disability and aged care services if the services employed more Indigenous health workers.²⁶
- 6.31 Although it appears that even in urban areas, Indigenous people can face difficulties accessing services, these difficulties are likely to be magnified for Indigenous carers living in rural or remote areas. The evidence that has been put to the Committee paints a stark picture of the challenges:

Remote communities are difficult to service. They are reached usually by four-wheel drive or by air. The road option takes time, the air option is expensive. Most contact to the Carers NT by carers is through health centres and by telephone. The telephone system

23 Carers Australia, Submission No 699, p 34.

24 Queensland Government, Department of Premier and Cabinet, Submission No 1203, p 15; Ms I Sullivan, Transcript of Evidence, 6 August 2008, pp 41-42; A-Prof R Parker, Transcript of Evidence, 26 November 2008, p 4.

25 Ms J Tongs, Transcript of Evidence, 3 December 2008, p 5.

26 Name withheld, Submission No 1304, p 5. See also: Ms S Freeburn, Transcript of Evidence, 6 August 2008, p 5.

can be very problematic. Many carers have only limited access to a phone to make outgoing calls, and often, no access to incoming calls. There is usually only one solar powered public phone on a community often not in working condition.²⁷

- 6.32 However, the lack of definitive information on the specific needs of Indigenous carers poses a significant problem for those seeking to provide community care services that are adequate and culturally appropriate.²⁸ As explained by Carers Australia:

In the light of what is known, it is possible to conclude that Indigenous carers and the people they support are significantly worse off than the majority of caring families. However it is difficult to bring before the Committee precise evidence about the circumstances and needs of Indigenous carers. Caring has not been a specific focus of the considerable research and consultation on needs or the development of national strategies to improve health outcomes and address other aspects of disadvantage and discrimination. There is little documentation of the way in which caring is occurring within communities, who is caring, the resources and supports that people are drawing on, the needs of family members providing care or the extent to which carers and families have access to services.²⁹

- 6.33 The Committee is concerned about the lack of evidence to the Inquiry from Indigenous carers, but more so about the more general the lack of information about the profile and needs of Indigenous carers. The Committee believes that further research on the specific needs of Indigenous carers, particularly as these pertain to community care services is required.

Recommendation 31

- 6.34 **That the Minister for Families, Housing, Community Services and Indigenous Affairs fund research into the profiles and specific needs of Indigenous carers.**

27 Carers NT, Submission No 685, p 17. See also: Dr Z de Ishtar, Submission No 1279, pp 9-10.

28 See for example: Ms S Freeburn, Transcript of Evidence, 6 August 2008, p 5.

29 Carers Australia, Submission No 699, p 34.

Recommendation 32

- 6.35 **That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing examine the adequacy of culturally appropriate community care services funded by the Australian Government for Indigenous carers, particularly for those living in remote areas, with the intention of increasing the accessibility and availability of those services.**
- 6.36 This latter recommendation is a special case of the more general recommendations made later in this chapter. However, the Committee believes that the dearth of information on Indigenous carers, their needs and the services (or lack thereof) available for them warrants special attention.
- 6.37 The Committee would also like to see improved outcomes for Indigenous carers reflected in the Council of Australian Governments (COAG) National Indigenous Reform Agreement in the future.³⁰

Respite Care Services and In-Home Assistance

- 6.38 In evidence to the Inquiry, carers identified a range of services for carers as being either unavailable, not available to the extent required, too expensive or failing to meet the needs of the carer and/or the care receiver. The shortages of case management and advocacy services have already been discussed in earlier chapter 4. However, the two services that were repeatedly mentioned as being of critical importance for carers, and also in short supply, are respite care and in-home assistance.

Availability of Respite Care Services

- 6.39 Respite services are defined by the Australian Bureau of Statistics as formal respite care which allows carers time for other activities which may be tasks related to their caring role or engagement in other activities

30 Council of Australian Governments website, viewed 12 February 2009 at www.coag.gov.au/coag_meeting_outcomes/2008-11-29/index.cfm#indigenous.

related to the carer's own needs.³¹ There are various forms of respite, which includes in-home respite either in the carer's presence or absence, or residential respite where the care receiver is cared for away from the family home, either overnight or for a longer period.

- 6.40 Many carers have indicated that access to appropriate, affordable, timely and regularly planned respite, as well as emergency respite when required, is crucially important in providing carers with a degree of choice in relation to the caring role and the ability to balance caring with other aspects of their lives. Furthermore, access to adequate levels of respite care is critically important in order for many carers to continue in their caring role.³² Not surprisingly, the need for respite is greatest for carers with multiple care responsibilities or in circumstance where the intensity of the caring role is high.
- 6.41 The following accounts are typical of the experience shared by many carers, emphasising both the importance of respite to them and the difficulties that many face in accessing these services:

Ms Sharon Guest and Mr Stuart Neal – carers for their daughter mild to moderate hearing loss, autism, moderate to severe global developmental delay, and the rare and fatal illness Sanfilippo Syndrome

We had to phone up respite organisation after respite organisation, repeating *ad nauseam* our devastating situation, only to be channelled elsewhere or told there was nothing on offer.

It took hundreds of phone calls to be either told that no services are available or that we could be put on a waiting list but that this would probably take years to bear fruit. Commonly our calls weren't returned. We endured this for six months - and got nowhere. ... It also became abundantly clear that respite is very

31 Australian Bureau of Statistics, *A Profile of Carers in Australia* (2008), p 59.

32 See for example: Ms E Shields, Submission No 35, p 1; Mr R Morrison, Submission No 40, pp 1-2; Ms A Seales, Submission No 52, p 2; Ms B Fischer, Submission No 140, pp 1-2; Mr R Elliot, Submission No 253, p 2; Ms J Bellamy, Submission No 337, p 3; Mr F Hambridge, Submission No 355, p 1; Mr R Anderson, Submission No 360, p 2; Name withheld, Submission No 512, pp 3-4; Ms L Baker, Submission No 807, p 5; Name withheld, Submission No 904, pp 1-3; Ms J Parrott, Submission No 916, p 2; Ms E Walker, Submission No 973, pp 2-3; Mr D Gill, Submission No 1136, p 2; Ms M Major, Submission No 1163, pp 1-3; Ms M Mockler, Submission No 1253, p 1; Ms S Crowe, Transcript of Evidence, 6 August 2008, p 81; Ms S Mina, Transcript of Evidence, 12 August 2008, pp 48-49; Ms A Stacey, Transcript of Evidence, 13 August 2008, p 21; Ms J Hope, Transcript of Evidence, 9 October 2008, pp 2-5; Ms K Pritchard, Transcript of Evidence, 28 November 2008, pp 1-2.

limited. Any respite - should you get it - is short term. Our situation was not short term. It was going to get progressively worse. We were horrified to discover that there is nothing available of any consequence for families such as us who are simply left to cope on their own.³³

Ms Glenis Hawthorne - long term carer with her husband for their daughter with intellectual and physical disabilities

Insufficient respite services are made available. In our caring role with our child, we have provided care for all but three nights in twenty seven years. There appears to be endless 'packages' to support the aged but very little available to support families who are caring for children with disabilities. What happens when you wear out the Carers and they are no longer able to fulfil their caring duties? Give us all a break before that happens!

Ms Oi yun Leongue - mother of four children, two of whom have autism

... there is a shortage of respite houses in my local area. The respite house my daughter currently attends is always unavailable for weekend bookings and we are always on the accommodation waiting list. As the Mother of two autistic children, my husband and I need a break. We are only given seven hours of respite per week and the years and years of stress and anxiety have taken a toll on our health. If this level of stress and worry continues, I fear we will soon reach our breaking point. We urgently need help now, in the form of more respite.³⁴

- 6.42 Many service providers also frequently reported that the supply of respite services is not keeping pace with the demand. As the Australian Red Cross explained:

Carers manage until they cannot manage. We cannot afford to then say, 'Oh, but we haven't got the services today or tomorrow; how does next week or next month suit you?' because carers are at breaking point and they are not very good at putting their hands up and asking for help. We take six of those calls a day, and it used to take us one or two calls to put respite in place for them. It can now take us 10 calls to put respite in place for them. It is getting harder to find appropriate services that can cope with the

33 Ms S Guest & Mr S Neal, Submission No 872, pp 4-5.

34 Ms Oi Yun Leongue, Submission No 1029, p 1.

numbers that are coming through and the complexity that is coming through.³⁵

- 6.43 The shortfall in respite services appears to be national and across the various respite service options. Ms Margaret Fisk, the National Coordinator of the Defence Special Needs Support Group, which provides supports to Defence Force families caring for a family member with a disability or special needs, provided a national perspective:

Respite waiting lists in many areas are closed or are extremely long with agencies reporting that they not taking any more referrals. For example in Townsville, the majority of respite is geared towards those caring for the elderly so if you relocate to Townsville and you care for a severely disabled member of your family, it is highly unlikely that you will receive any respite support for quite some time (other than short term or emergency offered by the CCRC) [Commonwealth Carer Respite Centre]. Similar situations occur in Canberra, areas of Melbourne, Sydney and Brisbane.³⁶

- 6.44 The situation in Western Australia seems similar:

Carers Advisory Council members have had opportunities to consult with carers in both metropolitan Perth and regional Western Australia. ... Without exception the lack of respite services and the lack of respite options is raised in these forums. In particular, carers comment that emergency, overnight, short and long stay options are often not available unless booked well in advance.³⁷

35 Ms L Crumlin, Transcript of Evidence, 23 July 2008, p 50. See also: Disability Assistance for Shoalhaven, Submission No 256, p 2; Neuro Muscular Alliance Tasmania, Submission No 569, p 2; Carer Support Network of SA, Submission No 675, p 2; YNH Services Inc and Yarrawonga Mulwala Carers Support Group, Submission No 678, p 3; National Seniors Australia, Submission No 686, p 6; Child and Adolescent Mental Health Services Eastern Health (VIC), Submission No 762, pp 1-3; ANGLICARE Sydney, Submission No 769, pp 25-30; Queensland Government, Department of Premier and Cabinet, Submission No 1203, pp 17-18.

36 Defence Special Needs Support Group, Submission No 695, p 3. See also: Carers Australia, Submission No 699, p 27.

37 The Hon Sue Ellery MLC, Minister for Child Protection; Communities; Women's Interests; Seniors and Volunteering, Submission No 761, p 4.

Affordability of Respite

6.45 Services like respite need not only to be available, but also to be affordable.³⁸ The cost of respite care services, particularly overnight respite, can be beyond some carers. Many carers on low incomes find the costs associated with accessing respite and other support services unfair and unrealistic. The priority for one carer was:

Realistic and affordable respite that Carers can afford to pay. They get paid a pittance for doing the same job, so can hardly be expected to afford the ridiculous rates charged.³⁹

6.46 A typical situation was described by Ms Beverley Schulz who cares for her 22 year old daughter:

Carers need more respite hours/nights per year to be made available, at less dollars per night. At present we pay \$25.00 p/night so have had to cut back on how often we access respite ... We simply can't afford to pay \$25 for night stays.⁴⁰

6.47 Another carer, Ms Helen White who provides care for her 17 year old son with significant intellectual disability and autism also called for more affordable respite options, recounting:

I had one respite provider price out from 3 pm Friday until 9 am Monday at over \$3000! Clearly my son will not be going there!⁴¹

6.48 The impact of the cost residential aged care respite on a household income was also raised by Mr Peter Aris, a Tasmanian carer, who cares for his wife:

We are allowed at present nine weeks a year for respite. How can we possibly afford respite when the full pension is taken off the patient when they go into respite care? Most carers cannot afford to take respite. No wonder their health deteriorates. I believe carers should have a higher financial status than that of pensioners due to their greatly increased costs.⁴²

38 See for example: Ms D Lamond, Submission No 46, p 4; Ms S Jakanski, Submission No 446, p 3; Carers SA, Submission No 684, p 22; National Seniors Australia, Submission No 686, p 6; MS Society of Tasmania, Submission No 747, p 3; St George Migrant Resource Centre, Submission No 746, p 37; Ms N Brown, Submission No 951, p 12; Ms R M Painter, Submission No 1143, p 2; Ms S Gambin, Transcript of Evidence, 12 August 2008, p 72.

39 Ms D Edwards, Submission No 159, p 5.

40 Ms B Schulz, Submission No 286, p 1.

41 Ms H White, Submission No 72, p 1.

42 Mr P Aris, Transcript of Evidence, 9 October 2008, p 23.

Respite Needs to be Flexible

6.49 For carers to have a degree of choice in their own lives, respite care services should be flexible enough to meet the needs of both carer and carer receiver. However, there appears to be limited opportunity to tailor respite services to the needs of the carer, the care receiver or both.⁴³ Some carers have observed that the respite services offered appear to suit the funding priorities and organisational structures of the respite providers rather than the needs of their clients.⁴⁴ As acknowledged by the Western Australian Government, providing respite should require flexibility and consideration of diverse client needs:

The very great challenge for respite is to be sufficiently flexible and responsive to meet the individual physical, emotional, financial and cultural needs of carers and the persons they care for within a wide range of changing economic, social and environmental situations and circumstances.⁴⁵

6.50 A number of submissions identified the need for the timing and duration of respite to be more responsive to the needs of carers, for example, to be provided overnight, on weekends or during school holidays.⁴⁶ While some carers emphasised the importance to them of overnight or residential respite to allow them time away from their caring role⁴⁷, others expressed the preference for respite to be provided in the home setting.⁴⁸

6.51 Yet others have suggested that more respite be provided in such a way that it allows the carer, the care receiver and their families to spend quality time together in a supportive setting. For example, Mr Frank Poole, who provides care for his wife with severe physical disabilities suggested:

43 See for example: Ms M Bartlett, Submission No 58, p 1; Ms H White, Submission No 72, pp 1-2; Name withheld, Submission No 559, p 3.

44 See for example: Ms J Mann, Submission No 192, p 2; Ms C Franklin, Transcript of Evidence, 23 July 2008, p 45; Ms M Sweeney, Transcript of Evidence, 6 August 2008, p 89; Ms L Light, Transcript of Evidence, 6 August 2008, p 92; Mr T Stroud, Transcript of Evidence, 12 August 2008, p 49.

45 WA Government, Department for Communities, Submission No 761, p 4.

46 See for example: Ms H White, Submission No 72, p 1; Ms S Bailey, Submission No 370, p 2; Ms S Gibb, Submission No 1135, p 3; Ms J Waymouth, Transcript of Evidence, 23 July 2008, p 55; Mr W Haynes, Transcript of Evidence, 6 August 2008, p 65.

47 See for example: Ms E Shields, Submission No 35, p 1; Mr R Morrison, Submission No 40, p 2; Ms S Menegatos, Submission No 63, p 3; Ms J Whitehill, Submission No 65, p 2.

48 See for example: Ms H Davies, Submission No 28, p 1; Ms M Huddleston, Submission No 37, p 1; Ms P Haldane, Submission No 41, p 2; Ms D Osborne, Submission No 43, p 2; Ms J D'Angelo, Submission No 60, p 2; Ms A Bellchambers, Submission No 349, p 2.

It would be nice if facilities existed for the carer and the cared for to be able to have a weeks respite together where there was someone to do the housework and cooking and give the carer a break at least from these chores but still not feel guilty about leaving a loved one in someone else's care.⁴⁹

- 6.52 Evidence suggests that accessing respite is particularly challenging for carers of people with dual diagnosis or high level and/or complex care needs.⁵⁰ For example, Ms Careen Dew, a young carer who assists in providing care for a younger brother with multiple disabilities, explained that her family did not meet eligibility criteria for many respite services as his case was classified as a 'medical' problem rather than as a 'disability'. As a result, Ms Dew noted:

Over the past nine years we have only had respite during the night twice, so it is something that we definitely need. For some reason we have to apply every six months with these respite agencies and we are still being refused and rejected just for little amounts of time, four hours here and there.⁵¹

- 6.53 In the case of younger care receivers (i.e. under 65 years) with high care needs, another criticism repeatedly made is that often the only respite option available is in an aged care facility – an option resisted by many. As explained by Ms Glynis Thyer, who provided care for her husband (now deceased) with multiple sclerosis:

To place a person in their 20's, 30's 40's or 50's in an Aged Care Facility for respite is incredibly difficult for their Carer. The person in need often fights/opposes the idea of going in to respite, especially in to a place that is not suitable to their needs. This puts added emotional pressure on the Carer.⁵²

- 6.54 Carers reported not using respite services because the only option available to them was a placement in an aged care facility:

I would love there to be more respite care accommodation for my husband that is not an aged care facility. It is not fair to think that

49 Mr F Poole, Submission No 67, p 1. See also: Ms C Polak & Mr W Polak, Submission No 902, p 4; Ms B Cardona, Transcript of Evidence, 6 August 2008, p 17; Ms S King, Transcript of Evidence, 6 August 2008, p 34.

50 See for example: Ms A Bellchambers, Submission No 349, p 2; Ms S Scrivener & Mr D Scrivener, Submission No 1113, p 4; Ms S Crowe, Transcript of Evidence, 6 August 2008, pp 80, 84.

51 Ms C Dew, Transcript of Evidence, 6 August 2008, pp 45, 50.

52 Ms G Thyer, Submission No 679, p 2. See also: Ms E Ingram, Submission No 242, p 1.

when I need a rest I have to put him in an old person's home so rather than do that I try to carry on the way things are now and not have a rest.⁵³

- 6.55 The need for respite to take into consideration cultural issues was also raised in evidence.⁵⁴ At a hearing in Sydney, Ms Beatriz Cardona provided the Committee with a number of situations where community care services had failed to accommodate specific cultural or religious requirements. The following example relates to an elderly carer from Macedonia who refused the offer of respite on the basis that she could not accompany her daughter who has a disability:

This example highlights how concepts such as carer and respite resonate differently among different communities and individuals. The label 'carer' is often difficult to translate because it is partly embedded in a diversity of family rules and caring relationships. Moreover, the notion of respite for this family meant that both daughter and carer needed the respite, which did not equate with separation and nor did it equate with the notion of her daughter being a burden. The service was unable to meet the reality of this family's specific needs. We also have the issue of quality of service available. Part of the reason the mother wanted to go with her daughter was because of her concern that her daughter may not be adequately cared for.⁵⁵

- 6.56 As mentioned earlier, respite options in regional or remote areas are often more limited than in urban areas, meaning that facilities are some distance away, and then are sometimes still unsuitable. Carers NT explained the situation for people living in remote communities in the Northern Territory:

... until recently the only respite that could be provided was to fly the care recipient into Darwin and place her/him into a nursing home. Carers, the wider community and the care recipient resisted this option ...⁵⁶

53 Ms C Bazeley, Submission No 333, p 1.

54 See for example: Australian-Polish Community Services, Submission No 654, pp 1-2; Ethnic Disability Advocacy Centre, Submission No 787, p 17; Ms B Cardona, Transcript of Evidence, 6 August 2008, pp 17-18.

55 Ms B Cardona, Transcript of Evidence, 6 August 2008, p 17.

56 Carers NT, Submission No 685, p 17. Carers NT notes that local and culturally appropriate programs are beginning to be offered on some NT Indigenous communities e.g. the 'Troopy Program' described on p 22 of the submission.

- 6.57 The unsuitability of this respite option for Indigenous care receivers and carers living in remote locations was further explained by Carers NT:

Indigenous culture is absolutely associated with the land that is owned by the various groups. This connection inculcates the very essence of the people who believe that they belong to the land, rather than the land belonging to them. This connection is such that care recipients do not want to be taken from their land to attend hospital or access respite outside of their country. Older people are terrified that if they are placed in a nursing home in one of the urban settings, to provide their carer with respite, they will die away from their land. For example, out of 57 carers registered on one community only 5 care recipients agreed to access respite by coming into Darwin.⁵⁷

The Urgent Need for More Respite

- 6.58 The overwhelming evidence received by the Committee indicates that respite services are an essential support for sustaining carers in their caring role. The unmet need for respite services results in increased levels of stress for carers, their families and those being cared for, reduced economic and social participation and reduced levels of health and wellbeing.
- 6.59 The evidence suggests that current respite services are unable to meet the need from carers for both emergency and short term respite, as well as for planned, regular respite services. Access to those services that are available is often prioritised on the basis of the degree of urgency or severity of the caring and family situation. What alarmed the Committee however, is that this approach places carers and their families in the invidious situation of needing to present the worst possible picture of their circumstances. One carer explained an assessment process to access respite services used by the NSW Government in the following terms:

It would also be less stressful if families did not have to 'beg' each year for these services, currently families are assessed each year and given points ... more points are scored if your marriage is breaking down, more points if you are depressed, more points if a family member is dying!⁵⁸

57 Carers NT, Submission No 685, p 21.

58 Ms F Galbraith, Submission No 1089, p 3. See also: Family Advocacy, Submission No 768, p 3; Mr C Rook, Transcript of Evidence, 23 July 2008, p 42.

- 6.60 The Committee sees the shortage of local, timely, and appropriate respite services as one of the key issues facing carers. At the same time, services also need to be flexible, culturally appropriate, easily accessible and affordable. Many of the criticisms of respite services are manifestations of the fundamental problem that there are simply not enough respite services to meet demand. Ultimately, there needs to be more respite services which, in turn, requires a financial commitment from the Australian Government.

Recommendation 33

- 6.61 **Recognising the ageing demographic of the carer population and the increased longevity of many care receivers, that the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing increase capital and recurrent funding for respite care services funded by the Australian Government as a matter of urgency to more closely match demand across the country.**

Particular attention should be paid to improving the:

- **availability and accessibility;**
- **affordability;**
- **responsiveness to the needs of both carer and care receiver of respite services; and**
- **responsiveness to the needs of carers and care receivers in living regional, rural and remote areas.**

- 6.62 The Committee is conscious that state, territory and local governments also fund and administer respite services and that any increase in services by the Australian Government should not be offset by a diminution in services by other jurisdictions. Indeed the review process being undertaken by the Council of Australian Governments (COAG) discussed in chapter 1 and below will be an ideal mechanism to ensure that the provision of respite is increased without cost shifting or another round of the 'blame game' between governments.

In-Home Assistance for Carers

- 6.63 Many carers have identified in-home assistance or support as being highly valued.⁵⁹ The main forms of in-home assistance include:
- domestic assistance (e.g. assistance with household jobs such as laundry and ironing etc);
 - assistance with personal care for the care receiver (e.g. assistance with bathing, showering and toileting etc); and
 - assistance with general care and maintenance of the home and yard (e.g. changing light bulbs, lawn mowing and gardening etc)
- 6.64 Currently these types of in-home assistance are provided for people with a disability, for the frail aged and for their carers through the Home and Community Care (HACC) program. As noted earlier in the report, HACC is jointly funded by the Australian, state and territory governments, although the states and territories manage the day to day administration of the program. For the frail aged and their carers, in-home assistance is also available through the Australian Government's Aged Care Packages⁶⁰, and for veterans and their carers, though the Veterans' Home Care program.
- 6.65 As with respite services, evidence suggests that the demand for in-home assistance for carers exceeds supply, and that the levels of assistance when available are not adequate.⁶¹ An older carer, Mr Noel Sweeney, saw his priority need as a carer as:

Access to reliable home help. Some charities can help, but how clean could your house be with a half - hour's cleaning a fortnight?

It would be a total change to my life if there were more realistic help forthcoming. I eagerly look forward to stepping outside my

59 See for example: Ms P Haldane, Submission No 41, p 2; Ms L Bristow, Submission No 64, p 2; Mr T Vanderputt, Submission No 106, p 1; Ms S Vote, Submission No 134, p 1; Mr W Woolhouse, Submission No 201, p 1; Mr A Corbett, Submission No 251, p 1; Ms S Durkin, Submission No 329, p 2; Ms P Birch, Submission No 345, p 1; Ms E Forrester, Submission No 361, p 1; Ms A Esendag, Submission No 362, pp 1-2; Ms B McMahon, Submission No 705, p 1; Ms F Tountzis, Submission No 1140, p 2.

60 Community Aged Care Package (CACP); Extended Aged Care at Home (EACH); and Extended Aged Care at Home Dementia (EACHD).

61 See for example: Name withheld, Submission No 31, p 1; Ms B Borg, Submission No 76, p 2; Ms H Stone, Submission No 94, p 2; Ms S Vote, Submission No 134, p 1; Mr N Kaye, Submission No 143, p 2; Ms C Hunt, Submission No 271, p 2; Ms A Micallef, Submission No 272, p 2; Mr P Zachariadis, Submission No 279, p 2.

front gate one day, knowing that I don't have to do everything on my own.⁶²

- 6.66 Similarly, Mr Frank Poole, another older carer, suggested that elderly carers would benefit from:

More assistance to carers in the house cleaning, ironing, vacuuming side would be appreciated, as many carers are themselves elderly and in my case with having to support my wife and do these chores my own back is beginning to feel the strain and I am concerned that a time will be reached when my back will not allow me to care for my wife. Anything that can stall that off will be an advantage to all.⁶³

- 6.67 A carer with multiple caring responsibilities, Ms Diana Lamond, stressed the importance of adequate levels of domestic assistance and requested:

More domestic assistance. Queensland Health send a person to clean on a fortnightly basis - 2 hours. Running a home with two disabled men is exhausting. There is always housework, ironing, washing, shopping.⁶⁴

- 6.68 Carers of young children have also commented on the value of in-home help. For example, Ms Trish Welstead, the mother of two daughters one of whom has Cystic Fibrosis, explained that practical domestic assistance would be extremely helpful to her and her family, especially during periods when her daughter was hospitalised:

When Zoe goes into hospital, she stays for two weeks at a time minimum. I stay with her for most of that time and my husband stays for some days. By the time I get back home, I have a whole house to re-organise and try and catch up with washing, cleaning the toilet, bathroom, etc. My husband works long hours and only just manages to get our other daughter organised and off to school every day ... If it weren't for my parents who are in their late 60s and late 70s, I literally would not survive these times.⁶⁵

- 6.69 However, not all applications for domestic assistance are responded to positively. Ms Carmel Flavell, a sole parent carer, who has four children, described her attempt to access domestic assistance:
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62 Mr N Sweeney, Submission No 133, p 1.

63 Mr F Poole, Submission No 67, p 1.

64 Ms D Lamond, Submission No 46, p 4.

65 Ms T Welstead, Submission No 616, p 1. See also: Ms L Leggo, Submission No 773, p 3; Ms C Paisley-Dew, Submission No 826, p 5.

In order to lessen some of the demands made upon me I referred myself to Home Care of NSW hoping to get some domestic help. I was hoping Home Care could assist me even though I am working ... As for the domestic help, I have been waiting for 12 months now and have heard nothing.⁶⁶

- 6.70 Assistance with personal care, while principally a service for the care receiver, also reduces the care load for the carer. A large number of carers commented on the value to them of this type of support. As with domestic assistance however, evidence suggests that demand for this type of assistance exceeds supply and that where available, the level of assistance is inadequate.⁶⁷
- 6.71 Carers also frequently commented on the need for greater assistance with home maintenance, including yard maintenance. Some carers indicated that they were unable to undertake routine home maintenance tasks due to the physical demands or the need for skills and technical 'know how'. Often with limited financial resources, carers indicated that they could not afford to cover the sometimes significant costs associated with engaging tradesmen.⁶⁸
- 6.72 From the evidence it appears that in-home assistance and supports are highly valued by the carer, and particularly by older carers, carers of young children and adults with high care needs and by those with multiple caring responsibilities. However, like many of the other services for carers, the levels of help appear generally inadequate across the nation. To provide carers with the assistance they need to provide sustainable care the Committee concludes that the availability and levels of in-home assistance and supports also need to be increased to more closely meet demand. While the bulk of in-home assistance funded by the Australian Government is provided by DoHA through the HACC program, FaHCSIA, as the other major funder of carer services, should also consider increasing funding for in-home assistance.

66 Ms C Flavell, Submission No 186, p 3.

67 See for example: Name withheld, Submission No 22.1, p 1; Name withheld, Submission No 31, p 1.

68 See for example: Ms B Elliot, Submission No 36, p 1; Mr R Spring, Submission No 49, p 1; Ms M Weller, Submission No 53, p 2; Ms M Bartlett, Submission No 58, p 2; Ms M Trehwella, Submission No 154, p 2; Ms S Smith, Submission No 901, p 1; Name withheld, Submission No 1295, pp 12-13.

Recommendation 34

- 6.73 **That the Minister for Health and Ageing and the Minister for Families, Housing, Community Services and Indigenous Affairs increase funding for in-home assistance for carers in order to more closely meet demand.**

Waiting Lists as a Response to the Lack of Community Care Services

- 6.74 As noted earlier the evidence to the Inquiry indicates a national shortage of community based services for carers (and care receivers) generally, frequently resulting lengthy waiting to access services.⁶⁹ Moreover, some carers suspect that the widespread use of waiting lists to access services is a *de facto* mechanism to manage demand where it exceeds supply.⁷⁰ Tellingly, one carer even reported on the use of a waiting list to get onto a waiting list!⁷¹ Another carer explained how after three years on a waiting list for residential age care for her elderly mother, she had been advised that a place was available, one year after her mother had died!⁷²
- 6.75 Ms Maria Antonas, a carer in Western Australia, summed up the delay she experienced in getting assistance from an Extended Aged Care at Home (EACH) Package by saying:

I get nothing from any care-organisation other than 'You're on the list!!!' I need help with every aspect of caring. To be put on the 'EACH' Waiting List for over nine-months is unjust.⁷³

- 6.76 In practice, waiting lists mean that services are effectively not available for many in need as noted by Ms Sue Harmer, a carer living in Victoria:

I am submitting to the inquiry because of the complete lack of services available on the ground. There are services on paper, but if you attempt to get services for either yourself, as carer, or for

69 See for example: Ms D McIntyre, Submission No 187, p 1; Name withheld, Submission No 512, p 3; Ms C Phillips, Submission No 755, p 2; Ms K Boyd, Submission No 783, p 2; Ms L Coyte, Submission No 868, p 1; Ms S Gibb, Submission No 1135, p 3; Name withheld, Submission No 1248, p 2.

70 Mr M Beardmore & Ms J Beardmore, Submission No 59, p 2.

71 Ms S Harmer, Submission No 430, p 2.

72 Ms N O'Boyle, Submission No 327, p 2.

73 Ms M Antonas, Submission No 299, p 1. See also: Ms M Alford, Transcript of Evidence, 13 August 2008, p 4.

person/s with a disability, you will find that you will get the run around, and or placed on the waiting list, to which there is a list for everything ...⁷⁴

- 6.77 Another carer, who wrote about the use of waiting lists and the difficulties facing carers who attempt to access residential respite services in Victoria, even on an occasional basis, expressed the dilemma confronting many carers, in the following terms:

The wait lists in Victoria are a joke. It has taken over two years on a waiting list for us to access occasional residential respite with Yooralla for Nicholas. Let me put this clearly: the need is huge and the services paltry. Many people will struggle for years without help.⁷⁵

- 6.78 As explained by Ms Linda Glover at a hearing in Hobart, service providers struggling to meet demand are forced to resort to waiting lists:

We do have waiting lists. We have waiting lists in our aged-care programs. We have waiting lists of people wanting Community Aged Care Packages of care and a HACC program for school holiday respite for young people with disabilities.⁷⁶

- 6.79 The use of waiting lists by over stretched service providers may also discourage carers from seeking access to services. In its submission, Carers ACT observed:

Waiting lists are also a disincentive for many Carers. Anecdotal evidence received by Carers ACT often indicates that carers may be told there is a waiting list and give up without gaining a place on the list. Some carers are not told that the waiting list may be prioritized and that they will never reach a high-enough priority to actually receive services.⁷⁷

- 6.80 Carers are not only faced with waiting lists to access services, they are also faced at times with waiting lists to access assessments to determine eligibility for services. One carer explained the situation she and her sister were experiencing as they waited to access an aged care assessment to determine eligibility for residential respite :

Our second difficulty is with the ACAT [Aged Care Assessment Team] assessment system. Understandably, the assessment must

74 Ms S Harmer, Submission No 430, p 1.

75 Ms C Pereira, Submission No 880, p 3.

76 Ms L Glover, Transcript of Evidence, 9 October 2008, p 46.

77 Carers ACT, Submission No 702, p 24.

be carried out each year in order to determine that receivers are receiving their entitlements, or conversely are not receiving things they are not entitled to. However, it would appear that the department providing this service is seriously understaffed/overworked. We had our last assessment in March 2007. I telephoned to arrange this year's assessment in March or April of this year [2008], and we still have not been given an appointment ... Without a current ACAT assessment, we are unable to access respite care ...⁷⁸

- 6.81 To some extent the use of waiting lists is a legitimate mechanism for prudently managing and controlling supply of a service. However, excessively long waiting lists are an indicator of unmet demand. The consistent complaints from carers about ubiquitous and long waiting lists for services is yet more evidence that support for carers is inadequate.

Options for Reform

- 6.82 The Committee appreciates that it is neither desirable nor economically feasible for all care to be provided by the taxpayer. Indeed many carers have indicated that they do not want to give up their caring role, rather they want to continue to provide care with adequate support. This chapter has attempted to demonstrate the shortfall in services for carers from their perspective and in their own words. On this evidence, carers deserve better support from governments than they are currently receiving. Moreover, the shortfall in services is likely to grow as the population in need of assistance grows, and as government policies and the community continue to expect community living for care receivers.
- 6.83 This will challenge all governments to reduce the unmet demand for carer support services. It will involve more efficient use of existing resources and, as the Committee has already recommended, increased expenditure on a number of fronts. There will also be pressures to examine new ways of funding services.

Better Coordination

- 6.84 Carers have long drawn attention to the lack of coordination between

78 Ms S Scrivener & Mr D Scrivener, Submission No 1113, p 3.

government services, as Ms Cynthia Perieira, a Victorian carer, expressed colloquially:

At the moment the system that exists in Victoria is a dog's breakfast, complex beyond belief and what you access depends on luck, not need in many instances. ... Stop the buck passing between state and federal governments. Work together to achieve the above. Carers do not care who does what. We just want it to happen.⁷⁹

6.85 Australian governments are now collectively acknowledging the need to improve delivery of community based aged, disability and mental health services. As mentioned earlier in this report, COAG agreed in October 2008 on the need to reform the roles and responsibilities between the Commonwealth, States and Territories for:

- community and residential care services for aged people;
- community and residential care for people with disabilities; and
- community care and support services for people with mental illness.

6.86 COAG has advised that the anticipated reforms promise seamless service systems to better meet the needs of care receivers and carers on a national basis.⁸⁰ The Committee looks forward to the outcomes of COAG's deliberations with interest, particularly if they do actually lead to greater coordination between the governments.

Innovative Funding Models

6.87 However, many carers and organisations are arguing that better coordination within the existing system is not enough. One alternative model for allocating services to carers is via 'individualised funding'. Supporters of individualised funding (also known as self-managed funding, consumer directed care, self governed support or self directed support) packages argue that this funding model provides far greater control to carers and care receivers over the services they receive.⁸¹

79 Ms C Perieira, Submission No 880, p 2. See also: Ms K Tucker, Submission No 321, p 2; Ms M Bohan, Transcript of Evidence, 12 August 2008, p 34; Ms N Sheldon, Transcript of Evidence, 12 August 2008, p 86.

80 Council of Australian Governments website, COAG Communiqué 2 October 2008, pp 3-4, viewed 18 February 2009 at www.coag.gov.au/coag_meeting_outcomes/2008-10-02/index.cfm#aged.

81 See for example: Carer Support and Respite Centre Carer Group, Submission No 585, p 7; Julia Farr Association, Submission No 689, p 3; Mr C Dalton, Submission No 972, pp 2-3; Exhibit No

- 6.88 There are variations of the individualised funding model in operation in a number of jurisdictions, both at the state and territory level in Australia and internationally – most notably in Europe, North America and the United Kingdom.⁸²
- 6.89 In essence, a care receiver is allocated a personal budget after their needs have been assessed. The care receiver can then use that budget to purchase the support services they want – which could include paying a full time carer. The principle is to put people at the centre of assessing their own needs and tailoring support to meet their needs.⁸³
- 6.90 In the United Kingdom, once allocated a budget, a care receiver then devises a plan indicating how they will spend that money on their support (a ‘support plan’). A care manager has to approve the support plan, but within broad parameters, a care receiver can determine who, how and what services they want. Care receivers can take varying degrees of personal responsibility for devising their support plan and then purchasing the services. Receivers can use a family member or pay a service broker for assistance or, alternatively, trusts, legal guardians or carer organisations can act on a funding recipient’s behalf.⁸⁴ Importantly, regardless of the delegation of decision making, a recipient’s budget can only be spent on services to support that person.⁸⁵
- 6.91 A similar funding model based on a voucher rather than cash system is proposed by Carers WA for carers:
- A nationally funded program should be introduced to promote respite as a health promotion initiative and develop a highly flexible system via a voucher system which can provide carers with options to choose and design their own forms of respite.⁸⁶
- 6.92 The Julia Farr Association sees many potential benefits arising from individualised funding as it offers:

18, *Consumer-Directed care: A way to empower consumers*, Alzheimer’s Australia Paper No 11, May 2007; Ms B Epstein-Frisch, Transcript of Evidence, 12 August 2008, pp 90-91.

82 The individual funding model can be used more widely for delivering government programs. For example, the Australian Government uses case based funding for employment services.

83 United Kingdom, Northwest Commissioning Roadmap website, viewed 17 February 2009 at www.northwestroadmap.org.uk/index.php.

84 In Canada ‘microboards’ - small groups of committed family and friends that join together with a person with disability to create a small non-profit society – commonly perform equivalent roles.

85 United Kingdom, In Control website, viewed 17 February 2009 at www.in-control.org.uk.

86 Carers WA, Submission No 566, p 6.

... no greater cost to government and in some instances it produces savings; much greater satisfaction among people accessing it, so people and their families tend to report greater satisfaction with the arrangements because of that sense of control and the sense of being able to orchestrate something that feels more relevant; and also the evidence suggests that people are getting more from the arrangement in terms of actual things that go on in their lives – you know, in terms of material support and also social inclusion in the life of the wider community.⁸⁷

- 6.93 However, there are risks with individualised funding. It may place more responsibility on care receivers and carers than they wish to take on. Thus any system should allow care receivers to choose the level of self sufficiency they are comfortable with or allow carers or guardians to choose on their behalf. There is also the risk that governments may abrogate their responsibilities to people who have received a support payment. For service providers and agencies it would also mean a move away from contestable and tender driven funding of service delivery to an income model driven directly by consumer demand.
- 6.94 There are degrees of individualised funding built in to some of the existing aged care and disability programs. For example, funding allocated through Australian Government Aged Care Packages (CACP, EACH, EACHD) can be used to purchase services to assist older, frail people with complex care needs. Furthermore, brokerage funds are available through the Commonwealth Respite and Carelink Centres to support individual carers.⁸⁸ Also, a number of state and territory governments in Australia use individualised funding in one form or another and to varying degrees in order to improve the flexibility of disability services. For example, Disability ACT and Disability Services Victoria offer forms of ‘Individual Support Packages’ to those with disability⁸⁹.
- 6.95 The various forms and hybrids of individualised funding models are all attempts to provide care receivers (and indirectly carers) with greater

87 Julia Farr Association, Transcript of Evidence, 13 August 2008, p 91. See also: Julia Farr Association, Submission No 689, p 3; Ms F Anderson, Submission No 979, p 6; Ms L Kelly, Submission No 1173, p 2; Mr T Stroud, Transcript of Evidence, 12 August 2008, p 49; Brotherhood of St Laurence, Transcript of Evidence, 12 August 2008, pp 68-69.

88 Exhibit No 18, *Consumer-Directed care: A way to empower consumers*, Alzheimer’s Australia Paper No 11, May 2007, pp 8-9.

89 For the ACT www.dhcs.act.gov.au/disability_act/policies and for Victoria www.dhs.vic.gov.au/disability/supports_for_people/individualised_support_packages2, viewed 18 February 2009.

control over the services they receive. The Committee sees merit in the Australian Government exploring whether carers should receive cash or vouchers to manage the services they receive – for example respite and in-home assistance. In addition to empowering carers and increasing transparency in relation to expenditure, another possible advantage of the individualised funding model is that by determining the type and mix of services, demand from carers themselves can influence service availability, sustainability and mix at the local level.

- 6.96 One introductory step for individualised funding could be to transfer into the hands of carers the brokerage funds available through the National Respite for Carers Program currently provided to carers through the Commonwealth Respite and Carelink Centres in order that carers could determine how the money is spent.⁹⁰ Through pilot studies, different models of individualised funding for carers could be tested and any difficulties identified and ironed out. There may need to be quality assurance and accountability mechanisms put in place and certainly provisions would be needed for carers who do not want the added responsibility of managing their own support budget.

Recommendation 35

- 6.97 **That the Minister for Families, Housing, Community Services and Indigenous Affairs and the Minister for Health and Ageing undertake pilot studies to test the potential for the Australian Government's funding for carer respite and in-home assistance to be re-allocated directly to carers through 'individualised funding programs' (also known as 'consumer directed care' and 'self managed funding').**
- 6.98 Ultimately individualised funding programs, with appropriate safeguards, could be used to pool funding across governments for care receivers and carers.

The Need for Improved Data and Forward Planning

- 6.99 This chapter has used anecdotal, albeit consistent, comments of carers and carer organisations to illustrate the extent of unmet need for carer support services. The Committee has sought empirical data from a range of

90 Exhibit No 18, *Consumer-Directed care: A way to empower consumers*, Alzheimer's Australia Paper No 11, May 2007, p 9.

sources, including from the key Australian Government departments responsible for supporting carers and care receivers, on the capacity of the community services sector to meet the demand for services.⁹¹ While there is data on program clients, the data cannot be used to determine the total number of carers seeking access to services or identify those carers that do not use formal services.

- 6.100 There are significant gaps in the data available on carer numbers, profile, patterns of service use and needs. For example, the most reliable data on carers comes from the Australian Bureau of Statistics Survey of Disability, Ageing and Carers. That survey distinguishes between 'carers' and 'primary carers' but only collects detailed data on primary carers. The same survey does not classify carers under the age of 15 as primary carers and excludes data on intermittent or short term carers such as those caring for people with a mental illness.⁹²
- 6.101 The Committee is pleased to note, however, that the Australian Institute of Health and Welfare is examining the feasibility and utility of a National Carers Data Repository.⁹³ The Committee is aware of the challenges of calculating reliably the number of carers, their profile and the totality of support services they use. However, without comprehensive, consistent and integrated data it remains difficult to plan future services and, more importantly, accurately determine the levels of unmet need.

Recommendation 36

- 6.102 **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 collect nationally consistent data to more accurately determine the number of carers, their profile and the level of unmet need for community based carer support services.**

91 Australian Government Departments (FaHCSIA, DoHA & DVA) Submission No 1109.1, pp 1-3; Australian Government Departments (FaHCSIA, DoHA & DVA) Submission No 1109.2, pp 1-2; Australian Government Departments (FaHCSIA, DoHA and DVA), Transcript of Evidence, 28 November 2008, pp 20-21.

92 Australian Institute of Health and Welfare, Submission No 1033, p 19. See also: Ms E Fudge, Transcript of Evidence, 13 August 2008, pp 51-52.

93 Australian Institute of Health and Welfare, Submission No 1033, p 19.

The Community Care Workforce

- 6.103 As noted in the submission from Carers Victoria, the development of a robust and skilled workforce is fundamental to addressing shortfalls in community care services:

The ability to sustain and expand community care services remains dependent on the recruitment and retention of an adequate, skilled and robust workforce. Recruitment and retention issues are apparent in the current community care service system. This may be attributed, in part, to low pay, lack of career path, and the isolated nature of the work. The ageing of the current community care workforce is a further concern. Shortages in the availability of community care workers will become an increasing problem as the workforce shrinks and competition for workers increases. It is likely to become increasingly difficult, and more expensive, for community care providers to recruit the workforce they need to meet growing demand.⁹⁴

- 6.104 However, evidence from carers and organisations alike indicates that there is a chronic shortage of adequately trained and skilled paid support workers and other community care workers and very high levels of staff turnover.⁹⁵ The Carer Support Network of South Australia stated:

Carers report that the current system of paid in-home care workers is unreliable and of low quality. We hear incidents on a regular basis of the care worker being late or not turning up, not having the skill set required to provide good care, or not having an appropriate attitude towards the Care Recipient. Under these circumstances it becomes impossible for the Carer to be able to depend on reliable care and plan for their future participation in the workforce.⁹⁶

- 6.105 Many carers have also indicated that current services relying on paid support workers are unreliable and the quality of some services is questionable, as these excerpts from the evidence illustrate.

94 Carers Victoria, Submission No 652, p 33.

95 See for example: Ms A Rea, Submission No 14, p 1; Mr K Hewitt, Submission No 328, p 1; Name withheld, Submission No 1038, p 4; Ms N Sheldon, Transcript of Evidence, 12 August 2008, p 86.

96 Carers Support Network of SA, Submission No 675, p 8.

Mr C Howe and Mrs C Howe - parents of three daughters, including one with a physical disability

We have trained these workers in the needs of our daughter and organised a nursing visit to complete a catheterisation and tube feed while we are out. Whilst this respite service is so very necessary we are often extremely frustrated at the lack of reliability of these workers due to illness, studies, or moving on to permanent, better paid jobs. This frustration is amplified (for us and our children) when we have to meet and train new support workers on a regular basis. Support workers are paid a relatively low wage and often use this work as a 'second job' or a way of earning money while they are at Uni. Support workers are not seen as 'valuable' in our society today and yet for Carers their support worker can be their one lifeline to a regular break from Caring.⁹⁷

Ms Pamela Bianchi - provides care for her son with Duchenne Muscular Dystrophy

We have experienced first hand the incompetent, inexperienced, the uncaring and at times apathetic manner of some direct [paid] care workers. Each agency must be more accountable for the persons in its employ. One comment we received indirectly when we did make a complaint about a [paid] carer that was sent to us was that basically 'do we want a service or not?' Many carers, especially older people do not make complaints as they fear that they will be abandoned by the service provider or victimised.⁹⁸

Ms Jayne Lehmann - mother of three daughters, including one with intellectual and physical disabilities

We have had care workers who have seen Sarah have a seizure and then will not come back again as they are too scared. Funny, I thought that was what they were being employed to do - care for our daughter and her associated problems.

The turnover of [paid] carers is enormous, which makes it stressful in itself. You already feel like you are living in a gold fish bowl let alone having to have a steady stream of new people corning through your home. Most of the carers are not skilled enough to

97 Mr C Howe & Mr C Howe, Submission No 1193, p 2.

98 Ms P Bianchi, Submission No 809, p 3.

deliver the care we require and I have to do extra training and emotional support of them! Some agencies employ a lot of students or people looking to provide care for a short period of time, before moving onto something else. This increases the turnover issues.⁹⁹

- 6.106 To address these issues, carers and organisations have suggested better training, remuneration, employment conditions, and career progression for paid support workers and workers in the community care sector.¹⁰⁰
- 6.107 It is anticipated that an increase in community care workforce training places supported through the Australian Government's Productivity Places National Partnership with state and territory governments will alleviate shortages of trained workers to some degree.¹⁰¹ However, the Committee considers that an increase in training opportunities will also need to be complemented by initiatives to encourage greater workforce retention. This is likely to require greater recognition of the workers in the community care sector through improved remuneration and employment conditions, and options for career advancement.

Recommendation 37

- 6.108 **That the Minister for Education, Employment and Workplace Relations examine options to build capacity in the community care workforce, particularly initiatives to encourage retention of trained workers in the sector.**

Availability of Services for Care Receivers

- 6.109 An analysis of the services available for care receivers, as distinct from carers, is outside the scope of this report. However, the Committee's

⁹⁹ Ms J Lehmann, Submission No 1258, p 1.

¹⁰⁰ See for example: Ms L Walmsley, Submission No 353, p 3; Ms M Van de Vusse, Submission No 443, p 2; Ms P Bodegraven, Submission No 509, p 2; Huntingdon's Victoria, Submission No 670.2, pp 3-4; Young People in Nursing Homes National Alliance, Submission No 764, p 4; Ms E Scott, Submission No 839, p 7; Mr C Dalton, Submission No 972, p 2; Ms T Clough, Transcript of Evidence, 23 July 2008, p 44.

¹⁰¹ Australian Government, Department of Education, Employment and Workplace Relations website, viewed 16 March 2009 at www.deewr.gov.au/Skills/ProductivityPlaces/Pages/default.aspx.

evidence suggests that services for care receivers are also extremely important for carers. As one carer commented in the closing remarks of her submission:

... the best way to support carers is to address all needs of the young and aged with a disability ...¹⁰²

6.110 The Australian Institute on Health and Welfare explains this in the following terms:

Services for care receivers also assist carers. In other words, supporting carers involves providing services to address a carer's own needs but also ensuring that the wider service 'system' works for carers in relation to the people they assist.¹⁰³

6.111 In addition to targeted services for care receivers, care receivers and consequently carers are also affected by the availability and access to the 'wider service system' including areas such as transport, housing, employment and education. For example, many carers have commented on the lack of suitable public or community transport options to enable care receivers to attend school, day care, employment, medical or other appointments.¹⁰⁴ Carers themselves are often required to provide transport to address this shortfall.

6.112 The lack of affordable and suitable housing has also frequently been raised in evidence. While housing affordability is a national problem, particularly for people on low incomes, evidence indicates that people with a disability or mental illness carry a comparatively high risk of becoming homeless. In particular carers have emphasised that shortages of suitable public housing have resulted in carers and their families being placed on lengthy waiting lists for accommodation.¹⁰⁵ The Committee understands that the Australian Government has implemented a number

102 Ms D Beccari, Submission No 102, p 2.

103 Australian Institute of Health and Welfare, Submission No 1033, p 2. See also: Mental Health Council of Australia, Submission No 682, p 8.

104 See for example: Ms A Bannigan, Submission No 706, pp 1-2; Ms K McCann, Submission No 751, p 4; Ms S Walden, Submission No 900, pp 3, 4; Ms G Hunter, Submission No 1090, p 1; Ms R Houston, Submission No 1148, p 2; Ms L Light, Transcript of Evidence, 6 August 2008, p 92.

105 See for example: Name withheld, Submission No 22, p 1; Ms K Tucker, Submission No 321, p 2; Ms N Green, Submission No 831, p 2; Ms J Walsh, Transcript of Evidence, 13 August 2008, p 26; Ms B Tickner, Transcript of Evidence, 20 August 2008, p 89.

of major initiatives that are intended to alleviate shortages of affordable housing and address issues associated with homelessness.¹⁰⁶

- 6.113 In part, the demand for respite services discussed earlier in the chapter is linked to the shortfall in services for care receivers. For example, some carers gain a degree of respite if those they care for can obtain employment or can participate in community access services (predominantly day activity programs).¹⁰⁷ However, in June 2007, the Australian Institute of Health and Welfare reported significant levels of unmet demand for community access services for people with disabilities, particularly day activity services.¹⁰⁸
- 6.114 Under the National Disability Agreement, the Australian Government has responsibility for employment services for people with a disability. To ensure public accountability in this regard, data on the labour force participation rate for people with a disability aged 15-64 years will be published annually by the COAG Reform Council. In addition, strategies to address the barriers faced by people with disability and/or mental illness that make it harder for them to gain and keep work are being developed through the National Mental Health and Disability Employment Strategy described earlier in the report.¹⁰⁹ The Committee looks forward to viewing the Strategy when it is released later in 2009.
- 6.115 The plight of many older carers is particularly distressing as they struggle to find adequate support for those for whom they are caring. Many, who have often spent decades caring for sons and daughters with disabilities, are worried about the lack of alternative long-term care for their adult children.¹¹⁰ A submission from a carer, drawing on her own experience,

106 Australian Government, Department of Families, Housing, Community Services and Indigenous Affairs website; viewed 16 March 2009 at www.facs.gov.au/internet/facsinternet.nsf/housing/nav.htm.

107 See for example: Ms M Edwards, Submission No 30, p 1; Ms B Hunt, Submission No 348, p 1; Ms F Anderson, Submission No 979, p 6.

108 Australian Institute of Health and Welfare, *Current and future demand for specialist disability services* (2007), Disability services, Cat no DIS50, pp 77-78. See also: Australian Government Departments (FaHCSIA, DoHA & DVA), Submission No 1109.2, p 4.

109 Australian Government, Department of Education, Employment and Workplace Relations, viewed 30 January 2009 at www.workplace.gov.au/NR/rdonlyres/37D9990A-A765-4580-BF02-5850A37AA77E/0/StrategypaperFinalRTF.rtf.

110 See for example: Ms J Johnson, Submission No 16, p 1; Ms J Poat & Mr W McGhie, Submission No 24, pp 1-4; Ms E Shields, Submission No 35, p 2; Mr R Morrison, Submission No 40, p 2; Ms A Ferguson, Submission No 45, p 1; Ms E Smalley, Submission No 105, p 1; Ms D Sullivan, Submission No 126, p 5; Ms E Shutt & Mr S Shutt, Submission No 310, p 2; Ms K Tucker, Submission No 321, p 2; Ms J Bellamy, Submission No 337, pp 1; Ms R May, Submission 351, p 1; Ms M-J Galiazzo, Submission No 359, pp 1-2; Ms L Wetherill, Submission No 1025, p 2; Ms S

questioned the preparedness of governments to deal with the ageing profile of carers:

The government has no idea what is going to hit it in the next decade. There is an epidemic of children like Nicholas who survived a traumatic birth and multiple disabilities and will be becoming adults without a future. Who will look after him when we cannot? In the past such children would not have survived. Why did the doctors save him when the services that he will desperately need in the future are not there? ... I would like an answer to this question in particular.¹¹¹

- 6.116 The lack of appropriate, alternative accommodation and care options for care receivers is one of the most pressing concerns for carers.¹¹² It leaves carers with little or no choice but to continue caring, often well past retirement age as explained below:

The one measure that must be put in place with urgency is the measure that will eventually see us relieved of our caring role. The best support that a carer can have is to know that theirs is a finite tour of duty and that one day in the future they will no longer be required to care. This is because a strategy has been mapped and is being implemented to ensure that adults with a dependent disability, who are citizens with equal rights in this great and wealthy nation of ours, will be taken care of by the community. They will be taken care of, not when their parents have died or are about to do so, but when their parents have reached retirement age. It seems to me to be totally inequitable that those parents who have had the most difficult experience of parenthood are the same ones who may never have a retirement. Lifelong carers such as myself are desperate to see progress in the provision of supported accommodation, but we see only rhetoric, debate and promises.¹¹³

Schreiber, Transcript of Evidence, 13 August 2008, pp 22-23; Mr H Thomas, Transcript of Evidence, 13 August, pp 30-31.

111 Ms C Pereira, Submission No 880, p 3.

112 See for example: Nardy House, Submission No 17, p 3; Mr R Morrison, Submission No 40, p 2; Mr T Sexton & Ms R Sexton, Submission No 136, p 4; Ms P Bristow, Submission No 546, p 1; Ms J Barnes, Submission No 623, p 2; Ms M Turner, Submission No 715, p 1; Ms B Liskus, Submission No 720, p 1; Mr P Rankin, Submission No 759, p 5; Ms M Rouse, Submission No 1142, p 3; Ms R A Houston, Submission No 1148, p 2; Ms L Downing, Ms S La Fontaine and Ms C Straw, Transcript of Evidence, 26 November 2008, pp 10-15.

113 Ms E Shields, Submission No 35, p 2. See also: ARAFMI QLD, Submission No 574, p 5; Mr K Matthias & Ms M Matthias Submission No 710, p 1; Ms M Ross, Submission No 713, p 1;

- 6.117 It is clearly undesirable to have carers forced to continue in their role because there is no other option. In desperation, carers may resort to refusing to collect care receivers from short term residential respite care, which is distressing and undignified for all:

The truth is that most families with adult sons and daughters who want to transition out of the care role have just one option. That is to force governments hand by relinquishing the cared for person into respite care services so that government will make a place available within the supported accommodation program.¹¹⁴

- 6.118 At the other end of the age scale, carers are also burdened and worried by the lack of early intervention services for young children with disability as Ms Faye Galbraith, a mother of two sons, both with 'a severe, complex disability', raised:

I have often said that the most difficult aspect of having children with a disability is not so much having a child with a disability as such but having to fight to the point of exhaustion and despair for services and supports which should be freely offered by Government to parents and carers in our situation. I have heard many people say this. By no means is life easy but it is made a whole lot harder by bureaucratic red tape and the simple absence of funding in the area of disability.¹¹⁵

- 6.119 In Hobart, Ms Sue Hodgson told the Committee that the current expectation that carers will care until they die or until they become incapacitated themselves, should be replaced with an expectation, supported by policies and services and that people with a disability will be able to live separately from their families once they reach adulthood.¹¹⁶ The Committee can only concur.

- 6.120 Members were reminded again and again during the Inquiry that the needs of carers and those they care for are inextricably bound. In a more practical sense, the levels of support for carers are directly affected by the levels of support for care receivers and vice versa. While the Committee makes recommendations in this report to improve the lives of carers, the need to improve support for care receivers is just as pressing.

114 National Carers Coalition, Submission No 571, p 34.

115 Ms F Galbraith, Submission No 1089, p 1. See also: Ms K Tucker, Submission No 321, p 1; Ms M Anderson, Submission No 331, p 1; Ms A-M Newbold, Transcript of Evidence, 12 August 2008, p 98.

116 Ms S Hodgson, Transcript of Evidence, 9 October 2008, p 24. See also: Ms S Crowe, Transcript of Evidence, 6 August 2008, p 81.

