



LEGISLATIVE ASSEMBLY FOR
THE AUSTRALIAN CAPITAL TERRITORY

Respite Care Services in the ACT

**Report No. 5 of the
Standing Committee on Health
and Community Care
March 2000**

Resolution of Appointment

The following general purpose standing committees be established to inquire into and report on matters referred to it by the Assembly or, after the Assembly's endorsement, matters that are considered by the committee to be of concern to the community.

... a Standing Committee on Health and Community Care to examine matters related to health and community care policy, planning and purchasing acute, community health and population health services, hospitals and any other related matter.

Legislative Assembly for the ACT, *Minutes of Proceedings*, (1998), No. 2, 28 April 1998, pp 15 and 16, amended 25 November 1999.

Terms of Reference

The committee has the responsibility of inquiring into and reporting on the provision of respite care services in the ACT, with particular reference to:

- (1) the needs of people and their carers;
- (2) the availability of services;
- (3) the extent of unmet need;
- (4) the co-ordination of services, the continuity of care and the choice and type of services (including post-school options); and
- (5) any other related matter.

Committee Membership

Mr Bill Wood, MLA (Chairman)

Mr Harold Hird, MLA (Deputy Chairman)

Mr Dave Rugendyke, MLA

Secretary: Ms Beth Irvin (until 1 April 1999)

Mr David Skinner (from 12 April 1999)

Administrative Officers: Mrs Kim Blackburn

Mrs Judy Moutia

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Summary of issues

The following issues were raised in the course of the inquiry:

- there is not a sufficient volume of respite available across the board – most services are operating at capacity;
- respite care workers are often not adequately trained or skilled to deal with the specific needs of some client groups such as people with dementia, people with behavioural difficulties, people with autism and people with ADHD;
- there is insufficient dementia-specific respite available;
- there are inadequate services available for people with high/complex care needs;
- eligibility criteria for services have, in some cases, excluded people with demonstrable need from accessing respite services;
- assessment processes do not focus enough attention on the needs of carers;
- effective case management frameworks and the continuity of care provisions appear to be lacking;
- there is considerable under-funding at both the ACT and federal levels for respite services and more generally for the aged and disability services sector;
- due to gaps in service provision some people are in a position where they have to pay for very expensive private support packages, making access to services unaffordable;
- there is little trust or faith in the ability of some service providers to provide effective respite (particularly to people with challenging behaviours) because primary carers are often required to be on stand-by to ‘rescue the service’;
- there are no adequate respite services for children with autism - parents of children with autism experienced difficulty in accessing even generic respite services;
- some stakeholders argued that there may be too many service agencies providing respite care and that the duplication of infrastructure and other costs was an inefficient use of resources;
- there are very few support options for young people with disabilities after they leave school; and
- those receiving respite care much prefer to see a familiar face and are disconcerted at the too frequent appearance of new people.

Summary of recommendations

Recommendation 1

The committee recommends that in consultation the Government undertake a comprehensive empirical study to determine both the current and future levels of need (both met and unmet) for respite care in the ACT community.

Recommendation 2

The committee recommends that the Government develop uniform reporting mechanisms for service brokers, social workers, caseworkers and other service providers to give feedback about unmet need.

Recommendation 3

The committee recommends that the Government accepts that a substantial increase in respite care is of the highest priority.

Recommendation 4

The committee recommends that the Government continue making representations to the Commonwealth about the significant under-funding of disability services.

Recommendation 5

The committee recommends that the ACT Government match any federal funding provided to meet the respite care needs of people on a dollar for dollar basis.

Recommendation 6

The committee recommends that the Government consult with relevant stakeholders and investigate how to best recognise (through assessment processes and eligibility criteria) the needs of carers and the level of burden experienced by carers.

Recommendation 7

The committee recommends that the specific needs of young carers are taken into account in the assessment process, and that provisions are made to ensure that young carers are not performing roles which jeopardise their physical and psychological health.

Recommendation 8

The committee recommends that the Government examine the *Carer's Recognition Act* introduced in the United Kingdom, and evaluates the appropriateness of similar legislation for the ACT.

Recommendation 9

As part of a comprehensive study into unmet need for respite care, the committee recommends the unmet needs of people with dementia be accurately assessed and that an appropriate methodology is utilised to achieve this purpose.

Recommendation 10

The committee recommends that the ACT Government make representations to the Commonwealth about the need to fund a public communication program aimed at removing the stigma associated with dementia.

Recommendation 11

The committee recommends that the Government consult with relevant stakeholder groups to develop improved assessment processes to accurately determine the levels of need experienced by people with dementia and their carers.

Recommendation 12

The committee recommends that the Government make representations to the Federal Government about the need to apply additional funds to the aged care services sector.

Recommendation 13

The committee recommends that the ACT Government work together with service providers, the Commonwealth and other relevant agencies to develop uniform assessment processes that minimise the incidence of multiple assessments by different agencies.

Recommendation 14

The committee recommends that the Government ensure that eligibility requirements and assessment processes are underpinned by broad whole-of-life analyses which accurately reflect the needs of carers, care recipients and other family members.

Recommendation 15

The committee recommends that the Government ensure that people undertaking assessments for respite care have the necessary skills and training to accurately identify need levels and service requirements for particular caring situations.

Recommendation 16

The committee recommends that the Government seek the cooperation of respite services to provide on an ongoing basis up-to-date information to the Intake and Assessment Unit and service brokers about service capacity.

Recommendation 17

The committee recommends that the Government develop a strategic planning framework for respite care services.

Recommendation 18

The committee recommends that the Government facilitate a working group made up of industry/community representatives, carers, care recipients, the medical profession and government officials to review the future directions that respite care policy should take.

Recommendation 19

The committee recommends that the Government develop a strategic planning framework aimed at improving the range and quality of training opportunities for respite workers.

Recommendation 20

The committee recommends that the Government's contracting and purchasing arrangements encourage tenderers, where possible, to work with existing service providers to reduce the duplication of administrative and building infrastructure.

Recommendation 21

The committee recommends that surveys be carried out to assess quality standards and client satisfaction levels across service providers.

CHAPTER 1. BACKGROUND AND OVERVIEW

1.1. For some time now, Members of the Legislative Assembly have been made acutely aware of the intricate array of difficult issues confronting principal carers and people with special care needs. Members are often approached by carers and families lamenting the gaps in service provision and the inadequate quality of care available for people with disabilities or mental health problems, the aged and infirm, children with behavioural difficulties, and people requiring family support.

1.2. One area that has been the source of concern for industry professionals, principal carers and the cared-for alike, is the quality and quantity of respite care services.

1.3. On 10 December 1998, the Standing Committee on Health and Community Care informed the Assembly that it would inquire into and report on respite care services in the ACT. The committee sought public input to the inquiry and received 23 submissions from stakeholders. A list of submissions is in Appendix A. Public hearings were held on Wednesday 16 June and Monday 16 August 1999 with the committee taking evidence from 8 organisations. A list of witnesses appears in Appendix B.

1.4. The committee considers that respite care is a crucial support service for carers, allowing them to take temporary leave of their often unceasing and demanding responsibilities. The committee also recognises the many benefits of effective respite for care recipients.

1.5. The most compelling theme to emerge in the course of the inquiry was the pervasive unmet need for respite services in the ACT community. This was articulated by stakeholders in terms of the quality of currently available services and the limited quantity of care.

1.6. The committee was not sufficiently resourced to undertake an empirical investigation into the extent of unmet need in the ACT. However, the range, volume and quality of anecdotal evidence indicate that a study of this type is clearly warranted. With an accurate picture of the scope of current and future unmet need in-hand, the Government will be well placed to better target resources and develop a coherent and strategic approach to planning respite care services.

1.7. Numerous stakeholders advised the committee that inadequate provision of respite care services not only has deleterious effects on carers, clients and families but will also necessitate considerable spending in the future on crisis and long-term care.

1.8. In the committee's view, providing comprehensive and effective respite care services is sound public policy in terms of meeting the social needs of the community and in terms of good economic management of the health sector. It is a case of spending money now to save money in the future.

1.9. With the ageing population of the ACT growing faster than anywhere else in Australia, the need for respite care will only increase in coming years and the committee considers that appropriate planning and funding are essential if the ACT is to provide effective respite care into the future.

1.10. The committee sees that the main value in this report is that it has been able to bring together the views of stakeholders, reflecting the gaps in service provision in terms of both the quality and quantity of care for various client groups. It has also been able to report on the many ‘on-the-ground’ problems encountered by carers, care recipients and their families. It is a starting point from which the Government, service providers and client groups should be able to come together to discuss and debate the required policy directions for providing effective respite care.

Structure of report

1.11. This report is divided into 4 chapters.

1.12. A brief introduction to respite care and an examination of the elements of effective care and the nature of need is provided in Chapter 2.

1.13. The committee found that there are a range of respite needs which are common to many care situations. At the same time, it was evident that some people’s needs were quite specific to their particular situations. In the course of the committee’s inquiry, compelling anecdotal evidence was presented suggesting that the provision of respite care in the ACT is not meeting current levels of need because services are either not available or services offered are not of sufficient calibre to satisfy the demands of users. These issues are discussed in Chapter 3.

1.14. The committee received significant evidence indicating that much could be done to improve the coordination and integration of respite care services between agencies and that effective case management practices and planning frameworks are lacking in many areas. These issues are examined in Chapter 4.

1.15. An outline of available services and previous funding allocations based on ACT and Federal Government submissions is provided as an attachment (Attachment A).

CHAPTER 2. INTRODUCTION

What is respite care?

2.1. People with disabilities, frail older people, families at risk, children with behavioural difficulties, and people with a mental illness often require extensive assistance to achieve quality of life.

2.2. As the ACT Government advised the committee:

People with a disability, people with a mental illness and older people are entitled to expect the same opportunities and meaningful life activities as all citizens. These activities generally include, education, employment, recreation, access to community and opportunities for participation and involvement with other people. To access these opportunities and life experiences, people with a disability, those with a mental illness and older people will sometimes require additional services and/or support¹.

2.3. More often than not, caring and support roles are carried out by friends and families of the people being cared for. The Carers Association of the ACT advised the committee that 74 per cent of community care for frail aged people and people with a disability is carried out by families and carers ². Further, Australian Bureau of Statistics figures show that there are an estimated 10,800 principle carers over 15 years of age in the ACT, 7,100 of these live in the same household as the person being cared for³. This effort represents a massive economic and social contribution and without it, the health budget and the quality of life for many Canberrans would be severely affected.

2.4. Respite care is a type of short-term care provided to people with special care needs, in order that, among other things, primary carers are able to temporarily relieve the stress of their caring role. In its submission, the Commonwealth Department of Veteran's Affairs described respite care as, 'relief for a carer who has responsibility for a person requiring ongoing care, attention or support, or relief for those people who care for themselves'⁴. The committee heard that this type of care is provided with the intention that the carer will resume their caring role after an episode of respite ends⁵.

2.5. Depending on the needs of particular carers and care recipients, respite care can be provided for just a few hours, days or even weeks.

2.6. The ACT Government advised the committee that respite care services support the specific needs of clients by offering the care in a variety of settings. In its submission the Government outlined the following types of service:

¹ Submission 12, p 3.

² Submission 10, p 2.

³ ABS (1993) 'Disability, Ageing and Carers, Summary of Findings, ACT' cited in Submission 12, p 3.

⁴ Submission 14, p 1.

⁵ Submission 18, p 2.

Day and community access programs

Provide carer respite through creating opportunities for the person with support needs to participate in structured activity programs outside their homes, including the opportunity to socialise and thereby reduce isolation.

In-home respite

The person being cared for remains in their home and the caring role, or some aspect of it, is substituted by a provider. This enables the carer to attend to their own needs, commitments and aspirations, while minimising disruption to the day-to-day life of the person receiving the care.

Centre-based respite

Gives the carer respite by providing temporary, alternative supported accommodation for the person with support needs. The person who has support needs moves into a supported accommodation environment (typically a nursing home, hostel, or other residential facility) for a defined period.

Substitute care

Provides respite for carers of children with a disability. This can only be accessed for planned respite, and not for crisis or emergency respite. Children may either be cared for in the home of a host family, or be placed in a residential facility for the defined and planned period.

Recreational respite

The purpose is to provide recreational support to people with disabilities, but it is accessed on the basis of the respite needs of carers. The aim is to develop individualised care, in which activities undertaken reflect not only the person's disability, but also to account for their age, gender and personal preferences⁶.

Basic elements of effective service

2.7. Research conducted by the Carers Association of Australia indicates that respite care is highly valued among carers. This research also shows that carers want to be consulted about the types of respite that are available and that carers want services to be responsive to their needs⁷. Care recipients also have an important stake in consultations about their respite care needs.

2.8. Following on from this, responsiveness is perhaps the most important aspect of devising and providing respite care services. Funding structures, assessment processes, case management frameworks and frontline services cannot be designed in isolation from the end users.

2.9. Throughout the course of the inquiry, several common themes emerged from stakeholders about what constitutes effective respite care in terms of both the

⁶ Submission 12, p 16.

⁷ Submission 23, p 3.

necessary qualities and quantity of care. The committee has attempted to distil from the evidence some of the main elements considered necessary for providing effective respite care services.

Flexibility and customisation

2.10. Due to the variety of needs of care recipients and carers, it is not surprising that many stakeholders cited flexibility as an important element of respite service provision. Services need to be scalable and adaptable with solutions designed around the basic needs of carers and care recipients, not the other way around. This requires consultation and a commitment from service providers and funding bodies to demonstrate responsiveness and the capacity to customise many areas of service delivery.

2.11. The elements of flexibility and customisation are supported in ACT Government policy. In its submission the Government advised that committee that:

In keeping with best practice the majority of newly developed respite care services funded through HACC [Home and Community Care] and DSP [Disability Support Program] are home and community based. The policy emphasis also is on increasingly meeting individual needs through individually-focused activities, rather than in group activities which do not provide as much opportunity for people to receive personal attention and to be involved in positive developmental activities of their choice⁸.

2.12. This approach recognises that the needs of particular caring situations are often vastly different in each case. To this end, it is necessary that services are devised and implemented with particular clients in mind, requiring effective case management frameworks. Despite the Government's emphasis on individually focused respite, the committee notes that the majority of respite care provided in the ACT is still centre-based, largely as a result of the imperative to provide as much respite to people as possible with limited funds⁹.

2.13. One important element of flexibility cited by stakeholders was the idea that respite care services should be able to adjust to the changing needs of carers and care recipients. As carers and care recipients grow older, as their family situations change or as other situational factors change, so too do their respite care needs. Effective respite services must have capacity to adapt to these changes. It is also important that people seeking respite for the first time or seeking a change in the level of respite are properly facilitated by agencies.

2.14. Effective case management, with the capacity to provide ongoing assessments of the particular needs of clients, is imperative in any attempt to provide the necessary flexibility that respite care services require. This is explored in more detail in Chapter 4.

⁸ Submission 12, p 4.

⁹ *ibid*

Wide availability

2.15. One of the issues raised repeatedly by stakeholders was that there must be wide availability of services. That is, when people seek respite care services, there must be the capacity for providers to deliver them. This is primarily a measure of the quantity of care available to meet the needs of the community and is tied to government funding levels.

2.16. In keeping with the principle of flexibility outlined above, services must be made available on an adaptable and responsive basis. The value of respite care is significantly diminished if services are not available when a carer (and/or care recipient) requires a break. ACROD ACT argued that, ‘services should be available at any time of the day or night throughout each day of the year (including weekends and public holidays)¹⁰’.

2.17. Similarly, Marymead advised the committee that:

...one of the things about having respite is having it at the time of the day at the hour which is most useful to the rest of the family and if it is not at the time useful to the family then what is the point of taking it¹¹.

Integration

2.18. The committee notes that respite care is just one element of care, in what should be a comprehensive and coordinated approach to service delivery. It is important that respite care is properly integrated into other elements of care. As People First ACT argued in its submission:

Respite care should compliment the provision of other services such as accommodation, community access, employment, education and housing. It should not be provided as a “stand alone” service replacing other services because there is no other more appropriate service available. It should not be provided in an ad hoc way when people... are in a crisis situation¹².

2.19. Effective integration between the different agencies providing respite services, allowing for seamless service delivery, is also an important element of effective care for care recipients and carers. This is discussed further in chapter 4.

Wide accessibility

2.20. Effective respite services should be easily accessible for the people using them. This requires that services are conveniently located and/or capable of being provided in any location. ACROD ACT advised the committee that conveniently located services are particularly important where the carer is required to transport the person to and from the respite care facility or agency¹³.

¹⁰ Submission 18, p 5.

¹¹ Transcript, 16 June 1999, uncorrected proof, p 15.

¹² Submission 20, p 2.

¹³ Submission 18, p 6.

2.21. Where clients cannot access the services in their immediate region, Community Connections argued that transportation should be provided to overcome the barriers imposed by distance¹⁴.

2.22. The committee also considers that services need to be accessible to the wide range of clients groups and individuals that require some level of respite care. To this end, it is crucial that eligibility criteria do not have the effect of allowing people with demonstrable need to fall through the gaps.

Affordability

2.23. Effective respite care services must be affordable to those who use them. ACROD ACT noted in its submission that:

Few people are able to afford full payment for services received hence the heavy reliance on government funding support to fund agencies in order to subsidise services¹⁵.

2.24. This is particularly an issue for people with high support needs and for families with more than one person with a disability (often due genetically based diseases). In this regard ACROD ACT noted that:

Many families are unable to afford appropriate respite support due to the already high costs incurred for special equipment (eg wheelchairs) supplies (eg incontinence pads) and clothing (eg orthopaedic shoes).

Where respite care requires one on one carer support the additional costs borne by the family to pay for two people (person with disability plus carer) to enjoy entertainment eg pictures, often precludes such activities taking place¹⁶.

2.25. The committee was advised that the expense of caring for a person with high support needs can lead to financial difficulties for families and sometimes primary carers must give up their employment to take on the caring role¹⁷.

2.26. One point raised in several submissions was that effective respite has the ability to avert the breakdown in families due to the stresses of the caring role. It was argued that by preventing this breakdown, not only is a social benefit exacted but also the cost of providing expensive long-term accommodation and care is foregone, fulfilling an economic imperative¹⁸. In the committee's view, providing the funding to enable affordable respite care is both economically sensible and socially responsible.

¹⁴ Submission 4, p 1.

¹⁵ Submission 18, p 6.

¹⁶ Submission 18, p 5.

¹⁷ Submission 6, p 5.

¹⁸ *ibid*.

Trustworthiness

2.27. Stakeholders cited trust as being an extremely important determinant of effective respite care. It was submitted that if a carer and care recipient have a degree of trust in their respite care provider, the opportunities for optimal use of the caring break are realised. For example, trust in a service provider, and more importantly in a particular care workers, allows a primary carer/s to enjoy a short holiday without having to worry about the wellbeing of the loved one receiving the respite care.

2.28. Marymead conceived the issue of trust in the following way:

...very often there is the whole issue of trust between families and the people who are providing the respite, and sometimes that can be established and sometimes it cannot. In services where the respite giver works on a rotational basis they may not see the same person regularly enough to develop trust. And that limits the opportunity that families can have to actually utilise the respite that is available. So sometimes the respite is there but the parents – the family chooses not to make use of it because it is ... emotionally easier for them to stay with the child than to put them into respite¹⁹.

2.29. Trust is formed when the respite worker demonstrates the necessary skills, temperament and attitude to those in the care situation. However, it must be acknowledged that sometimes there are personality differences between care recipients and care workers that result in an absence of trust. Respite Care ACT advised the committee of the importance of ensuring that both the support worker and care recipient are happy with each other in the following terms:

I say to the support workers and to the clients when we sign each of them on separately, if you are not happy with the person that is providing your care please tell us because you are not going to get the best service possible, it is not going to be a quality service for you if you have a relationship problem or if you are not comfortable with the person providing the service. Likewise, I say to the support workers... you are not meant to love everybody in the world. If you are uncomfortable with a client because you do not like the way they speak to you or they do not like something – you do not like something about them you are not going to get a black mark against your name, please tell us and we will take you out of there because it is not going to be the most effective service if that is the situation²⁰.

Skills

2.30. Perhaps the most important element of effective respite care is that service providers have skilled and properly trained workers delivering the services. As Advocacy ACTion noted in its submission, ‘There is much anecdotal evidence to suggest that the quality of a service is most fundamentally reliant on individual workers [sic] commitment, expertise and attitude’²¹. At the end of the day, it is the workers that make a service what it is.

¹⁹ *ibid*, p 15.

²⁰ *ibid*, p 53, Ms Sedden.

²¹ Submission 19, p 6.

2.31. In order for respite care to be effective, carers must have the specific skills required to deal effectively with the often quite specific needs of carers and care recipients. A number of care recipient groups were identified in submissions and evidence where special skills and knowledge are required in order to be effective. These groups included people suffering from dementia, children with Attention Deficit Hyperactivity Disorder (ADHD) and other behavioural difficulties, people with autism, people with high support needs, and children at risk.

2.32. The Carers Association submitted that:

Resources must be suitable so that people across the board understand that carers providing the care understand that their parent, their child, their teenager or their young man are really important. They need to understand that the carers being provided have skills that are relevant to their particular family member²².

Quality infrastructure

2.33. The committee notes that the provision of effective respite services also requires that infrastructure and equipment is of a sufficient calibre to meet the needs of people receiving the care.

Comments about need, both met and unmet

2.34. For the purposes of this report, unmet need primarily refers to the, ‘numbers of people expressing the need or desire for a service, but not receiving the services, or receiving inadequate service or inappropriate service’²³.

2.35. However, the nature of need, both met and unmet, raises issues about the manner in which needs should be measured, how the relative need levels of people should be assessed, and what criteria, if any, should be used to make decisions to allocate services to particular people.

2.36. In the Australian Institute of Health and Welfare’s [AIHW] 1996 publication, *The Respite Care needs of Australians*, Gibson et al noted that, ‘the question of how much sleep deprivation must occur before a carer actually needs respite care, or what intensity of physical or emotional burden necessitates such care, illustrates the potential complexity of the debate’²⁴.

2.37. Gibson et al outlined three ways of operationalising or empirically measuring both met and unmet need²⁵. These three elements - use of existing services, expressed need and inferred need, were seen as being, ‘separate but interrelated components

²² Transcript, 16 August 1999, p 70, Ms Young.

²³ ACT Government, (1999) ‘Strategic Plan for Disability Service in the ACT’ p 17.

²⁴ Australian Institute of Health and Welfare, Gibson et. Al. (1996) ‘The Respite Care Needs of Australians’ AGPS, p 3.

²⁵ *ibid*, pp 4-5.

relevant to a needs analysis’²⁶. The committee considers that it is useful to include a brief examination of these approaches here.

Use of existing services

2.38. Quite simply, examining existing patterns of service use involves looking at what types of service are utilised, by whom, how frequently and for how long.

2.39. Gibson et al considered that an examination of existing patterns of service use is not an overall measure of the need for service as, ‘need and availability are... inextricably interrelated; availability and access necessarily structure the ways in which expressed needs for service are met, creating particular patterns of service use’²⁷.

2.40. However, Gibson et al note that such an approach does give an indication of, ‘the need for respite services as... expressed by clients within the context of the available system of respite care’²⁸.

Expressed need

2.41. Expressed needs for services, both met and unmet, were established by looking at the degree to which persons who want assistance were unable to obtain it. Gibson et al observed that this approach examines:

the level of expressed unmet need, the characteristics of those persons indicating unmet need, and how they differ from

(a) the users of respite care services who have not reported any unmet need;

(b) the non-users of respite care services who have not reported any unmet need; and

the difference between persons who indicate that they need respite services (met or unmet) and those who do not express such a need²⁹.

Inferred need

2.42. The inferred need approach to assessing need not only looks at the expressed needs as articulated by people seeking services but identifies a, ‘group of carers who could reasonably be expected to be in need of respite care, given the nature and intensity of their caring roles’³⁰. Gibson et al noted that, ‘the intensity of the caring role and the vulnerability of the carer – are used to operationalise the concept of inferred need’³¹.

²⁶ *ibid*, p 4.

²⁷ *ibid*, p 4.

²⁸ *ibid*, p 8.

²⁹ *ibid*, p 5.

³⁰ *ibid*, p 171.

³¹ *ibid*.

2.43. Under this analysis, intensity of the caring role was measured on the basis of how many ‘core personal activities’ were undertaken by the carer to assist the care recipient. Such activities included showering or bathing; dressing; eating or feeding; toileting; assistance with mobility within or outside the home; transferring a person between bed and a chair; and communicating³².

2.44. The vulnerability of a carer’s situation was ascertained by looking at carers’ responses to question about:

- whether the care recipient’s condition was likely to deteriorate;
- the existence of a fall-back carer;
- any reported unmet need for help in caring for the care recipient;
- whether any help was being provided; and
- the recipient’s capacity for self-care³³.

2.45. Using this approach, need is ascribed to people not according to an explicit expression by those seeking services, but is inferred based on the extent of carer burden.

2.46. This raises the issue of carers who do not report any needs that they might have in relation to respite care because their subjective assessment is that they do not need the services. Evidence was presented suggesting that people in this situation often end up suffering from ‘burn-out’ as the toll of the caring role increases with age and the absence of social supports³⁴. It is apparent to the committee that the community also has a responsibility to assist this group of people as well as those who express a need for services.

Allocating services

2.47. Gibson et al ask the following questions in relation to allocating services: ‘Can the need for respite care be determined by objective criteria, or should it be measured solely in subjective terms? If respite care is a public good, should all requests from persons who declare that they need access to the service be granted it, or should objective criteria apply?’³⁵.

2.48. The question of whether it is reasonable that services be provided to all people expressing a need for support is essentially related to the fact that there are limited resources available to the sector and rationing necessarily comes about. Following on from this are basic questions about the role of government in servicing the needs of the community such as: at what point does the community have an obligation to meet people’s needs for respite care services, be they objective or subjective? To what

³² *ibid.*

³³ *ibid.*

³⁴ Submission 18, p 8.

³⁵ Australian Institute of Health and Welfare, (1996) ‘The Respite Care Needs of Australians’ AGPS, p 3.

extent are the community and governments prepared to fund services for carers and care recipients and their families? There are no easy answers to these questions.

2.49. A view was put to the committee that governments must be seen as failing the community if they are not providing services that *fully* meet the expressed needs of people seeking them. Advocacy ACTION argued that:

The notion that compromise is okay is a fallacy. People in receipt of services or people casting around to try to find the right service or people making suggestion of how to improve services are often told that they must be willing to compromise. If you go to get a heart bypass would you find it acceptable for the doctor to say:- “I know what you need but for this and that reason you just can’t have it. You’ll have to compromise.” I do not believe so. Similarly people receiving human services such as respite care should not be made to compromise either³⁶.

2.50. The committee sees that it is difficult to discount this view when considering that public funds are often made available to what many would consider to be lower order priorities such as car races and stadium redevelopments.

The need for data

2.51. Unfortunately, there is no solid data available on the extent of need both met and unmet for respite services in the ACT. The committee considers that this paucity of data remains an impediment to devising effective forward planning policies and a coherent strategy for respite care service provision. As the Council on the Ageing (COTA) pointed out in its submission, ‘the actual need is unquantified, information is often anecdotal and this creates a barrier to government and others developing a practical response’³⁷.

2.52. Assessing need in an empirical sense, whether expressed or inferred, met or unmet, was beyond the scope and resourcing of this committee. However, the committee considers that as a matter of urgency, the ACT Government must commission a study of this kind to determine the extent of unmet need for various client groups and individuals now and into the future. The committee is of the view that this study must assess respite needs, both met and unmet, in terms of both the quantity of services and the extent to which the quality of services meet people’s needs. Many stakeholders in the course of the inquiry supported such a study.

2.53. The committee considers the approach taken by Gibson et al may be instructive for any agency undertaking a study of the extent unmet need in the ACT community.

2.54. With the results of the study in-hand, it is obviously important for the Government to allocate adequate funds to address unmet need across the sector. For this reason the committee sees value in the study providing estimates in dollars terms for meeting any unmet need that is identified.

³⁶ Submission 19, p 5.

³⁷ Submission 11, p 6.

Recommendation 1

The committee recommends that in consultation the Government undertake a comprehensive empirical study to determine both the current and future levels of need (both met and unmet) for respite care in the ACT community.

Uniform reporting

2.55. One submission argued that it would be useful to develop mechanisms for service organisations to report on unmet need³⁸. Ideally, it would be useful to have uniform reporting processes which would allow useful data to be compiled about the extent of expressed unmet need as observed by service providers. Action for Autism (AfA) submitted that the reporting measures should be used by service brokers, social workers and caseworkers and that training in the measures would be important³⁹. The committee sees value in this approach.

Recommendation 2

The committee recommends that the Government develop uniform reporting mechanisms for service brokers, social workers, caseworkers and other service providers to give feedback about unmet need.

Funding

2.56. As noted above, issues relating to unmet need primarily relate to funding levels and the committee was reluctant to make recommendations to the Government about where funds should be allocated. It is true that more funding is needed across the board and the committee supports the allocation of additional funds (especially at the federal level), but without a comprehensive empirical assessment of both the met and unmet needs of people in the community the committee will not attempt to suggest priorities.

2.57. The danger of making recommendations in the absence of this evidence is that inevitably there will be areas of unmet need that have not come to the committee's attention. Different organisations, representing diverse interests within the sector have provided varying levels of advocacy on behalf of their interest groups and there are also other groups which, for reasons of limited time or financial resources, have been unable to make any representations whatsoever to the committee.

2.58. The committee is concerned that in the absence of an exhaustive, empirical examination of unmet need, any funding recommendations would be made on the basis of incomplete information and improper conclusions would be difficult to avoid.

2.59. Instead the committee has set out in Chapter 3 the areas of need in the community as expressed in submissions and evidence in the public hearings and has examined the extent to which these needs are not being met.

³⁸ Submission 15, p 10.

³⁹ *ibid.*

2.60. While the committee has called for more accurate data on the shortfall in services, it is beyond question that what is provided is considerably less than the minimum need. Most submissions, and those from groups who are reminded on a daily basis of the demand, point graphically to the inability to respond to all needs.

2.61. There are a large number of people who miss out on the support they need, causing considerable distress. There are very, very many dedicated carers – families and friends who are under severe stress in caring for a loved one where more care should be provided by government. These efforts provide a considerable saving to government.

2.62. The committee would have been justified in nominating an amount to substantially increase the expenditure in each of the areas of respite care but it understands the circumstances under which the Government operates.

2.63. A large increase in the level of respite care of all types is of the highest priority and one purpose of this report is to highlight that desperate need. Hence the committee's major recommendation:

Recommendation 3

The committee recommends that the Government accepts that a substantial increase in respite care is of the highest priority.

CHAPTER 3. ARE SERVICES MEETING CURRENT NEEDS?

3.1. Considerable anecdotal evidence was presented to the committee indicating that respite services in the ACT are not meeting the current needs of the community. Stakeholders saw unmet need as being evident in terms of insufficient availability and inadequate quality of services.

3.2. Below is an examination of the particular needs of different client groups vis-à-vis the extent to which these needs are not being met by current services. The client groups examined include carers, people with disabilities, people with a mental illness, the aged and infirm, people requiring family support, war veterans and children with Attention Deficit Hyperactivity Disorder.

3.3. The committee was moved by anecdotal evidence presented by carers and industry professionals and has included the various experiences of these people throughout this section.

Insufficient availability of services

3.4. The committee was advised that there is simply not sufficient availability of services to provide for the full range of people's needs. Stakeholders conceived the limited availability of services as being primarily a result of under-funding in the sector.

3.5. ACROD ACT, concerned for those with a physical disability, reported that, 'The availability of respite care services in the ACT is limited not so much by the number of agencies currently available or the range of services offered but more by the limitation imposed by funding constraints placed on existing agencies'⁴⁰.

3.6. In a similar vein, Respite Care ACT, one of the major providers of respite care services in the ACT, noted that:

We have found that people already receiving care want funding to cover more of what they currently receive from those who provide it and with whom a long standing relationship already exists. A common feeling mentioned in the client satisfaction survey of December 1998 is 'We want more of what we are getting'⁴¹.

3.7. The following statements further highlight the extent to which people working in the field view current arrangements as inadequate.

'... there is an absolute shortage of respite services in the city'⁴² –
Marymead Child and Family Centre

⁴⁰ Submission 18, p 6.

⁴¹ Submission 16, p 4. - The committee considers that this inclination towards receiving 'more of what we are getting' as expressed by clients highlights the trust and goodwill that has been established by existing service providers.

⁴² Submission 9, p 1.

‘There is a critical shortage of accessible, flexible respite, both residential and in-home’⁴³ – **Carers Association**

‘There never seems to be enough respite for families, especially exceptionally high needs families’⁴⁴ – **Marymead Child and Family Centre**.

‘... there are a whole range of families we could service if we had more resources’⁴⁵ – **Barnardos**

‘It is all very well telling people they can stay at home... but they are not sending the dollars out to the community sector to enable that to happen. It is as simple as that’⁴⁶ – **Respite Care ACT Inc.**

‘Another critical factor is the extent to which support needs are not currently being met... There is anecdotal evidence that some groups within the population of people with disabilities are particularly likely to have unmet need for support services... These groups include children entering adolescence; school leavers; people whose elderly carers can no longer support them; people with challenging behaviours; people with a dual diagnosis; and people with a recently acquired disability who have not yet established support networks; and people with intensive and complex support needs.’ – **The ACT Government Strategic Plan for Disability Services**⁴⁷.

‘Service providers on the whole seem to be working to their maximum capacity within existing financial restraints to meet the needs of their clients and it is clear that much good work is being done by people who demonstrate a high level of personal commitment to helping their client’.⁴⁸ – **The Community and Health Complaints Commissioner**.

3.8. These statements on the extent of unmet need range across all areas where respite is provided including the frail aged, families in crisis and disability services.

3.9. The committee shares the view of the Community and Health Complaints Commissioner about the quality of services provided and commends the carers, both paid and voluntary for the work they do. It is the view of the committee that funding levels must increase in the sector before satisfactory service levels can be achieved.

Statistics

3.10. Several organisations provided the committee with information on the extent to which current services are not able to meet the needs of the community.

ACT Government

3.11. In its *Strategic Plan for Disability Services in the ACT*, The ACT Government cites a 1996 AIHW study which estimated that there were 230 people that had,

⁴³ Submission 10, p 3.

⁴⁴ Transcript, 16 June 1999, p 14, Mr Zilber.

⁴⁵ Transcript, 16 June 1999, p 3, Ms Sharp

⁴⁶ Transcript, 16 June 1999, p 56-57, Ms Seddon.

⁴⁷ ACT Government, (1999) ‘*Strategic Plan for Disability Service in the ACT*’ p 16.

⁴⁸ Submission 6, p 1.

‘support needs in relation to their basic daily living activities which were not being met, or not adequately met, because services were not available or could not be arranged’⁴⁹.

3.12. In addition to this level of unmet need, the strategic plan acknowledges that increased availability of services is required to ‘keep pace’ with the growth in number of people aged between 15 and 64 with severe or profound disabilities in the ACT⁵⁰. The AIHW estimated that community access places must increase by 1.9 percent each year in order to keep up with this growth⁵¹.

3.13. The Government also identified the problem of ACT’s ageing carers noting that:

In 1993 (most recent figures) there were 132 parent-carers in the ACT aged over 65. These carers support a daughter or son with a severe or profound disability. Almost half of the carers will now be 70 and over. Between 1993 and 1998 the number of carers over the age of 65 is estimated to have grown by more than 11 in the ACT⁵².

3.14. The committee welcomes the Government’s announcement in September 1999 that \$251,000 (over four years) will be made available to people with disabilities and their ageing carers through the Commonwealth State Disability Agreement (CDSA)⁵³. However, on the face of it, it appears that additional funding will be required on an ongoing basis.

Respite Care ACT

3.15. In its submission, Respite Care ACT advised the committee that at the time of writing its submission (May 1999), the organisation had identified significant need for its services that were unable to be met. The organisation indicated that there were, ‘10 people assessed as low priority who would require 30 to 50 hours of service per week; 10 people assessed as medium priority who would need 40 to 60 hours per week; and 23 people assess as high priority who require 102 hours of respite care per week’⁵⁴.

The National Council on Intellectual Disability

3.16. The National Council on Intellectual Disability has estimated that respite care services are unavailable for approximately 120 carers of people with severe disabilities in the ACT⁵⁵.

⁴⁹ ACT Government, (1999) ‘Strategic Plan for Disability Service in the ACT’ p 17.

⁵⁰ *ibid.*

⁵¹ Submission 12, p 12. However, several stakeholders including the ACT Government and argued that the AIHW figures were conservative estimates and probably underestimate the extent of unmet need.

⁵² *ibid.*

⁵³ Minister for Health and Community Care, Michael Moore, Media Release, 15 September 1999.

⁵⁴ Submission 16, p 5.

⁵⁵ Submission 12, p 12.

The National Brain Injury Foundation

3.17. The National Brain Injury Foundation (NBIF) advised the committee that it would receive approximately 20 calls per year from people requesting planned and emergency in-centre respite that cannot be catered for, predominantly because they, 'fall through the gaps in service provision'⁵⁶.

Burrangiri Centre

3.18. A submission from the Salvation Army's Burrangiri Centre noted that between 1 October 1997 and 30 September 1998, 770 referrals for residential respite care were received, resulting in 404 admissions. Of the rest of the 770, 142 cancelled the request, 66 did not follow up, 83 did not meet eligibility requirements or were considered inappropriate for Burrangiri due to medical instability or mental health problems, 74 were unable to be admitted because no bed was available when required, and 2 were unable to be admitted due to the client mix and staffing ratios⁵⁷.

Federal under-funding

3.19. A ministerial statement by the ACT Minister for Health and Community Care, Michael Moore, MLA, on the outcomes of the meeting of disability ministers held in Canberra on 9 April 1999⁵⁸, addressed the issue of unmet need for disability support services. Quoting from the 1997 report of the Australian Institute of Health and Welfare (AIHW), *Demand for Disability Support Services in Australia*, Mr Moore stated that there is estimated unmet demand nationally for accommodation or respite services for 13,400 people and for day programs for 12,000 people. The estimated cost of meeting this demand is \$294 million, which would translate to approximately \$5 million in the ACT. This funding would need to be recurrent and the AIHW estimates were thought to be conservative.

3.20. The committee is aware that the Minister has consistently applied pressure on the Commonwealth in relation to the under-funding and the committee commends the Minister's efforts in this regard. Notwithstanding the proposal by the Minister for Family and Community Services, Senator Jocelyn Newman, to allocate \$150 million to disability Services across Australia, the committee sees that there is substantial under-funding in the disability services sector.

3.21. The committee understands that Senator Newman failed to attend a meeting of state and territory health ministers in November 1999 to further negotiate on disability funding. The committee considers that the approach taken by the Senator with regards to the negotiations does not bode well for people with disabilities.

⁵⁶ Submission 2, p 2.

⁵⁷ Submission 22, p 7.

⁵⁸ Michael Moore MLA, Minister for Health and Community care, Ministerial Statement on the outcomes of the meeting of disability ministers held in Canberra on 9 April, 1999.

Recommendation 4

The committee recommends that the Government continue making representations to the Commonwealth about the significant under-funding of disability services.

Recommendation 5

The committee recommends that the ACT Government match any federal funding provided to meet the respite care needs of people on a dollar for dollar basis.

Respite consumer's needs

Carers

3.22. As mentioned earlier the social and economic contribution made by carers is vast. Caring for loved ones can be physically, emotionally and financially demanding and effective respite care has the capacity to alleviate some of the stress associated with this role. The often-intensive nature of providing care for another person can sometimes lead to a person's isolation from the social and professional aspects of their life, where the caring role becomes all consuming.

3.23. In this regard, the Carers Association of the ACT advised the committee that:

Providing care for another person, whether part-time or full-time, impacts on other aspects of the carer's life. Many carers experience disruption to employment and social networks, and their capacity to respond to other life demands and pursue personal interests is diminished. The withdrawal or absence of other activities can increase isolation and add to the stress experienced by the carer⁵⁹.

3.24. As noted above, the level of respite care required by a carer varies according to a number of factors including the severity of the care recipient's condition; whether there is a fall-back carer available; the capacity for a care recipient to care for themselves; the likelihood that the recipient's condition will deteriorate; whether other social supports and informal care networks are available ⁶⁰; and other demands on the carer's time such as children.

3.25. However, the committee was advised that currently there is insufficient consideration of the needs and individual situations of carers in the assessment process. The Carers Association of the ACT argued that:

Carer needs must be given a greater priority in the assessment process and service providers need to focus on the needs of both the carer and the care-recipient.

⁵⁹ Submission 10, p 5.

⁶⁰ Australian Institute of Health and Welfare, Gibson et. Al. (1996) 'The Respite Care Needs of Australians' AGPS, p 171.

The assessment process is vital to the development of flexible respite options and addressing individual needs and it must consider the whole situation from the perspective of all involved – the care recipient, carer and family⁶¹.

3.26. This view was supported in the 1996 Respite Review commissioned by the then Department of Human Services and Health. Citing the review, the Federal Government noted in its submission that, ‘there needs to be greater recognition of carers’ needs and circumstances, including the extent of carer burden, in assessment processes and service responses’⁶². The committee concurs with this view.

3.27. One witness proposed that it might be useful to use the, ‘geriatric depression scale or some other type of carer stress scale’ as one means of properly assessing the extent of carer burden and stress⁶³.

3.28. The committee considers that the work done by Gibson et al in empirically measuring need may have implications for how assessment processes actually determine the needs of carers.

3.29. Additional comments about assessment processes can be found in Chapter 4.

Recommendation 6

The committee recommends that the Government consult with relevant stakeholders and investigate how to best recognise (through assessment processes and eligibility criteria) the needs of carers and the level of burden experienced by carers.

3.30. The committee was advised that often carers are reluctant to seek assistance and until their position as carer has reached a crisis point and become untenable. The Carers Association pointed out that this was both a result of the unwillingness of some families to have respite workers in their home and the reluctance of some people to ask for help. The Association noted:

A lot of barriers are put up from within the family dynamics. A lot of people find it difficult to say, “I can’t cope”... It is not easy to have two, three or four people wandering in and out of your home to care for a relative. It really exposes you a lot⁶⁴.

3.31. The committee heard that the emotional and physical toll on carers whose needs, for whatever reason, are not being properly met, is considerable. The Carers’ Association advised the committee that the ‘huge emotional stress on carers’ can lead to premature death and that many carers die soon after the person for whom they had been caring dies⁶⁵. The Association noted that:

⁶¹ *ibid*, p 2.

⁶² Submission 23, p 14.

⁶³ Transcript, August 16, p 73, Mrs Gregory.

⁶⁴ *ibid*, p 70, Ms Young.

⁶⁵ *ibid*, p 70, Ms Young.

We know that caring takes a huge toll on health and that it is very stressful work for a lot of people, depending on the support they have or the family networks that they have, or the disease of the person they are caring for⁶⁶.

3.32. The committee is aware that the Carers Association is in the process of conducting a comprehensive survey into the effects that caring roles have on carers. The committee eagerly awaits the findings of this study⁶⁷. The Carers Association advised the committee that early data from the study have revealed some very dire situations, noting that:

People have multiple caring responsibilities. They are not only caring for one other person; they may be caring for two or three. One survey form talked about a mother caring for two of her children with schizophrenia, two sons with a severe mental illness problem⁶⁸.

3.33. A report of the Carers Association Forum, *Towards a Community that Cares Well* argued that:

Notwithstanding the rewards which many experience, caring is usually emotionally and physically demanding... Many carers spoke of stress and burnout, pointing out that it was not until a point of crisis is reached that many carers seek help. Strategies directed to providing support and assistance to carers before they reach breaking point were a major focus in discussion⁶⁹.

3.34. The committee sees as a matter of common sense that there is a need to identify improved means of 'reaching out' to carers before their position becomes untenable. General Practitioners may play a useful role in reaching out to patients with caring responsibilities about the need to seek respite.

3.35. ACROD ACT made particular mention of the need for services to be available and accessible to those people who care for themselves in order that they are able to enjoy a break from their situations⁷⁰.

3.36. Additional analysis of the needs of carers is provided throughout this chapter in relation to the needs of other client groups.

Young carers

3.37. The committee's attention was drawn to the unique challenges facing young carers and the importance of providing adequate respite support for this group. There are a significant number of young carers (carers under the age of 18) in the ACT with a recent study indicating that there are approximately 600 young carers in Canberra⁷¹.

3.38. Marymead described young carers as:

⁶⁶ *ibid*, p 71, Ms Radndge,

⁶⁷ Transcript, August 16, p 71, Mrs Radnedge.

⁶⁸ *ibid*, p 71, Mrs Radnedge.

⁶⁹ Carers Association of the ACT, (1998). 'Towards a Community that Cares Well – Report of a special forum for carers in the ACT' attached to Submission 10.

⁷⁰ Submission 18, p 6.

⁷¹ Submission 8, p 2. However, it is believed that this figure is an underestimate.

...children or young people under the age of 18 who help look after – or they look after an ill or disabled relative and that can be any member of the family. It can be parents, brothers, sisters, grandparents and anybody they feel they are looking after and as part of the caring role they can do a variety of tasks. A lot of the caring role is about domestic duties because adults and family might not physically be able to do them or it might be emotionally looking after somebody⁷².

Psychological health

3.39. The committee was advised that children's development can suffer under the burden of their caring role. Often young carers miss significant periods of school, drop out of school early, and develop a sense of 'false maturity'. Young carers not only face the challenges of providing care to a person but also the ongoing roles of attending school, socialising with friends and just growing up.

3.40. The committee heard a number of stories reflecting the range of pressures placed on young carers and instances where the emotional life of a child was adversely affected due to the pressure of the caring role.

One 10-year-old child had a mother with a significant psychiatric disability, plus a younger brother with ADHD. That 10 year old child was responsible for monitoring her younger brother's medication which is something that would not happen in a usual family situation. The mother also had a significant back condition which meant that the 10 year old was doing all of the domestic duties before she went to school. She was going to school, she was keeping an eye on her brother at lunch time, making sure he had his medication at lunchtime. Her mother might have been unwell in the afternoon, so she would watch that her younger brother did not run on the road; that he was actually kept physically safe and was eating the appropriate food. She monitored that the bills were being paid. She monitored that doctor's appointments were kept. On top of this she was trying to do school work...⁷³

...one young man I spoke to heard a siren as he sat in the classroom he thought an ambulance was going to his mum, so his primary concentration went, "What is happening at home? Is she okay? I should be there to look after her". He had great difficulty concentrating at school. Another young woman I spoke to was overachieving at school. Her dad had MS and she felt it was her responsibility to give him hope, to give him something to live for, so she would overachieve at school to make him proud⁷⁴.

Physical health

3.41. The often-onerous role performed by young carers is not only detrimental to the social and psychological development of these children but also to their physical health. The committee was advised that children are not physically equipped to perform many of the tasks required by a care recipient. Marymead pointed out that:

⁷² Transcript, 16 June 1999, p 15, Ms Gays.

⁷³ *ibid*, p 18, Ms Agnew.

⁷⁴ *ibid*, p 16 Ms Gays.

If a child is lifting their parent in and out of bed or in and out of the bath, then they have got a lot of responsibility. And they are not taught how to do it, so the chances are they are going to impair their own physical health through lifting someone heavy⁷⁵.

3.42. It was submitted that flexible services allowing young carers to take time out of their caring role are very important in ensuring the physical and psychological wellbeing of these children. In particular, the committee was advised that young carers have a major need to be put in contact with children of their own age who may be in similar situations. It was argued that young carers are often without friends their own age and by mixing with each other a sense of normalcy can be gained along with the understanding that they are not alone in their situations⁷⁶.

Unresponsive services

3.43. In the past, respite services have primarily been focused on the needs of the care recipient or on adult carers only. However, in keeping with the principle of responsiveness, the committee was informed that it is very important that young carers are involved in developing the forms of respite best suited to their needs⁷⁷. It was argued that sometimes respite provisions are not made available for young carers when an adult is also providing care in the family. This is due to both the eligibility requirements of some programs and the reluctance of some families to describe a child as being the primary carer due to feelings of guilt or embarrassment⁷⁸.

3.44. One witness argued that Australia is considerably behind best practice in providing services for young carers citing England as a country where progress had been made. In particular, England's *Carer's Recognition Act* is aimed at supporting young carers by mandating the assessment of young carers' needs when assessments of care recipients are made. This legislation, it was argued, has established a duty of care to assess the impacts of a person's illness or disability on a child and to provide adequate services to prevent or ameliorate any negative effects that may arise in a care situation⁷⁹.

3.45. The committee supports the ACT Government's undertaking to consider programs specifically aimed at assisting young carers and urges the Government to implement these programs as a matter of urgency.

3.46. The committee applauds the introduction of an information kit for young carers in September 1999 developed by the Young Carers Support Network and Marymead. The kit provides information on how to provide effective support to young carers in the manner that best reflects their needs.

⁷⁵ *ibid*, p 16.

⁷⁶ Transcript, 16 June 1999, p 18, Ms Gays.

⁷⁷ Submission 8, p 2.

⁷⁸ Transcript, 16 June 1999, pp 23, Ms Agnew and Mr Zilber. Submission 8, p 2.

⁷⁹ Transcript, 16 June 1999, p 22, Ms Gays.

Recommendation 7

The committee recommends that the specific needs of young carers are taken into account in the assessment process, and that provisions are made to ensure that young carers are not performing roles which jeopardise their physical and psychological health.

Recommendation 8

The committee recommends that the Government examine the Carer's Recognition Act introduced in the United Kingdom, and evaluates the appropriateness of similar legislation for the ACT.

People with disabilities

3.47. Based on 1993 figures, approximately 16 percent of the ACT population reported that they had a disability and 12 percent indicated that there was a handicap associated with their disability. Of the people in the ACT with a disability, 15 percent had profound handicaps, 15 percent had severe, 20 percent had moderate, 31 percent had mild and 19 percent had handicaps with an undetermined level of severity⁸⁰.

3.48. In the ACT, 98 percent of people with disabilities receive the majority of their support from friends and family members⁸¹.

3.49. The needs of people with disabilities are recognised in the UN Standard Rules on the Equalisation of Opportunities for People with Disabilities which states the objective of improving, 'the lives of disabled people (sic) through their rehabilitation, education, employment, and integration into economic and social life'⁸².

3.50. The committee supports the philosophy of social role valorisation which underpins the *Disability Services Act 1991*. This philosophy places importance on social integration, community living and providing the least restrictive care environments possible⁸³. The driving principle of social role valorisation is the idea that people with disabilities should be enabled through good public policy and service delivery to, 'achieve their maximum potential as members of the community'⁸⁴.

3.51. The committee considers that respite care plays an important role in assisting people with disabilities to realise their potential as members of the community.

Need levels

3.52. The range of disabilities affecting people who require some degree of care is vast and the full range will not be explored here. However, in its submission, ACROD

⁸⁰ ACT Government, (1999) 'Strategic Plan for Disability Service in the ACT' p 11.

⁸¹ *ibid*, p 11.

⁸² *UN Standard Rules on the Equalisation of Opportunities for People with Disabilities*, cited in Submission 15, p 3.

⁸³ Submission 6, p 5.

⁸⁴ *Disability Services Act 1991*

ACT categorised people with disabilities into three groups according to levels of need. It identified the following groups: those with low-support needs, those with medium support needs and those with high and complex support needs.

3.53. The committee considers that it is useful to include the profiles for these different categories, as outlined in the ACROD ACT submission.

Low support needs

The profile of a person with a disability ... [in this category] who has low support needs would be a child with a mild physical/intellectual disability who is ambulant (walks), continent (able to control movements of bowel and bladder) and has most of the living/social skills appropriate for age. The child attends a mainstream school and lives at home. The family members, in combination, are able to provide the carer support with little or no requirement for external assistance or respite care service

Medium support needs

The profile of a person ... [in this category] would be a twenty year old person with moderate physical/intellectual, often multiple disabilities, who is generally neither ambulant or continent. This person will have limited living skills and may have difficulties communicating. This person may be in employment, possibly for limited hours and generally living at home. The family members, in combination are unlikely to be able to cope alone and require significant respite care service support.

High/complex needs

The profile of a person with a disability ... [in this category] would be a thirty year old person with severe physical/intellectual, generally multiple disabilities, who is neither ambulant or continent. This person will have few living skills and will require support 24 hours a day of each day of the year. Employment for this person will not be appropriate. Family members in combination are unable to cope alone and require significant care support. It is possible that this person will transition quickly from respite care of limited duration in out-of-home supported accommodation (provided by a community based organisation or government agency) to full time care in that supported situation⁸⁵.

3.54. These varying levels of disability, obviously require different levels of respite and different strategies for managing people's needs.

3.55. The committee acknowledges that the care needs of people with disabilities change as they grow older, as their carer/s grows older, as family situations change, and as other situational factors change. It obviously follows that carers too have varying levels of need for respite care depending on the level of care that is required by a care recipient.

⁸⁵ Submission 18, p 2-3.

People with high support needs

3.56. The committee heard from numerous groups that it is particularly difficult to find appropriate support services for people at the high-support-needs end of the spectrum.

3.57. In its submission, the office of the Community and Health Services Complaints Commissioner noted this quite clearly. In the submission, the Commissioner noted that:

... our view is that some of those at the extreme high end of the spectrum of need, with severe challenging behaviours, still find suitable services hard and sometimes impossible to find⁸⁶.

3.58. Providing respite care services to people with high support needs is necessarily expensive. As noted earlier, people in this category require intensive support to assist them in routine, day-to-day, activities such as bathing, going to the toilet and eating meals. When respite is provided for people in this situation, often the most appropriate setting is out of the home in a residential setting. ACROD ACT submitted that this type of care has high unit costs with the requirement for 24-hour care and costs for accommodation, rates, taxes, fuel, lighting and food. This is in sharp contrast to care provided in an in-home setting where these costs are already covered by the client⁸⁷.

3.59. Several stakeholders advised the committee that there is insufficient availability of residential respite. ACROD ACT submitted that:

Our experience is that out-of-home respite... certainly does not meet the needs in the ACT. There are very few places to go to. There is the ACT Society for the Physically Handicapped or there are the ACT Disability programs... There is not that much else, unless we can get someone to put something together, which is extremely expensive. None of them can really offer families enough to provide respite out of the home⁸⁸.

3.60. Where in-home respite is provided for people with high supports needs, it is often necessary to engage more than one respite worker to effectively manage the care needs of the person⁸⁹. This too, is expensive.

3.61. In relation to complaints received by parents of children with autism, the Complaints Commissioner attributed limited availability of these services to the fact that they are expensive and that, 'providing services to... [these high needs clients] does not create an obvious economic return in an economic climate where returns are a priority'⁹⁰. In its submission, the Carers Association of the ACT echoed this view noting the comment of one carer that, '[the] level of dependency of the care recipient

⁸⁶ Submission 6, p 6.

⁸⁷ Transcript, 16 June, p 65, Mr Bray.

⁸⁸ *ibid*, p 65, Ms Field.

⁸⁹ Submission 10, p 4.

⁹⁰ Submission 6, p 6.

seems to be a factor in services determining availability of care. It seems it is easier to access service if the person is compliant and doesn't have challenging needs'⁹¹.

3.62. However, the Commissioner noted that the social and financial costs of managing the inevitable crises that emerge in the absence of adequate care are considerable. The Commissioner put the situation in the following terms:

... it seems to be a matter of commonsense that families looking after severely disabled children who are not adequately supported, will collapse and the disabled person will become in need of emergency care, perpetuating a culture of crisis management on the part of service providers and planners. We understand that this is in fact the experience of those in the business of providing services to disabled people in the ACT⁹².

3.63. The committee concurs with the Commissioner's assessment of the current situation and supports improved support services for high-needs clients and their families. The committee asks itself what the true social and economic costs of not providing effective respite services for this group will be into the future.

3.64. The ACT Division of General Practice represents doctors who are greatly involved in the delivery of health services to people with complex needs. With an emphasis on aged care, the Division argued that:

There is a trend, not only in Australia, but internationally, towards the provision of community-based care rather than long term institutional care for people with complex chronic care needs. This trend requires the development of a community infrastructure to support the capacity of the community to manage these people. The ageing of the ACT population combined with pressures on the volunteer sector as potential carers continue in paid employment highlights the need to proactively support community-based care⁹³.

3.65. When appearing before the committee, the Division indicated that there is not enough community infrastructure in place at this stage⁹⁴.

Emergency residential respite

3.66. The National Brain Injury Foundation [NBIF] submitted that emergency centre based respite care services in the ACT were of very limited availability, describing them as being, 'either non-existent or very difficult to obtain'⁹⁵. Outlining the difficulty in obtaining centre based respite on an emergency basis, NBIF recounted the following story.

NBIF was involved in a situation where the relationship between a mother and her brain injured son had broken down suddenly, where she evicted him without notice. The

⁹¹ Submission 10, p 4.

⁹² *ibid*, p 6.

⁹³ Submission 5, p 1.

⁹⁴ Transcript, 16 August 1999, p 86, Dr Jarvis.

⁹⁵ Submission 2, p 2.

mother had been the carer of her son, aged in his twenties, for some fifteen months since his accident.

NBIF contacted several agencies for emergency respite but were unsuccessful. It was finally arranged for this man to stay the first night at Ainslie Village and then to place him in a crisis refuge for a number of weeks. The refuges were very helpful, however, this type of accommodation was far from suitable for someone with cognitive and physical disabilities. The Carer Respite Service was able to provide some assistance to this man while at the refuge which made the situation workable. It is our understanding, however, that they, normally, can only provide this type of care in the home and were extending their service due to the lack of available centre based respite⁹⁶.

3.67. While it is admirable that the Carer Respite Service was able to provide a ‘work-around’ for this particular client, offering the necessary flexibility to support his needs, the lack of centre based respite is a cause of concern for a range of client groups and appears to be a pervasive problem. In this regard, the committee considers that ad hoc solutions will produce ad hoc results, highlighting the need for better case management and additional services.

3.68. The Carers Association of the ACT also identified emergency residential respite as a problem, claiming that:

There is a need for more short-term residential emergency respite. Burrangiri Aged Care facility is the only facility available for this purpose and provides care for people over 60 years of age. Due to the high demand for this type of care, it is becoming increasingly difficult to obtain a place at Burrangiri particularly for people with dementia and people with challenging behaviour⁹⁷.

3.69. The Association submitted that there is a critical need for residential respite for people with dementia that are wanderers; younger people with dementia; people with mental illnesses, challenging behaviour, or diseases such as multiple sclerosis, motor neurone disease, and stroke⁹⁸.

3.70. Following on from this, the Association argued that there is demonstrable need to develop a purpose-built facility to provide effective residential based respite for people with challenging and high care needs⁹⁹. The committees considers that this proposal warrants further investigation by the Government.

Post-school options

3.71. Between 5 and 15 students leave ACT special schools every year¹⁰⁰ and the committee was advised that there is a severe lack of post-school support services for young people with disabilities, particularly for children with high supports needs¹⁰¹.

⁹⁶ *ibid.*

⁹⁷ Submission 10, p 3.

⁹⁸ *ibid.*, p 3.

⁹⁹ *ibid.*, p 4.

¹⁰⁰ Transcript, 10 June 1999. P 189, Ms Cain.

¹⁰¹ Submission 6, p 10.

3.72. Where a young person's level of disability is extremely high, attending a tertiary institution or employment-supported service following school are not viable options and it appears that many young people with high needs are falling through the gaps in service provision after school ends¹⁰².

3.73. In evidence before the Standing Committee on Education's inquiry into Educational Services for Students with a Disability, a provider of post-school support services, Sharing Places, noted that there are currently 30 people on its waiting list and some of these people have been on the list for up to four years¹⁰³.

3.74. The organisation informed the education committee that because there are limited post-school options for this group, the resources expended in helping them develop basic living skills earlier in life are wasted as they are not maintained after their schooling ends.¹⁰⁴

3.75. Sharing places stated the problem in the following terms:

It is a terrible waste of taxpayers' money, absolutely shocking waste, because once they lose those skills they get to the stage where the family cannot cope any more and they have to have some sort of crisis accommodation. Because they have lost the skills they need much more help, they need further support, whereas if they could have retained those things there would be much less need for support in the future¹⁰⁵.

3.76. The committee heard that in the event that a high-support needs child is unable to access a post school service, the consequent effect on families, who are required to intensify their caring role, can be disastrous. In this regard Sharing Places noted that:

When they [high needs children] reach their 21st birthday they [the parents] do the opposite to what everybody else does in giving the[m] [the] key to the door. Mum and dad have to give up work. It is exactly the opposite because there is nothing else. The destruction there is absolutely unbelievable and in many cases these individuals end up in institutional care or group homes because the family cannot cope¹⁰⁶.

3.77. In its submission, the ACT Government recognised the need to improve the available options to young people with disabilities after they leave school. It noted that additional funding was provided in early 1999 to ACT Community Care and the Community Programs Association to provide increased services in this area¹⁰⁷.

3.78. Notwithstanding the additional funding that has been put into post-school services, the committee sees that considerable gaps appear to exist in the provision of services for young people with disabilities when they leave school. The committee urges the Government to address this area of unmet need as a matter of urgency.

¹⁰² Transcript, 10 June 1999, p 187, Ms Crawford.

¹⁰³ *ibid*, p 188-189, Ms Reisch.

¹⁰⁴ *ibid*, p 190, Ms Cain.

¹⁰⁵ *ibid*, p 191, Ms Cain.

¹⁰⁶ *ibid*, p 89, Ms Reisch.

¹⁰⁷ Submission 12, p 16.

Behavioural problems

3.79. The committee heard that providing respite care support for people with extremely challenging behaviours is particularly difficult for families and carers. Marymead outlined the following case that provides an indication of some of the difficulties confronting families placed in this situation.

One case that springs to mind, is an adolescent who frequently – and this might happen several times a day – will go into a form of rage, usually resulting in aggression against people. At home, it means that the parents are physically vulnerable because as an adolescent he is about the same size of the parents. In the work setting and at school, it also means that the staff frequently are at risk of being hit, bitten, punched... very physical risks where injuries do occur fairly regularly. The concern is very much with the home situation where the parents are with this child at all hours other than school and that has been recently reduced and some after school care. They are there 24 hours a day other than those school hours. They are there every night which can sometimes be disruptive and it is a family that is trying to maintain some semblance of family life, both for the child with a disability and for other children, one is still at home and others have moved out.¹⁰⁸

3.80. The committee heard that it was a long struggle for the family to receive respite care services it needed.

People with dementia

3.81. The committee was advised that people with dementia and their carers have quite specific care needs. Dementia is not just a condition that affects older people, it has been known to affect people as young as thirty years old¹⁰⁹.

3.82. The Alzheimers Association ACT describes dementia in the following terms:

“Dementia” describes a set of symptoms indicating brain failure. The brain is the organ of thinking and behaviour, so the symptoms of dementia consist of aberrant behaviours such as language difficulties, failure to recognise people, mood changes, an inability to care for oneself, and underlying all these, a loss of memory¹¹⁰.

3.83. In evidence presented at the public hearing, a representative of the Alzheimers Association ACT recalled a conversation with a sufferer describing the impact of the condition on her: ‘I am slowly losing pieces of myself and I will never get them back. The really scary thing is that I don’t even remember which pieces have gone any more’¹¹¹.

3.84. In the ACT, there are approximately 2000 people who have been diagnosed with dementia, with that number expected to rise to around 7000 in the year 2041¹¹². Approximately 25 per cent of people over the age of 80 and 5 per cent of people over

¹⁰⁸ Transcript, 16 June 1999, p 11-12, Mr Zilber.

¹⁰⁹ Submission 13, p 2

¹¹⁰ Submission 13, p 11.

¹¹¹ Transcript, 16 June 1999, p 33, Ms McGrath.

¹¹² Transcript, uncorrected proof, 16 June 1999, p 28, Ms Boden.

the age of 65 have some form of dementia, and approximately 50 per cent of people with dementia are supported in the community by carers¹¹³.

3.85. The committee was advised that often people diagnosed with dementia feel shameful about their condition and that services need to be sensitive to this¹¹⁴. Effective respite for people with dementia provides the family of a sufferer with an opportunity to spend time away from their loved one and this ‘time-out’ was cited as important in helping both the family and the person come to terms with the condition¹¹⁵.

Inappropriate services

3.86. The committee received evidence from the Alzheimers Association ACT that there is an insufficient level of dementia-specific respite care services available in the ACT¹¹⁶. When respite is required often sufferers are placed inappropriately in aged care facilities, which are not able to deal with the particular circumstances and needs of people with dementia and their carers, especially younger people.

3.87. A stark example of this gap in service provision was presented to the committee in the Alzheimers Association ACT submission.

Quite recently one of our members had a fall and was hospitalised and unable to care for his wife. His wife, a lady of fifty-four diagnosed with “Lewy-Body” dementia, was placed in an aged care hostel for one week’s respite. During her stay this lady commenced menstruation, when she had run out of her own personal hygiene products she asked if they could help her. The only thing the staff in an aged care hostel could provide were incontinence pads. This caused a great deal of embarrassment to the lady, until another product could be purchased. Aged Care facilities, by their very nature are not equipped to care for younger people¹¹⁷.

3.88. The committee heard that there is only one dementia-specific hostel in the ACT capable of providing residential respite care. The committee was also advised that the three ACT nursing homes providing residential respite, do not have beds in a secure area and therefore cannot accommodate people with dementia who exhibit wandering behaviour¹¹⁸.

3.89. However, the Commonwealth Government submitted that residential respite is often an inappropriate form of respite for people with dementia as many sufferers are distressed by the changes to their daily routines that necessarily come about in this setting. In its 1997 report, *‘Respite Care Needs of Carers of People with Dementia’*,

¹¹³ Submission 23, p 14.

¹¹⁴ Submission 13, p 2.

¹¹⁵ *ibid.*

¹¹⁶ Submission 13, p 3.

¹¹⁷ Submission 13, p 2.

¹¹⁸ Submission 10, p 5.

the Alzheimers Association (Aust) argued that in-home respite is the preferred setting for carers as it minimises the disruption of sufferers' daily routines¹¹⁹.

Inadequate skills

3.90. The Association advised the committee that respite workers often do not have the appropriate skills for dealing with the specific needs of people suffering from dementia. In particular, an appreciation of the state-of-mind of sufferers and knowledge of the strategies for managing their anxieties and concerns is crucial if services are to be effective for this client group. Good communication was cited as being the key to effective respite care, while it was argued that inappropriate communication, 'can lead to behavioural problems, an exacerbation of what appears to be the dementia itself, whereas in fact it is the environment for the person that makes their behaviour worse'¹²⁰.

3.90. In this regard, The Association submitted that:

The wife of one of our client's has been away overseas, and the support workers that have been going in every day. While being very good, he would say every morning, "I don not know when my wife will be back". Instead of them saying to him, "She has been gone since this date, she will be back on that date, which is so many weeks; it must be lonely for you; you must really be missing her," they would brush it aside by saying, "Oh yes, she will be home later on. She won't be long. She will be home today, or she will be home tomorrow". Of course this man would get really quite worked up¹²¹.

3.91. Underlying this sort of inappropriate interaction is the lack of an adequate training regime needed to develop the specific skills for effectively dealing with sufferers. The committee was advised that while the Association provides training for respite workers to improve their interactions with sufferers and knowledge of their needs, the argument was put that more trained carers are needed¹²². The committee considers that organisations may not be properly fulfilling their duty of care to clients with dementia if their carers are not appropriately trained and the Association presented evidence that this is the case with some organisations¹²³. The Association note that:

...we have had phone calls from [one agency] [with] their own workers saying, "I have to go and visit somebody with dementia, and I have no idea, could you please send me some information, can you tell me what I can do and cannot do. How will I communicate with that person?" To me that is really quite criminal. There is a duty of care there on behalf of this organisation.

¹¹⁹ Alzheimers Association Australia (1997) 'Respite Care Needs of Carers of People with Dementia' cited in

Submission 23, 14

¹²⁰ Transcript, 16 June 1999, p 37, Ms Boden.

¹²¹ *ibid*, p 38, Ms McGrath.

¹²² *ibid*, p 38, 39.

¹²³ *ibid*, p 38, 39.

We get phone calls from the support worker saying, "Please give us information".

Inappropriate care has a direct impact on the person with dementia. In the support group we meet people who may have had a different care worker not well trained. You can tell. They are terribly depressed; they are upset; they are more confused. Their whole behaviour is totally different because they have had a different care worker that morning¹²⁴.

3.92. However, it was acknowledged that it is difficult to take respite workers away from actually providing care to allow proper training to be undertaken. The Association submitted that:

The Alzheimers Association does provide dementia training on a fee for service basis, but it is very hard... how do you ask a service to take their respite workers from doing hands on business, which is needed, to be trained, if there is no money to do that... [There is a] need for training, but there is the need to provide the service as well... which comes first, the chicken or the egg¹²⁵.

3.93. In terms of the need to provide quality carers and develop trust with clients, the committee sees that there is significant unmet need for people suffering from dementia. The fact that respite workers are already working at capacity and appear to have limited time to undertake training in this and other areas, indicates that there are simply not enough care workers available generally.

Unreported need

3.94. The Association advised the committee that because many people are ashamed of being diagnosed with dementia, they often deny having the disease and consequently do not seek any assistance. This, it was argued, has lead to a degree of unreported need.

3.95. The Association outlined the problem in the following way:

The openness [regarding dementia] is needed in order to be able to access the services, call for the services and demand the services. Currently there is an unmet need, because the need is not pressing for the services. They are hiding in their homes. There is certainly unmet need for respite care¹²⁶.

3.96. The committee considers that it is important to assess the unreported unmet needs of people suffering from dementia but recognises that due to the reluctance of some sufferers to acknowledge their condition, it is a difficult area to measure. As part of a larger study assessing the unmet need for respite, the committee supports the development of an appropriate methodology to assess this unreported need for dementia-specific respite.

¹²⁴ Transcript, 16 June 1999, p 39, Mrs McGrath and Ms Boden.

¹²⁵ *ibid*, p 42.

¹²⁶ Transcript, 16 June 1999, p 33, Ms Boden.

3.97. The ACT Division of General Practice indicated that it might be useful to survey GPs to determine levels of unmet need in this area¹²⁷.

Recommendation 9

As part of a comprehensive study into unmet need for respite care, the committee recommends the unmet needs of people with dementia be accurately assessed and that an appropriate methodology is utilised to achieve this purpose.

Information and education

3.98. Effective education and information resources are an essential means of encouraging people suffering from dementia to access services. The committee considers that by improving the wider community's awareness of the condition, the stigma associated with it could be considerably lessened, with the flow on effect that sufferers would be more accepting of their condition and less reluctant to seek assistance.

Recommendation 10

The committee recommends that the ACT Government make representations to the Commonwealth about the need to fund a public communication program aimed at removing the stigma associated with dementia.

Assessment process

3.99. The committee was advised that the current assessment process can often work against delivering the best respite outcomes for people suffering from dementia and their carers. The Carers Association of the ACT submitted that when an ACAT (Aged Care Assessment Team) assessment is done, usually both the care recipient and the carer are present. It was argued that it is difficult for a carer to provide an accurate indication of the difficulties confronting them whilst in the presence of the loved one for whom they care. The Association submitted that:

...it is quite difficult for the carer to talk about things over the top of the person they are caring for. The behaviour may be really difficult, but because Jack or Fred is sitting there listening to all of this the carer does not tell the full story¹²⁸.

3.100. The committee considers that the pressure, in this situation, on a carer to understate the problems that they are encountering has the potential to result in assessments that have little bearing on the true needs of the carer or the care recipient.

Recommendation 11

The committee recommends that the Government consult with relevant stakeholder groups to develop improved assessment processes to accurately

¹²⁷ Transcript, 16 August 1999, p 89, Dr Richards.

¹²⁸ Transcript, 16 August 1999, p 73, Ms Gregory.

determine the levels of need experienced by people with dementia and their carers.

Association funding

3.101. The Association advised the committee that every other Alzheimers Association across Australia receives core funding through the Home and Community Care (HACC) program. The ACT Association is the only organisation of its type not to receive this core funding for basic infrastructure and payment for an Executive Director. The Alzheimers Association ACT operates on a totally voluntary basis¹²⁹.

3.102. The committee sees that the job of providing effective advocacy on behalf of people with dementia and their families, especially about the need for dementia-specific respite, is made more difficult by the lack of funding for this body. The committee notes the high quality of the association's activity.

People with autism

3.103. Autism spectrum disorder (ASD) is a life long developmental disability which manifests during the first three years of life as the result of a neurological disorder. It presents symptoms such as abnormal responses to sensations, absence or delay of speech and language, and abnormal methods of relating to people, objects and events¹³⁰.

3.104. Action for Autism (AfA) advised the committee that respite care services for people with ASD should assist integration into the community by, 'providing positive communication episodes and rewarding social encounters with the community'¹³¹. By furthering integration through respite programs of this type, it was argued that sufferers would be less likely to, 'withdraw into stereotypical behaviours or inappropriate self-stimulation characteristic of untreated ASD'¹³².

3.105. AfA noted that families and carers of young people with ASD had the following specific needs:

- effective two-way communication with providers of respite care services;
- reasonable access to appropriate and effective respite services;
- credible assurance that respite care services respect and maintain the rights of young people with ASD;
- services that assist parents to integrate into economic and social life; and

¹²⁹ *ibid*, p 36.

¹³⁰ California Departments of Education and Developmental Services (1997) 'Best Practices for Designing and Delivering Effective Programs for Individuals with Autistic Spectrum Disorders: Recommendations of the Collaborative Working Group of Autistic Spectrum Disorders' cited in Submission 15. p 11.

¹³¹ Submission 15, p 5.

¹³² *ibid*.

- evidence that respite care services are appropriate and effective¹³³.

Inadequate skills and experience

3.106. The committee was informed that parents/carers of people with autism have little confidence in current respite services and a feeling existed that very few of the needs outlined above were being fulfilled by these services. Of particular concern was the absence of ASD-specific services, skills and experience in the sector¹³⁴.

3.107. It was argued that little empathy for, or even recognition of, the condition exists among some service providers. The Office of the Community and Health Services Complaints Commissioner noted in its submission a comment from one service broker that, “People still think that, on some level, these kids are intentionally bad and that you, as a parent, could do more”¹³⁵.

3.108. At the heart of effective respite for this group is the need for workers in the field to be properly trained in the modes of communication of people with ASD and in the strategies required to effectively manage the complex behaviours often exhibited by these people. AfA advised the committee that inappropriate behaviour management strategies only reinforce disruptive or antisocial behaviours¹³⁶.

3.109. To this end, AfA argued that each individual with ASD needs to be acknowledged as having a specific *modus operandi* and effective services should be, ‘familiar with their specific program and communication system’¹³⁷.

3.110. Unfortunately, it appears that this level of service is not currently available for people with autism and their families. The committee was advised that the experience of many of its members is that the programs available in special schools tend to provide a, “baby-sitting” model of respite ... which fail[s] to deliver observable functional, social or educational outcomes for children with ASD’¹³⁸.

3.111. It is difficult to see how this client group can receive effective respite care without a pool of workers that have been specifically trained to provide care that meets their unique needs.

Services unavailable and unaffordable

3.112. The Commissioner noted that Marymead is the only appropriate respite care service available for teenage autistic children with high personal care needs. However, the Commissioner argued that this service is not affordable for clients without a funding package.

¹³³ *ibid*, p 5.

¹³⁴ *ibid*.

¹³⁵ Submission 6, p 6.

¹³⁶ Submission 15, p5.

¹³⁷ *ibid*, p 5.

¹³⁸ *ibid*, p 5.

3.113. The Commissioner noted that:

Marymead conservatively estimated its charges for 24 hours of care (with one on one support, including a sleepover shift): these amounted to \$555 for week days and \$645 at the weekend¹³⁹.

3.114. Costs in this order obviously preclude all but the wealthiest people in the community from accessing such a service unless a funding package is provided. The Commissioner noted that this situation is in sharp contrast to the subsidised residential respite care services offered to less challenging clients through the Disability Program¹⁴⁰.

3.115. The Commissioner advised the committee that providing respite services to this client group should become part of the Government's 'core business' and would most appropriately be delivered through the Disability Program. Further, the Commissioner argued that where a standard service is 'unable to cope', the ACT Government should be prepared to buy in a service that meets the needs of people with autism, 'rather than leaving the child's carer to seek help in the private sector'¹⁴¹.

3.116. The committee was advised that the people with ASD are unable to access mainstream services either due to eligibility requirements or the unsuitability of most services.

3.117. For instance, the Commissioner advised the committee that the current generic holiday respite programs are not likely to be effective for high needs children such as those with autism. The Commissioner noted a comment from one service provider that, 'these [programs] tend to be loud, noisy and unpredictable, whereas autistic children need order, quiet and focus, and can't manage creative social situations set up for normal kids'¹⁴².

3.118. In its submission, the ACT Government acknowledged that as part of an effort to enhance respite services in the ACT, it needed to address the issues associated with meeting the special needs of people with autism. The committee urges the Government to seriously investigate how to best meet the needs of people with autism and their families and work towards positive outcomes for this group.

Family support

3.119. In the ACT, respite care services are available to impoverished families experiencing stress, violence and the absence of viable social supports in their lives. One of the important aims of this type of respite is to provide some relief to a parent or parents from the stress of parenting. This form of respite also allows children, who

¹³⁹ Submission 6, p 5.

¹⁴⁰ *ibid*.

¹⁴¹ *ibid*, p 5-6.

¹⁴² *ibid*, p 6.

are often at risk of abuse and/or have behavioural problems, to experience meaningful relationships with caring adults¹⁴³.

3.120. The provision of effective respite in this area can circumvent the need for children to go into emergency crisis care which is expensive to provide and distressing for the children¹⁴⁴.

3.121. The committee heard that there is an urgent need to provide community-based placements for teenagers, 'when family breakdown occurs and the young person and family need a short time apart'¹⁴⁵.

3.122. A major service provider in this area, Barnardos, advised the committee that providing care with a caring family in a household setting is the most appropriate mode of service delivery for young adolescents. Barnardos argued that youth refuges are inappropriate venues for providing effective care for young adolescents as these facilities often expose children to older 'streetwise' adolescents and that this can have a negative influence on a young child¹⁴⁶.

3.123. A care family can deliver focused attention to a child and provide an opportunity for the responsible agency to establish conciliation between the child and his or her family. Barnardos argued that opportunities for attempting this mediation are often foiled due to lack of appropriate respite services with the result that many young people become homeless or enter the substitute care system¹⁴⁷.

Eligibility requirements

3.124. Barnardos advised the committee that it has often had to refuse to provide services to people seeking assistance due to the eligibility requirements that it operates under.

A number of those families that we cannot service are people who might have jobs and a mortgage and actually need a break from the children but because they have an income and the children really are not at risk of going into long term care they do not get that support. So there is a whole middle range of people who miss out¹⁴⁸.

3.125. On the face of it, this situation suggests that there is a degree of unmet need for people in this situation. There is obviously a strong argument about the need to means test respite services to target the services to those most in need. However, Barnardos argued that people in this middle group of people seeking respite are falling through the gaps and also have significant and demonstrable need. In evidence, the organisation submitted that:

¹⁴³ Submission 3, p 2.

¹⁴⁴ *ibid*

¹⁴⁵ Submission 3, p 3.

¹⁴⁶ *ibid*, p 3.

¹⁴⁷ *ibid*.

¹⁴⁸ Transcript, 16 June 1999, p 3.

There really is not any other agency available that services that particular group of people and if you really wanted to do good preventative work then those people should get the break as well¹⁴⁹.

Insufficient number of carers

3.126. One of the problems confronting organisations like Barnardos, in terms of meeting the needs of their client group, is the difficulty it faces in recruiting suitable carers. Barnardos cited the inadequate allowances paid to carers as one impediment in this regard, advising that families providing respite care are provided with \$25 per night per child¹⁵⁰. This allowance has remained unchanged for nearly 10 years and has obviously not maintained parity with the expenses incurred by care families. Barnardos submitted that, 'this barely covers the cost of having the child in the carer's home let alone... [acknowledging] the degree of difficulty of the child's behaviour at times nor the disruption to that family's life'¹⁵¹.

3.127. Barnardos advised the committee that to be able to recruit skilled carers, funds must be available to allow payments of \$40 per night per child and an additional allowance if the child has behavioural difficulties¹⁵².

3.128. The committee heard that Barnardos started its respite care operations nine years ago, providing services to six families. Today, the organisation provides services to approximately 50 families and has only received one funding increase for extra care days since its inception¹⁵³.

Inadequate skills

3.129. Another area of unmet need raised by witnesses was the lack of options for placing children with extremely challenging behaviour. The major complaint in this regard was that even where services are available for this group, they are often of insufficient quality to be effective. Barnardos noted in evidence that:

...boys from, say, 12 up who are quite difficult and often very angry young people and it is very difficult then to find a family who can accommodate them. Most of the people who are able to do respite care have small children of their own. You certainly cannot add, say a violent adolescent to a home where you have small children¹⁵⁴.

We have also heard many stories, especially about some of these children more difficult to look after. A child has gone into respite – including long-term, residential, overnight, week-long respite – but the parents have been unable to use that opportunity for substantial breaks themselves to visit other family out of town or such like. They are

¹⁴⁹ *ibid*

¹⁵⁰ *ibid*, p 1-2.

¹⁵¹ *ibid*, p 3.

¹⁵² *ibid*.

¹⁵³ Transcript, 16 June 1999, p 9.

¹⁵⁴ Transcript, 16 June 1999, p 4, Ms Sharpe.

expected to be stand-by so that if things go wrong in the respite they have to come and take the child out¹⁵⁵.

3.130. This situation indicates that there may not be an adequate reservoir of suitably skilled carers able to provide effective respite for families in this situation. The committee considers that this may be due in part to the inadequate allowances paid to carers. The skills required to deal effectively with children exhibiting behavioural difficulties are quite specific and require appropriate training and experience.

3.131. As noted earlier, it is difficult to establish trust between carers and the people requiring care if the carer is unable demonstrate the skills and aptitude required to deal adequately with the care recipient.

3.132. In Chapter 4, the issue of improved training is discussed further.

Attention Deficit Hyperactivity Disorder

3.133. Attention Deficit Hyperactivity Disorder (ADHD) is a neurological condition that reduces the ability of sufferers to, 'maintain attention without distraction; control of doing, or saying something due to impulsivity and lack of appropriate fore-thought; and [inability to] control the amount of physical activity appropriate to the situation'¹⁵⁶.

3.134. In its submission, the Attention Deficit Disorder Support Group noted that children suffering from ADHD and their carers are confronted with significant challenges in dealing with the condition. Often children with the disorder have double or triple diagnoses such as 'intellectually challenged', oppositional defiant disorder or conduct disorder¹⁵⁷.

3.135. It was submitted that ADHD is a genetic based disorder and, as a result, often families have more than one member suffering from the condition. Children with the disorder also suffer from allergies and are often intolerant to food and chemicals¹⁵⁸. This hypersensitivity can make executing normal home duties very difficult for parents. In its submission, the support group noted that:

...hyperactive children can get very upset when taken grocery shopping, the florescent lighting, the colours, the movement and being in a different situation can all bring about a reaction. Coupled with all the foods and lollies on show and with these having colourings, flavourings and additives can make the shopping impossible and very stressful¹⁵⁹.

¹⁵⁵ Transcript, 16 June 1999, p 14, Mr Zilber.

¹⁵⁶ Berkshire AD/HD Research Group 'What is ADHD?' accessed from <http://www.web-tv.co.uk/wotsadd.html> on 28 September 1999.

¹⁵⁷ Submission 21, p 1.

¹⁵⁸ *ibid*, p 2.

¹⁵⁹ *ibid*, p 1.

3.136. Respite care services for this group need to be mindful of these issues if they are to be effective. The support group noted that in the absence of effective respite care, families could become dysfunctional¹⁶⁰.

Insufficient services

3.137. The committee was advised that there is a large portion of families with a child or children with ADHD that do not receive family support. The support group noted that Fabric is the only respite care service available for children with ADHD but because the organisation is working at capacity, parents face a 12-month wait to receive services¹⁶¹.

3.138. The committee did not receive a great deal of evidence as to the extent of unmet need for children suffering from ADHD. However, a number of stakeholders pointed out that it is currently difficult to determine where the most appropriate programs for these children are. Barnardos advised the committee that:

There are other programs that look specifically at children with disabilities but there is a whole range of children say with ADD, ADHD, who often cannot be accommodated in... [disability or family support programs] and where those children actually are best fitted is a difficult one to gauge¹⁶².

3.139. The committee considers that it is important to ensure that these children and their families have sufficient access to respite care services which properly meet their needs and calls on the Government to further investigate means of improving service delivery in this area.

Older people

3.140. The committee noted evidence from the Council on the Ageing who submitted that:

The *ACT Population Forecasts 1999 to 2012* predict that the number of people aged 65 years and older will increase from 24,100 in 1998 to 37,200 by 2010. This is an overall increase of 54%. At the same time, the proportion of the population aged 65 years and older will increase from 7.8% to 10.7%. In 1997, people aged 80 years and older represented 1.5% of the ACT population, but in 2010 they will represent 2.3% of the population¹⁶³.

3.141. In its submission, the ACT Government argued that this increase in the number of older people will not necessarily require additional services. Instead, it was argued that the type of services might need to *change* in the future if older people's needs are to be met¹⁶⁴. The committee is not convinced that services will need only to change

¹⁶⁰ *ibid*, p 3.

¹⁶¹ *ibid*, p 2.

¹⁶² Transcript, 16 June 1999, p 4, Ms Sharpe.

¹⁶³ Department of Urban Services, June 1998, '*ACT Population Forecasts 1998 to 2013*' cited in submission 11, p 3.

¹⁶⁴ Submission 12, p 13.

rather than receive supplementation given the likely increase in demand in coming years.

3.142. A recent COTA sponsored forum on residential respite care argued that Federal Government policies to 'keep people at home' have resulted in increased need and demand for respite care¹⁶⁵. However, some submitters argued that while the Federal Government's rhetoric extols the virtues of older people staying at home rather than going into a nursing home, the financial resources to allow this to be done effectively have not been allocated. In this regard, Respite Care ACT noted that:

The Government's Staying at Home program and the message that [it] is delivering to the community is causing the community to have expectations which we cannot meet. You know, it is all very well telling people they can stay at home, and I think that is a wonderful philosophy, but they are not sending the dollars out to the community sector to enable that to happen. It is as simple as that ¹⁶⁶.

3.143. The committee is concerned that while people are being encouraged to stay at home, the requisite funding does not appear to have been allocated and this has led to increased unmet need.

3.144. COTA argued that the move away from institutional care is placing additional pressure on the respite sector and that the ACT must be able to effectively argue its case for a fair share of federal funding. In its submission COTA noted that:

The policy direction of government and especially the Federal government, towards encouraging older people to live in the community rather than institutions places an increasing demand on family and the community to provide care. The result is that increasing numbers of people have need for short to medium term respite from the caring responsibilities.

The move toward reliance on informal care requirements should result in significant savings to the government from reduced institutional care costs. The federal government is responding to this charge with the carer allowance and increased funding for respite care. Without pre-judging whether current initiatives are adequate, it is essential that the ACT be able to effectively present a case to achieve an appropriate share of funding¹⁶⁷.

3.145. The committee considers that following an empirical investigation into unmet need for respite services (recommendation 1), a more compelling case can be made for additional federal funding.

3.146. In its submission, COTA also raised the following issues:

Other than Burrangiri, the principle places for residential respite care are the nursing homes and hostels, but no clear consistent approach to access exists...

Nursing homes and hostels can not take people who have not been assessed by ACAT...

¹⁶⁵ Submission 11, p 9.

¹⁶⁶ Transcript, 16 June 1999, p 57, Ms Sedden.

¹⁶⁷ Submission 11, p 4.

Many nursing homes require pre-booking for residential respite care with some being booked for up to 12 months. Very few are equipped to cope with short-term crisis care...

Residential respite care places are being used to meet convalescent requirements post hospitalisation possibly to the detriment of respite care needs...

Respite needs are equated to the ACT's number of nursing home and hostel beds and CACP packages. The ACT is told by the Commonwealth that we have our correct number of beds and packages, but COTA (ACT's) calculations indicate that this is not correct.¹⁶⁸

Recommendation 12

The committee recommends that the Government make representations to the Federal Government about the need to apply additional funds to the aged care services sector.

People suffering from mental illness

3.147. The committee did not receive a great deal of material about the respite care needs of people with a mental illness. However, the committee did find some evidence that problems are evident in current respite arrangements for this client group.

3.148. The Carers Association argued that in-home and residential respite for people with a mental illness is a problem. The Association noted that it is, 'critical in the case of emergency residential respite but still a problem in the home due to lack of trained respite workers'¹⁶⁹.

3.149. The Carers Association also raised the problem of eligibility criteria preventing some people with psychiatric disabilities from accessing services. The association noted that:

A person may be caring for a young person who may have psychiatric disabilities but whose psychiatric disability is not such that it is recognised by Mental Health Services as being a criterion for them intervening and providing resources. That person can have behavioural difficulties or can be suicidal or aggressive at times but is not going to meet the criteria for Mental Health Services. They have no daily activities they can join in. They are not appropriate for the resources that are there for many young people, because their behaviour does not make them manageable¹⁷⁰.

Veterans

3.150. Limited information was provided to the committee about the needs of veterans and the extent to which they are met. However, a submission by the Commonwealth Department of Veterans Affairs noted that, 'there are some difficulties in obtaining

¹⁶⁸ Submission 11, p 6.

¹⁶⁹ Submission 10, p 5.

¹⁷⁰ Transcript, 16 August 1999, p 70, Ms Young.

HACC funded respite in the ACT, and this is reflected through our expenditure on supplementary assistance for the veteran community in this region'¹⁷¹.

¹⁷¹ Submission 14, p 1.

CHAPTER 4. COORDINATION, PLANNING AND ADMINISTRATION

4.1. In the course of the inquiry stakeholders indicated that a number of problems existed in the administrative arrangements, planning processes and coordination of respite care services.

4.2. Issues identified as being problematic included repetitive assessment processes, lack of effective forward planning strategies, duplication of infrastructure amongst providers, ineffective cross-agency coordination, and ineffective case management and continuity of care provisions. These issues are dealt with in this chapter.

Assessment processes

4.3. Several submitters provided evidence that current assessment processes and eligibility criteria are excessively layered, with people seeking care often required to undergo numerous assessments from different agencies. In this regard, the Carers Association noted that:

...[carers] say it to us regularly – that the constant stream of assessors, the constant asking of similar questions by a range of providers, is in itself another great stress for people. When I say “streamlining”, I am even thinking of HACC [Home and Community Care] services. There is an assessment form called the CIARR form, which some services use and some do not. I think we could see a considerable rationalisation, streamlining, of the assessment process, even if across the board within those services a common assessment form is used.

Clearly, the way things are done at the moment is very intrusive. People find it very difficult and very stressful. Often they will say it is not worth it. They are telling me that it is really not worth accessing a service they can only get for two hours a week anyway. There is a whole range of people involved in the assessment process¹⁷².

4.4. In a similar vein, Marymead submitted that:

Many families get sick and tired – and “tired” is the critical word – of having to continuously justify the need for more respite. Every time they feel they have an increased need they might like to ask for more respite, but then they have to justify it. There is this notion of repetitive assessments and criteria setting¹⁷³.

4.5. The committee understands that the Government is currently conducting a review of assessment processes. The committee believes that it is important that the review examines the level of repetitive assessments and that measures are adopted which have the effect of reducing repetitive assessments by different agencies.

4.6. However, the committee notes that in order to ensure that responsive and flexible services are directed to people in need, it is important that individual caring situations

¹⁷² Transcript, 16 August 1999, p 72, Mrs Radnedge.

¹⁷³ Transcript, 16 June 1999, p 14, Mr Zilber.

are reviewed over time in the context of case management. This issue is discussed later in the chapter.

Recommendation 13

The committee recommends that the ACT Government work together with service providers, the Commonwealth and other relevant agencies to develop uniform assessment processes that minimise the incidence of multiple assessments by different agencies.

Social Workers and whole-of-life-analyses

4.7. As noted earlier, it is crucial that if respite care services are to be effective they must be designed and implemented with the needs of the care recipient, the carer and the family in mind. To this end, it is important that assessment processes are able to accurately identify the level of need based on a broad range of factors and the life circumstances of those in the caring situation. In this regard the Carers Association submitted that:

There seems to be numerous sets of eligibility criteria for gaining access to respite services in the ACT. This mixed approach to providing respite services requires considerable resources to administer. Many of these criteria are focused on the care recipient and not the carer and have inherent rigid service guidelines which can act as a barrier to provision of a truly flexible respite service which meets the needs of the care situation¹⁷⁴.

4.8. Another point that was raised in the course of the inquiry was the lack of trained social workers involved in the assessment process. It was argued that social workers are often in a better position to be able to identify the need for respite services based on a broad range of factors.

4.9. The Carers Association noted in the public hearing that:

...there has been a move away from social workers, from skilled trained people, doing these assessments. I know that some of the assessors at the moment come from a trained nurse background, and many of them would not have the skills and training that social workers have... If people are going to be in roles where they are the central point of assessment that leads to a whole range of services and supports being negotiated or suggested, they need to have the appropriate skills to be able to do that assessment.

A very competent, well-trained person is able to zero in on the needs of the cared-for person and the needs of that family – the needs of that holistic situation. If the antennae are not up, a person is not alert to carer stress or the fact that the male partner in the family is working two jobs. What time would he be able to put into the caring situation, particularly if there are three or four other members of that family? What needs do other members of that family have? Is there family support? Is there a good neighbourhood network? Is there a good church network? If those sorts of things are not picked up at

¹⁷⁴ Submission 10, p 2.

assessment, it can be a barrier to the sorts of services that might be offered to that family or that caring situation¹⁷⁵.

4.10. Against this background, the committee considers that while assessments do not always have to be undertaken by social workers, it is important the staff doing the assessments possess the relevant expertise to be able to correctly assess the needs of people based on a broad range of factors.

Recommendation 14

The committee recommends that the Government ensure that eligibility requirements and assessment processes are underpinned by broad whole-of-life analyses which accurately reflect the needs of carers, care recipients and other family members.

Recommendation 15

The committee recommends that the Government ensure that people undertaking assessments for respite care have the necessary skills and training to accurately identify need levels and service requirements for particular caring situations.

Improved information

4.11. The committee understands that often the Intake and Assessment Unit within ACT Community Care will refer people to certain providers and subsequently discover that there is insufficient capacity for the provider to allocate services.

4.12. This results in many people seeking care having to undergo a 'run-a-round' - going from provider to provider. The committee considers that if service providers were to provide the Unit and service brokers with accurate up-to-date information about service capacity, carers and care recipients would be more likely to be referred to a service with spare capacity immediately. This process could easily be incorporated with the uniform report mechanisms for unmet need as proposed in recommendation 2.

Recommendation 16

The committee recommends that the Government seek the cooperation of respite services to provide on an ongoing basis up-to-date information to the Intake and Assessment Unit and service brokers about service capacity.

Case management and cross agency coordination

4.13. The committee received a substantial amount of evidence from a range of service organisations and advocacy groups calling into question the effectiveness of current provisions for case management and continuity of care. Case management

¹⁷⁵ Transcript, 16 August 1999, p 74, Mrs Radnedge.

involves the strategic management of the needs, both current and future, of particular caring situations. A case management approach has the capacity to prevent services being applied in an ad hoc fashion and is particularly important in managing complex care needs over time.

4.14. ACROD ACT informed the committee that:

...“case management” is open to interpretation, but it covers the notion of bringing together and coordinating complex needs provided to an individual from various agency sources. As I understand it, there has been a tradition within the ACT that no one agency will provide from its own resources the total needs of a complex case. Therefore a framework has been established formally and informally that requires multiagency input to meet complex needs. That raises the issue of who should coordinate that¹⁷⁶.

4.15. It seems that in many cases the people coordinating services are the carers themselves. Advocacy ACTION pointed out what a difficult situation this places carers in, noting that:

...there are many families/carers who spend so much time and energy coordinating services in a frustrating environment full of barriers, they lose sight of their other relationships with that individual. That is, it's hard to be a mum or a dad or a partner or a child or a friend when you're the case manager. There are many families/carers who believe they would benefit from this sort of support and case management¹⁷⁷.

4.16. Following this, the ACT Division of General Practice noted in evidence that operating in the current system is, 'like trying to work your way through a maze' in that it is difficult for people, indeed the GPs themselves, to negotiate the system and assimilate information about services. The Division noted that:

Often there are a myriad of small non-government organisations providing quite a decent range of services. You try to remember which one you need where and when and how to get in touch with them. They are sending out different little pamphlets and brochures and letters reminding you every year or so of their service. You think, “Now what did I do with that? Where do I go for this particular service?”¹⁷⁸.

4.17. The coordination system as it stands appears to place much of the onus on carers and their families to access services and manage the care situation. A letter to one member of the committee outlined a stark example of how some people are being poorly served by ineffective coordination and case management practices.

¹⁷⁶ Transcript, 16 July 1999, p 66, Mr Bray.

¹⁷⁷ Submission 19, p 4.

¹⁷⁸ Transcript, 16 August 1999, p 91, Dr Richards.

Ruth is a young adult in her last year at school for the intellectually disabled. She suffers a degenerative disease and has significant behavioural problems exacerbated by the pain following recent damage to a kidney – the result of an altercation in a care situation.

As a result the family now care for her in their home. While she and her family receive support from a number of agencies it does not provide all that is needed. And there is a further considerable problem as it is a major exercise just in itself to marshal that support. The advocacy agency expresses it in a letter to officials: ‘You may not fully understand that at the moment, to meet the basic support needs of this family, eight agencies have become involved; with five separate brokerage pools being used to fund the support. The situation is cumbersome, inefficient, illogical, confusing and results in a heightened feeling of insecurity for the family’¹⁷⁹.

4.18. Deficiencies in case management were also cited in relation to aged care. The Carer’s Association noted that:

When ACAT [Aged Care Assessment Team] first set up in the ACT, it had more of this role where it was not just filling in the form, getting the Commonwealth data, doing the assessment, qualifying people for the level of care that they need and then opting out. It was much more a service that took the person – the carer or the client – through where they were at and moved them on to where they wanted to be. But now it is very much a one-off thing, and I think that is a significant limitation¹⁸⁰.

4.19. The Carers Association saw some benefits in having a central coordination point for people to help them manage and review their needs. The Association argued that:

Regular review of the caring situation, with very open communication, allows a family or a particular care relationship to get back to a central person to say that things have changed or that a particular situation has arisen. I think ongoing review and assessment are a very critical part of the whole scenario¹⁸¹.

4.20. However, the Association and other agencies noted that they would have concerns about establishing a central assessment and coordination model or ‘gateway’ model across the board¹⁸².

4.21. Respite care submitted that:

There has been a lot of talk about the single gateway and all of these sorts of things, but the problem is that the one attempt that we have at a single gateway in the ACT is predominantly the nursing medical model, which is superfluous to us. We need to be cognitive of the client’s needs in that regard. The kind of information they would collect in an assessment is really of no interest to us at all

¹⁷⁹ Letter from an advocate provided to the committee

¹⁸⁰ Transcript, 16 August 1999, p 75, Mrs Radnedge.

¹⁸¹ Transcript, 16 August 1999, p 74, Mrs Radnedge.

¹⁸² Transcript, 16 August 1999, p 72, Mrs Radnedge.

...It is a fairly complex problem and I do not think you would get two agencies agreeing on that. We have all got our different philosophy on whether that [a single gateway] is a good thing or a bad thing. Until you can get a consistent standard of assessment in any one area, be it a gateway or be it all across the board, I do not think that that would be an equitable way of doing it either, because people play favourites¹⁸³.

4.22. The committee understands that the ACT Government has received a consultant's report on case management and that it may recommend that a single agency or community group undertake a coordination role. The committee understands that this approach is a matter of some contention in the sector and will continue to be the subject of ongoing debate. Ahead of the report's presentation, the committee makes no recommendations in this regard but considers that the case management approach, whether implemented via a central agency model or via decentralised providers, has merit.

4.23. People with high or complex care needs and their carers will no doubt be better served if case managers are appointed to take on the assessment and coordination of individual care situations. If done effectively, this approach has the capacity to minimise the run-around experienced by many carers and shifts the emphasis from generic care solutions towards 'custom-built' ones.

4.24. The ultimate goal for the agencies providing respite services should be to develop seamless and integrated service delivery strategies that minimise the amount of time and energy expended by those seeking care. Ideally, those seeking services should be able to access agencies (either central or decentralised) that act as one-stop shops to meet the holistic care needs of individual care situations.

4.25. As part of an effort to improve cross-agency coordination, Barnardos argued that an inter-agency group that looked just at respite care might be useful'¹⁸⁴. The committees sees that this might also be a valuable means of increasing connections and communication flows between the various agencies providing care.

4.26. A comprehensive submission from the Office of the Community and Health Services Complaints Commissioner identified a number of systemic problems with the coordination of respite services it encountered whilst investigating complaints made by parents of autistic children. These problems were echoed by other stakeholders throughout the course of the inquiry and appeared to cover a wide range of client groups. In his submission, the Commissioner made the following recommendations:

...provision for the appointment of a case manager for people diagnosed with a disability characterised by complex care needs (needing one or more services such as speech pathology, physiotherapy, occupational therapy, social work, respite care). This person would be appointed as soon as the client was diagnosed with a disability such as autism or other disability at the high needs end of the spectrum. Their role would be to

¹⁸³ Transcript, 16 June 1999, p 56, Ms Seddon.

¹⁸⁴ Transcript, 16 June 1999, p 5, Ms Sharp.

work in partnership with the parents and service providers to develop a plan for child..., to negotiate service pathways with the parents, to coordinate these, and to arrange support for the family in dealing with the issues surrounding the diagnosis.

Provision for the development of individual 3-5 year plans for these people, reviewable annually. These plans should be developed by the relevant specialist service areas in collaboration with the child's case manager, parents(s) or guardian and advocates if appropriate. This might look something like the Management Assessment Panel (MAP) process managed by the Community Advocate's Office, in which key decisionmakers in relevant agencies meet to make arrangements for particular cases. This partnership approach would also ensure that the services provided complemented the help which the parents were able to give the child. The plan should also take into account the needs of the carer as well as the client, which means that respite care should be built into it.

Provision for more innovative funding mechanisms to allow for

- Funds to be allocated based on recognition that money spent now can result in future savings over the longer term (ie beyond the current budget or political cycle);
- Longer term funding to community service providers (with appropriate mechanisms to ensure accountability) to facilitate their own forward planning and resource organisation, and to enable them to offer better services and training to staff; and
- Continuing funding for complex care clients to support their individual plans, without the uncertainty of annual budget renegotiation¹⁸⁵.

4.27. The committee fully supports the views of the Commissioner and urges the Government to further investigate how these recommendations can be implemented as a matter of urgency.

Strategic planning

4.28. While the committee is supportive of the ACT Government's attempt to develop strategic plans for disability services and aged care, it is not convinced that the current planning framework is sufficiently advanced to develop effective respite services in coming years. The committee considers that the disability strategic plan, in particular, is very broad ranging but with little depth and appears to be more of a 'plan to plan' rather than a tangible strategic framework.

4.29. The committee considers that because respite care services form such a crucial area of service delivery for the range of people utilising them and those wishing to utilise them, a separate strategic plan may be warranted. If strategic planning is about determining, where the respite sector currently is, where it wants to be and how it is going to get there, then it seems to be a matter of common sense that a respite strategy should be informed by accurate and detailed information about the extent of need for services in the ACT.

¹⁸⁵ Submission 6, p 9.

4.30. COTA supported a respite-specific strategy noting the importance of accurate data in its development. In its submission COTA noted that:

The ACT needs to develop a comprehensive and wholistic [sic] strategy around the respite care needs of its people. This strategy must include the collection of statistics and other hard data to allow it to present a consistent approach both to the community and other governments¹⁸⁶.

4.31. The committee agrees with COTA and sees value in using the data collected in the empirical study (Recommendation 1) to inform the development of a respite care strategy. The committee sees as imperative the need for all organisations and individuals with an interest in the development of respite services to have a high degree of involvement in respite planning.

4.32. To this end, the committee sees value in the Government facilitating a working group made up of interested parties to progress policy development and improvements to service delivery.

Recommendation 17

The committee recommends that the Government develop a strategic planning framework for respite care services.

Recommendation 18

The committee recommends that the Government facilitate a working group made up of industry/community representatives, carers, care recipients, the medical profession and government officials to review the future directions that respite care policy should take.

Cross border coordination

4.33. In relation to cooperation and coordination between the ACT and NSW, the committee notes a submission made by the Mayor of Queanbeyan. In his submission the Mayor informed the committee that changes to ACT respite programs may impact regional services and that these services should be informed if any changes are to be made.

4.34. The Mayor further noted that:

... in the long run the most effective way to deal with the issues arising from the provision of respite and other disability services to NSW residents by the ACT Government would be to negotiate a formal inter-governmental agreement on the issue. This would provide certainty, assist in long term service planning and would facilitate the proper allocation of costs. We would urge the ACT Government to open negotiation with the NSW State Government on this matter¹⁸⁷.

¹⁸⁶ Submission 12, 4.

¹⁸⁷ Submission 7, p 2.

4.35. The committee sees value in developing a formal framework for respite services in the region.

Training

4.36. As noted in Chapter 3, the lack of appropriately trained carers in the respite care sector has meant that available services are not able to adequately meet the needs of some client groups including people with dementia, people with challenging behaviour, children with autism, and people with ADHD.

4.37. The committee considers that it is important to develop a training program for the sector which identifies the areas where training is needed and outlines a clear implementation plan with priority areas and targets.

4.38. In its submission, the Carers Association argued that:

There is an urgent need for accredited training programs to address [the] critical shortage of care providers and volunteers available especially for children with disabilities with challenging behaviour and people with mental illness. Many families can not access much needed respite because services do not have appropriately trained staff to provide substitute care for difficult clients with different behaviours. These training programs will provide workers with the skills and knowledge to manage and deal with the problems encountered in providing care to this high needs group. It will also provide workers with the resources to ensure that respite provides meaningful and therapeutic activities for the cared for person.

In the absence of this accredited training, many ACT families will continue to miss out on much needed time out from constant, very difficult and demanding care responsibilities. Either because they do not feel confident in the ability and skill of the respite worker or the respite service simply can not provide the service¹⁸⁸.

Recommendation 19

The committee recommends that the Government develop a strategic planning framework aimed at improving the range and quality of training opportunities for respite workers.

Duplication of infrastructure

4.39. Several stakeholders indicated that there might be an excessive duplication of infrastructure and administrative overheads due to the high number of smaller agencies operating.

4.40. The ACT Division of General Practitioners noted in evidence that:

I think there are too many little organisations. I suspect there is quite a high administrative overhead for each of them. That has been an historical trend. Community groups are formed to address a particular need. Multiple needs have been identified and multiple organisations have formed. It may be that that system needs to be rationalised

¹⁸⁸ Submission 10, p 6.

to some degree. It is largely funded through the HACC program now and a lot of money, I suspect, is going on lots of smaller organisational infrastructures¹⁸⁹.

4.41. The Carer's Association noted that:

Carers will tell you quite regularly that they think there are too many [services] and that there are too many administration bases. That is a fairly public debate¹⁹⁰.

4.42. In the committee's view, it would seem sensible to attempt some form of rationalisation of administrative and physical infrastructure throughout the sector. Where possible efficiencies might be gained by promoting co-location between some of the smaller agencies, allowing for economies of scale, shared building spaces and administrative staff and in some cases a single phone number.

Recommendation 20

The committee recommends that the Government's contracting and purchasing arrangements encourage tenderers, where possible, to work with existing service providers to reduce the duplication of administrative and building infrastructure.

Quality surveys

4.43. The committee was advised that it is important that quality and client satisfaction levels of agencies should be assessed from time to time and that currently there is very little accountability in this regard. Respite Care ACT noted that:

I would suggest that the funding body ought to engage the services of an external consultant or do it with their own staff... I have a problem with the fact that they [service agencies] can spend public funds to this extent in the whole sector and there is absolutely no monitoring of client satisfaction or quality in any of the HACC services¹⁹¹.

4.44. The committee agrees that monitoring service quality and client satisfaction is an important element in working towards service improvements and in further developing and industry ethos of responsiveness.

Recommendation 21

The committee recommends that surveys be carried out to assess quality standards and client satisfaction levels across service providers.

Bill Wood, MLA
Chairman

29 February 2000

¹⁸⁹ Transcript, 16 August 1999, p 92, Dr Richards.

¹⁹⁰ Transcript, 16 August 1999, p 77, Mrs Radnedge.

¹⁹¹ Transcript, 16 June 1999, p 52, Ms Seddon.

APPENDIX B: LIST OF SUBMISSIONS

1. Society of St Vincent de Paul
2. National Brain Injury Foundation Incorporated
3. Barnardos Australia
4. Community Connections Inc
5. ACT Division of General Practice Inc
6. ACT Community and Health Services Complaints Commissioner
7. The City of Queanbeyan
8. Young Carers Network Forum
9. Marymead Child and Family Centre, Disability Support
10. Carers Association of the ACT Inc
11. Council on the Ageing (COTA) ACT
12. ACT Government
13. Alzheimers Association ACT Inc
14. Commonwealth Department of Veterans' Affairs
15. Action for Autism
16. Respite Care ACT Inc
17. ACT Society for the Physically Handicapped Inc
18. ACROD ACT Division
19. Advocacy ACTion
20. People First ACT Inc
21. Canberra-Queanbeyan Attention Deficit Disorder Support Group Inc
22. Burrangiri Centre, The Salvation Army
23. The Commonwealth Department of Health and Aged Care

APPENDIX C: LIST OF WITNESSES

1. Barnardos Australia
2. Marymead Child and Family Centre
3. Alzheimers Association ACT Inc
4. Respite Care ACT Inc
5. ACROD ACT Division
6. Carers Association of the ACT Inc
7. ACT Division of General Practice
8. ACT Government

ATTACHMENT A

Funding and services

Both the ACT and Federal Governments fund respite care services in the ACT. In its submission, the ACT Government noted that the Commonwealth are primarily responsible for funding respite services for older people while the ACT Government provides the majority of funding (80%) for services for people with a disability. Both governments fund services for carers of older people and people with disabilities through the Home and Community Care program (HACC)¹⁹².

The committee considers that it is worth outlining some the main programs currently in operation and has summarised below the available respite care services in the ACT as outlined in the ACT and Federal Government submissions. Although not an exhaustive examination, this section provides a general overview of the respite care services available.

Disability-specific respite

Disability-specific respite care services purchased in 1997/98

Service Provider	Funding	Output
ACT Community Care – Centre based respite	\$819 112	170 people assisted on a regular basis
Respite Care ACT Inc. – Home based respite	\$264 078	11 500 hours of direct support per annum
ACT Society for the Physically Handicapped	\$71 304	Respite care to be available 52 weeks per year
TOTAL	\$1 154 494	

The ACT Government advised the committee that the Disability Program has provisions for centre-based care for both planned and crisis needs, and provides respite care to approximately 170 people on a regular basis¹⁹³.

New disability respite services purchased in 1998/99

Service Provider	Funding	Output
ACT Community Care	\$310 320	6 respite care places
Centacare	\$125 000	1 respite place for people with acquired brain damage at Dorothy Sales Cottage

Home and Community Care (HACC) services

The HACC program is jointly funded by the ACT and Federal Governments and is primarily aimed at supporting the wellbeing of people with disabilities, older people living in their own homes and carers. By providing ongoing support, HACC services

¹⁹² Submission 12, p 2.

¹⁹³ *ibid*, p 5.

attempt to avert the premature of admission of clients to institutions. In its submission, the ACT Government noted that while respite services are central to the HACC program, other HACC services such as home help, home maintenance, meals on wheels and community cursing also contribute to providing respite for carers¹⁹⁴.

In 1997/98, \$2 068 150 or approximately 20 percent of HACC funding was spent on respite care services. Below is a list of the providers receiving HACC funds along with the output levels for respite care and the funding allocations for each provider¹⁹⁵.

HACC respite care services purchased in 1997/98

Service Provider	Funding	Output
Australian Red Cross – in home	\$85 851	4000 hours of respite per annum
Belconnen Community Services – centre based	\$32 319	6360 hours of respite per annum
Centacare + Marymead – host family	\$35 020	4100 hours respite per annum
CAPS Access – day and community access	\$111 260	4500 hours of respite per annum
Fabric – Integrated in home – In home – Additional hours	\$106 093 \$760 416 \$14 636	5350 hours of integrated respite per annum 38 500 hours of respite care per annum 745 hours of respite – part year effect of increase of 5760 in full
Finnish Rest Home – centre based	\$12 000	Non-recurrent to provide centre based care
Mirinjani Nursing Home – centre based	\$8 509	160 client-hours per annum
Nth. Belconnen Day Centre – day and community access	\$37 978	576 hours of respite per annum
Northside Community Services – day and community access	\$50 179	6 176 hours of respite per annum
Respite Care ACT Inc – In home – Integrated	\$407 824 \$119 456	19000 hours of respite per annum 4100 hours of integrated respite per annum
Southside Community Services – day and community access	\$9 151	3400 shard-respite hours per annum
Tuggeranong Community Services –	\$15 682	3000 respite hours per annum

¹⁹⁴ *ibid*, p 6.

¹⁹⁵ *ibid*, p 7.

day and community access		
Weston Creek Community Services – day and community access	\$25 957	6768 respite hours per annum
Woden Community Services – day and community access	\$15 377	2592 respite hours per annum
ACT Narrabundah Health Centre – centre based	\$93 869	2363 occasions of client attendance
Sharing Places – day and community access	\$126 573	2786 service units with a maximum of 7 places
Total	\$2 068 150	

New HACC respite services purchased in 1998/99

Service Provider	Funding	Output
Kincare	\$114 000	8760 respite hours per annum

In its submission, The ACT Government also noted that 11,150 occasions of service for day respite care are provided by ACT Community Care at Belconnen, Tuggeranong and Dickson.

Crisis respite

The ACT Government purchased \$0.839m in crisis respite services from Burrangiri Crisis Respite Centre, operated by the Salvation Army. The centre provides centre-based residential crisis respite and day programs for frail older people¹⁹⁶.

Mental health services

The following service providers deliver respite services for people with a mental illness.

- The Mental Health Foundation's Warren I'Anson Respite House provides three to four (non-government) short-term respite care places for self-supporting adults with a psychiatric disability¹⁹⁷.
- Barnardos provides respite services for children with a mental illness and for children whose parents have a mental illness. In 1997/98 the ACT purchased 340-

¹⁹⁶ *ibid*, p 7.

¹⁹⁷ *ibid*, p 8.

400 care-days from Barnardos. Funds were also applied to provide school holiday respite including week and day camps¹⁹⁸.

- The ACT Government provider, ACT Mental Health Services, also provides respite services through three main service models. These are:
 - acute respite in a residential unit;
 - planned respite at Hennessy House; and
 - urgent accommodation or transience are managed via the Crisis Assessment Team (CATT) accessing the Macquarie Motel¹⁹⁹.

The ACT Government advised the committee that \$40,000 had been allocated for 1998-1999 to provide new respite care options for people with a mental illness.

Palliative Care

The ACT Hospice, managed by the Little Company of Mary aims to provide two beds for respite care, although sometimes there may only be one bed in use depending on the nursing needs of palliative care patients. These beds are generally available for two weeks at a time.

There is frequently a waiting list for people wanting to access these respite beds and the committee was informed that there was a feeling at the hospice that access to these beds allowed people with terminal illnesses to be maintained at home longer.

Respite services are also provided through volunteers supported by the ACT Hospice and Palliative Care Society²⁰⁰.

Families and children at risk

The Family Services Branch in the ACT Department of Education and Community Services provide respite services directed towards families with dependent children who are at risk of placement outside the family home because the family has inadequate supports.

Both planned and emergency respite services are available for this client group from the following service providers.

- Barnardo's Temporary Family Care Program provides 2460 care-days per year, one thousand of these are for community referral for emergency respite care and the other 1460 care-days are for people referred by Family Services to receive emergency care. Throughout 1997/98, 1559 care-days were used by community referrals by 132 children.

¹⁹⁸ *ibid*, p 8.

¹⁹⁹ *ibid*, p 8.

²⁰⁰ *ibid*, p 9.

- Marymead Family Support Service provides a total of 300 care-days per year with referrals accepted from parents, community agencies, Family Services or other Marymead programs. Throughout 1997-98, 64 children accessed these services and 491 care-days were utilised.
- The ACT Society of the Physically Handicapped provides support services for high needs children that are already in foster care²⁰¹.

Federal Government's National Respite for Carers Program

As part of the Federal Government's National Respite for Carers Program, Carer Resource Centres were established across Australia to provide information and advice on the caring role, including a referral service for respite care.

The ACT Carer Resource Centre was allocated \$93,500 in the 1998-1999 financial year with the Carers Association of the ACT receiving \$70,000 under the Carers Information Program²⁰².

Between October 1998 and December 1998, the ACT Carer Resource Centre indicated that the total number of carers assisted through the frontline telephone service had increased by 29% and on a whole-of-service basis had provided 14% more assistance to carers.

Carer Respite Centres were also established as part of the National Respite for Carers Program. These centres act as coordination points for the provision of respite care services, administering a brokerage budget to purchase short-term or emergency respite on behalf of carers.

In the 1998-99 financial year, the ACT Carer Respite Centre received \$262,390 in funding. Collocated with the Resource Centre, the Respite Centre has, according to the Federal Government, been able to 'trial innovative approaches to respite care... [such as offering] five hours of respite care to twenty-five carers for one Friday evening to enable the carers to enjoy late-night shopping'²⁰³.

Under the Commonwealth Respite for Carers Program, there are currently four community initiatives providing respite care services.

- The Dementia Respite Service/Mobile Respite Response Team (MRRT) provided by the ACT Carer's Association and the Alzheimers Association has been allocated \$402,500 in funding over four years. The MRRT provides 200 hours of in-home respite each month (including 40 hours of volunteer peer support), offering individual clients this respite support for up to eight weeks. The team also

²⁰¹ *ibid*, p 10 – 11.

²⁰² Submission 23, p 6.

²⁰³ *ibid*, p 8.

provides education and information on dementia to employees working in the scheme and develops individual care plans for both carers and care recipients.

- The Burrangiri Saturday Program has recurrent funding of \$64, 500 to provide the only Saturday day-care program for people with dementia and respite service for their carers. There are currently 15 clients using the service.
- The Mirinjani Day Program provides care for frail aged people, people with dementia and young people with high support needs. The program receives recurrent funding of \$9,700. This centre-based program currently has 12 clients and operates 1 day per week, 40 weeks per year, offering a variety of recreational activities.
- The Narrabundah Day Program for Younger Men with Dementia provides respite services for physically able men with a dementing illness. The program receives recurrent funding of \$13,650 per year. Average monthly attendance at the program is 25²⁰⁴.

Community Options

ACT Community Options provides a brokerage service for frail older people, younger people and their carers. The service is widely used by people from diverse cultural and linguistic backgrounds, with 32 percent of carers using the service coming from non-English speaking backgrounds. The service concentrates on providing respite on a short-term and one-off basis; it is focused on being flexible and responding to the changing needs of carers. The service receives \$91,620 in recurrent funding²⁰⁵.

Caregiver Recreational Respite Program

The Caregiver Recreational Respite Program funded through an Aged Care Program Support Grant provided respite for three to four hours a week, for seven weeks, to 39 carers. The program was aimed at providing opportunities for carers to pursue a range of recreational activities on offer or to participate in recreational activity of their own choosing²⁰⁶.

Residential respite

The Commonwealth Government submission noted that residential respite services are operating at close to full utilisation²⁰⁷. In the ACT, there were 13,505 respite days available in residential aged care facilities throughout the 1998/99 financial year. In the 1998 calendar year, over 96 percent of available care days in the ACT were utilised compared to only 59% nationally²⁰⁸.

²⁰⁴ *ibid*, pp 8-11.

²⁰⁵ *ibid*, pp 11-12.

²⁰⁶ *ibid*, p 12.

²⁰⁷ *ibid* p,12.

²⁰⁸ *ibid*, pp 12-13.

Dementia respite funding

On 16 August 1999, the Federal Government announced a set of initiatives valued at \$82.2 million aimed at increasing respite support services for carers of people with dementia and cognitive or behavioural difficulties. The funding will be provided over four years and will be applied to the following three broad programs:

- expansion of Carer Respite Centre network (\$15.2m)
- development of additional respite services (\$55.5m); and
- additional improvement of respite service quality (\$6m)²⁰⁹.

²⁰⁹ Mr Michael Moore, Letter, 9 September 1999.