

STANDING COMMITTEE ON HEALTH, COMMUNITY
AND SOCIAL SERVICES

Love Has Its Limits - Respite care services in the ACT

DECEMBER 2010

Committee membership

Mr Steve Doszpot MLA (Chair)

Ms Amanda Bresnan MLA (Deputy Chair)

Ms Mary Porter AM MLA

Secretariat

Grace Concannon Secretary

Lydia Chung Administrative Assistant

Contact information

Telephone 02 6205 0129

Facsimile 02 6205 0432

Post GPO Box 1020, CANBERRA ACT 2601

Email committees@parliament.act.gov.au

Website www.parliament.act.gov.au

Resolution of appointment

On 9 December 2008, the Legislative Assembly for the ACT resolved to establish the **Standing Committee on Health, Community and Social Services** to:

Examine matters related to hospitals, community, public and mental health, health promotion and disease prevention, disability matters, drug and substance misuse, targeted health programs and community services, including services for older persons and women, families, housing, poverty, and multicultural and indigenous affairs.¹

Terms of reference

To inquire into and report on government and non-government respite care services in the ACT, with particular reference to:

- the Auditor General's Report, No 3 of 2009, Management of Respite Services in the ACT;
- the needs of care recipients (including children, teenagers and adults with a disability, elderly people, people with mental health issues and people from culturally and linguistically diverse backgrounds) and their carers;
- the needs of staff who provide respite care, including working conditions and training;
- the range, availability and suitability of respite care services, including any unmet need;
- the interaction between government and non-government providers of respite care;
- the experience of service users who utilise government and non-government providers of respite care; and
- any other related matter.

¹ Legislative Assembly for the ACT, *Minutes of Proceedings No 2*, 9 December 2008, pp 12–13

TABLE OF CONTENTS

Committee membership	i
Resolution of appointment	ii
Terms of reference	ii
ABBREVIATIONS.....	V
FOREWORD.....	VII
RECOMMENDATIONS.....	IX
1 INTRODUCTION.....	1
Conduct of Inquiry	1
Auditor-General's report	3
The policy context	4
Structure of this report.....	6
2 WHAT IS RESPITE?	9
3 NEEDS OF CARE RECIPIENTS AND CARERS	15
Needs of carers	16
Needs of care recipients.....	22
Young carers	30
Older carers	33
Aboriginal and Torres Strait Islander people	36
Culturally and linguistically diverse people.....	39
Attention Deficit Hyperactivity Disorder	42
4 RANGE, AVAILABILITY AND SUITABILITY OF RESPITE SERVICES	45
Flexible respite	45
Lack of other support services.....	47
Alternative models of respite.....	51
Quality assurance	54
Managing complaints.....	60
5 DISABILITY, MENTAL HEALTH AND COMMUNITY CARE WORKERS	63
Shortage of qualified staff.....	66

Staff training needs	69
Minimum standards for workers	71
Portable long service leave	74
6 NAVIGATING THE SYSTEM (INTERACTION BETWEEN GOVERNMENT AND NON-GOVERNMENT PROVIDERS)	77
Access to information.....	78
Case management.....	80
Community partnerships	82
'No wrong door'	83
Experience of service users	85
7 CURRENT AND FUTURE NEED	87
The ageing population	88
Managing current demand	90
Future demand.....	92
8 CONCLUSION.....	95
APPENDIX A: SUBMISSIONS	97
APPENDIX B: PUBLIC HEARINGS	99
APPENDIX C: RESPITE CARE SERVICES IN THE ACT ..	101

ABBREVIATIONS

ABS	Australian Bureau of Statistics
ACAT	Aged Care Assessment Team
AIHW	Australian Institute of Health and Welfare
AG	Auditor-General
ADHD	Attention Deficit Hyperactivity Disorder
ATSI	Aboriginal and Torres Strait Islander
CACP	Community Aged Care Package
CALD	culturally and linguistically diverse
CIT	Canberra Institute of Technology
CLP	Community Living Project
CSTDA	Commonwealth State and Territory Disability Agreement
DSO	Disability Support Officer
EACH	Extended Aged Care at Home
EACH-D	Extended Aged Care at Home Dementia
FaHCSIA	Australian Government Department of Families, Housing, Community Services and Indigenous Affairs
MHACT	Mental Health ACT
MHRP	Mental Health Respite Program
NDA	National Disability Agreement
NDS	National Disability Services
NDSS	National Disability Service Standards
NRCP	National Respite for Carers Program

STANDING COMMITTEE ON HEALTH, COMMUNITY AND SOCIAL
SERVICES

RACF	Residential Aged Care Facility
SDAC	Survey of Disability, Ageing and Carers
TOCC	Taskforce on Care Costs

FOREWORD

Families have taken on the primary caring role, since the deinstitutionalisation of people living with a disability and /or a mental illness. While it is appropriate for families to care for their loved ones, it is difficult to imagine the physical and emotional toll on the primary carer and other family members. Through the submissions received and oral evidence, the Committee was able to gain some insight into the plight of carers in the ACT.

People do not choose to become carers. They do so out of necessity when a child is born with a disability; a child or partner develops a mental illness or chronic condition; or an elderly parent develops an age related disability. Most families accept their caring role as an extension of the love of the family unit. However, love alone is often not enough to meet all the needs of care recipients. For example, children with disabilities, like everybody else, grow into adults with intellectual, emotional and social needs that cannot necessarily be fulfilled within the family unit. Adults living with a mental illness or an intellectual disability require support outside the family unit to develop independent living skills, in preparation for a time when their primary carer may no longer be able to provide care. For all people, young and old, with a disability or without, social interactions and friendships outside the family unit can only improve ones quality of life.

For this reason, the Committee chose the title *Love Has Its Limits*² for this report, in recognition of the difficult and frustrating situation in which many carers find themselves.

The Committee embarked on this inquiry to make a difference to the lives of carers in the ACT, but was surprised at the lack of confidence expressed by many carers, that anything would change. As one carer told the Committee

² Ms Karna O'Dea, Transcript of Evidence, 14 April 2010, p 9

'ACT families are too focused and too fatigued to concern themselves with yet another bureaucratic inquiry, to answer yet more questions that have been asked a thousand times and see the same tokenistic action'.

During all the inquiries, policies and action plans that have gone before, the voice of the carer was clear, little has changed over the years. While carers have a range of needs depending on age, ethnicity and the care recipient's needs, respite care was identified as an essential service for all carers. Without it, many families would not be able to continue in their caring role for as long as they do.

Care recipients also need access to quality services to occupy their days, particularly in the post school years or when their primary carer is no longer able to continue in the caring role.

This was not an easy inquiry. The angst and frustration expressed through submissions and directly by carers who appeared before the Committee at public hearings was disturbing. The daily struggle for these families was exacerbated by the lack of certainty for the future of their loved ones.

The Committee has made 28 recommendations aimed at improving the lives of carers and the people they care for. It is now up to the government to consider the recommendations in the context in which they have been made, to deliver real change for carers and to ensure this report is not simply filed away to become yet another wasted inquiry.

Steve Doszpot MLA

Chair

RECOMMENDATIONS

RECOMMENDATION 1

2.20 The Committee recommends that the Department of Disability, Housing and Community Services (DHCS) and ACT Health develop a common definition of respite that includes the role, purpose and benefits of respite care for the carer and care recipient and promote the information on their websites and in relevant policy documents.

RECOMMENDATION 2

3.28 The Committee recommends that the ACT Government provide more information about how the aims and objectives of all ACT Government policies, strategies and action plans relating to carers and respite care services will be met, and to ensure that there are adequate services to fulfil the intended goals of all such documents.

RECOMMENDATION 3

3.39 The Committee recommends that Disability ACT conduct a review of the programs and activities at the four ACT Government centre based respite houses with a view to engaging external expertise to provide therapeutic and creative outlets for the residents.

RECOMMENDATION 4

3.60 The Committee recommends that the ACT Government seek to establish after-school care programs at the four ACT Government special schools, The Woden School, Black Mountain School, Cranleigh School and Malkara School to ease the pressure on respite care services and working carers.

RECOMMENDATION 5

3.76 The Committee recommends that the ACT Government determine the level of need for young carers and provide additional funding as required to young carers programs to ensure that young carers have access to appropriate support when required.

RECOMMENDATION 6

3.87 The Committee recommends that the ACT Government determine the number of older carers, over the age of 60, providing primary care for an adult child with a disability and/or a mental illness in the ACT, and based on the findings increase the capacity of the Stepping Stones for Life Program or establish a similar service.

RECOMMENDATION 7

3.103 The Committee recommends that the Minister for Disability, Housing and Community Services table, in the Assembly, by March 2011, the Government's response to the recommendations made by The Echidna Group in its *Feasibility Study for Respite Care for Aboriginal & Torres Strait Islander Peoples* and state the Government's intention in relation to an Aboriginal and Torres Strait Islander specific respite facility in the ACT and the timeframe intended to complete this.

RECOMMENDATION 8

3.111 The Committee recommends that the ACT Government develop bilingual programs for new and emerging communities in the ACT aimed at de-stigmatising disability and mental illness and raising awareness about respite care services and other support services, with a particular emphasis on the benefits for both carer and care recipient.

RECOMMENDATION 9

4.10 The Committee recommends that the ACT Government continue to support Tandem to ensure that the provision of weekend respite for people with a disability and those living with a mental illness is sustainable in the long term.

RECOMMENDATION 10

4.19 The Committee recommends that the ACT Government give serious consideration to organisations such as the Community Living Project's proposed 'urban village' model of supported accommodation for people with a disability, given the shortage of supported accommodation options in the ACT and the significant support this model has among families caring for a child/adult with a disability.

RECOMMENDATION 11

4.24 The Committee recommends that the ACT Government identify the number of people that require supported accommodation and take appropriate action to meet the current and future housing needs for people with a disability and/or mental illness including the identification of alternative housing models.

RECOMMENDATION 12

4.37 The Committee recommends that the ACT Government investigate flexible respite options to meet the diversity of needs, with a view to establishing new models of respite services in the ACT that are truly responsive to the needs of carers and care recipients.

RECOMMENDATION 13

4.50 The Committee recommends that the Minister for Disability, Housing and Community Services table in the Assembly, by the last sitting day in March 2011: 1) the outcomes of the internal review assessing Disability ACT services compliance with the National Disability Service Standards (particularly the respite care houses); and 2) details of the communication and compliance strategy for community service providers.

RECOMMENDATION 14

4.51 The Committee recommends that DHCS increase its current capacity of conducting five service audits per year, by engaging an external auditor to review all ACT Government funded organisations providing respite care services by the end of 2011, to ensure they are in compliance with the National Disability Service Standards, as many services have not had an external review since 2006.

RECOMMENDATION 15

4.55 The Committee recommends that the Minister for Disability, Housing and Community Services report to the Assembly how the external monitoring for compliance against the National Quality Framework for Disability Services in Australia will be conducted and what additional resources will be required and the timeframe for implementation.

RECOMMENDATION 16

4.67 The Committee recommends that the ACT Government establish an Official Visitor Scheme for disability services located within the Office of the Public Advocate of the ACT.

RECOMMENDATION 17

4.75 The Committee recommends that the ACT Government promote the role of the Commissioner for Disability and Community Services in handling complaints through websites and community outlets.

RECOMMENDATION 18

4.78 The Committee recommends that community organisations funded by the ACT Government to provide respite care services be required to promote their complaints policy and procedures on their websites with a direct link to the Department of Disability, Housing and Community Service's Compliments and Complaints webpage.

RECOMMENDATION 19

5.28 The Committee recommends that the ACT Government expands its funding program to enable a greater number of government and non-government workers to complete the Certificate IV in Disability Work and to include Certificate III in Community Studies for mental health workers.

RECOMMENDATION 20

5.41 The Committee recommends that the ACT Government work with the disability sector to establish a minimum mandatory qualification for all paid disability support workers in government and non-government services and develop a framework to ensure that all volunteers be appropriately trained.

RECOMMENDATION 21

5.48 The Committee recommends that the ACT Government factor the cost of the Portable Long Service Leave Scheme into service funding agreements to ensure that community organisations are not financially disadvantaged.

RECOMMENDATION 22

5.49 The Committee recommends that the ACT Government conduct an education campaign detailing the provisions and requirements of the Portable Long Service Leave Scheme for the community sector to ensure that community services are aware of their obligations under the scheme.

RECOMMENDATION 23

6.14 The Committee recommends that DHCS work with ACT Health to extend its disability marketing and communication plan to promote information access points in the community sector, to people with a mental illness and the frail aged and their carers.

RECOMMENDATION 24

6.23 The Committee recommends that the ACT Government increase its capacity to provide case management and/or case coordination for people of all ages whose needs require them to access and negotiate a complex range of health and other services.

RECOMMENDATION 25

6.29 The Committee recommends that the ACT Government examine the community partnership model developed by Dr Leanne Craze as part of the *Building Capacity in Community Mental Health Family Support and Carer Recognition* project with a view to supporting its implementation across government and non-government service providers.

RECOMMENDATION 26

6.31 The Committee recommends that the Minister for Health, table in the Assembly, by the last sitting day in March 2011, the results of the community sector mental health services review.

RECOMMENDATION 27

6.41 The Committee recommends that the ACT Government ensure that the development of the 'no wrong door' model of service delivery is well planned and fully resourced and extends across the disability and mental health sectors.

RECOMMENDATION 28

7.21 The Committee recommends that a formula for growth funding be developed for disability services, as per health funding, and that this formula be applied to the 2011–2012 Budget process, as recommended by the Select Committee on Estimates 2010–2011.

1 INTRODUCTION

Conduct of Inquiry

- 1.1 The Auditor-General's Report No. 3 of 2009: *Management of Respite Care Services* was brought to the Committee's attention by the ACT Legislative Assembly Standing Committee on Public Accounts.³ Concerned with the findings of the report the Committee resolved, at a private meeting on 16 December 2009, to conduct an inquiry into the provision of respite care services in the ACT. While the focus of the Auditor-General's report was on government respite houses for people with a disability, the Committee decided to broaden the scope of the inquiry to include the full range of respite care services for people with a disability, or mental illness and the frail aged.⁴
- 1.2 The inquiry was advertised in *The Canberra Times*, *The Chronicle* and on the Legislative Assembly website. Electronic networks were also utilised to publicise the inquiry.
- 1.3 Submissions were sought through written invitation to a range of services providers and community organisations.
- 1.4 The Committee received 45 submissions, the majority of which (32) were from families caring for a child/adult with a disability. Submissions were also received from carers of people living with a mental illness and elderly parents, care recipients and disability and mental health service providers. The full list of submissions is at Appendix A.
- 1.5 The Committee is grateful for the submissions received, particularly those from individuals who shared their personal experiences. Mindful of protecting the privacy of these families, the Committee elected to withhold publication of

³ ACT Auditor-General reports are referred to the ACT Standing Committee on Public Accounts (ACT PAC). A summary of the current procedures the ACT PAC adopts in examining reports of the ACT Auditor-General is available at: <http://www.parliament.act.gov.au/committees/External.pdf>

⁴ The Committee decided that palliative care needs did not fit within the scope of this inquiry, due to the specific circumstances of the caring relationship.

the names of 15 submissions. The Committee also formally accepted, but elected to not publish a further seven submissions due to the personal details of the stories, and because the size of the ACT would have seriously compromised the confidentiality of these families.

- 1.6 The Committee held six public hearings on 14 April, 28 April, 21 July, 1 September, 3 September and 8 September 2010, and heard from a wide range of witnesses, including the Minister for Health, the Minister for Disability, Housing and Community Services, carers, care recipients, service providers and an academic with expertise relating to the needs of older carers of adult children with intellectual disabilities.
- 1.7 The Committee also hosted a community forum on 7 April 2010, to raise awareness about the inquiry, raise awareness about the needs of carers and care recipients and to hear from carers and other interested people in a less formal way than a public hearing. The forum was attended by over 70 people and a number of key issues were raised, including access to information, complexity of the community care system, lack of respite options and lack of flexibility, access to after school hours care and post school options. Guest speakers included: Ms Cheryl Pollard, Chief Executive Officer, Tandem; Ms Dee McGrath, Chief Executive Officer, Carers ACT; Ms Andrea Simmons, Manager, ACT Disability, Aged and Carer Advocacy Service (ADACAS); and Ms Sue Healy, Vice Chair, National Disability Services ACT.
- 1.8 Prior to the forum, the Committee was contacted by a number of family members who considered the presence of support services limited their ability to speak freely about their experiences. To accommodate their concerns the Committee changed the format of the forum to enable community members to directly address Committee members during the facilitated discussion, rather than the panel of service providers, as previously intended. The Committee noted that it was a public forum and no one could be excluded but was concerned that families expressed being fearful of repercussions if they spoke out against a service provider.
- 1.9 To better inform itself, the Committee also visited two of the Government respite houses on 29 November 2010. These were Kese House, catering for children up to 12 years of age and Teen Respite, catering for teenagers 13 to 18 years of age. The Committee was welcomed by the staff of the respite houses

who took the time to answer the Committee's queries and provided detailed tours around the facilities. The Committee appreciated the opportunity to visit the respite houses and see for themselves the environment in which respite is provided to this group of young people with a disability. Time constraints prevented the Committee from visiting further facilities.

Auditor-General's report

- 1.10 In 2009, the Auditor-General conducted a performance audit on ACT Government respite houses to examine whether:
- access to respite care services was on the basis of relative need;
 - quality of services provided met the national standards through effective quality assurance processes;
 - service delivery was effective and efficient compared to other states, territory and national averages, as well as other performance indicators;
 - accountability and governance framework supported the effective management of the respite services; and
 - needs or demands for disability services were reliably measured and managed.⁵
- 1.11 The audit did not assess the impact on the well-being of people with a disability and their carers and did not include respite care services provided by non-government organisations.
- 1.12 The audit concluded that services met client's basic needs for safety and respite care and that access to services was reasonable, with most services being provided to people with the greatest need. However, the audit also found scope for improvement to the quality and equity of services and made 14 recommendations. Of those, the ACT Government agreed to 10, agreed in part to one and noted three. As of April 2010, the Government reported all actions resulting from the recommendations had been completed.⁶

⁵ Auditor-General's Report, *Management of Respite Care Services*, Report No. 3 / 2009, pp 3–4

⁶ Submission no 42, ACT Government, Attachment A, *ACT Government Implementation of Recommendations of Auditor-General's Report, No. 3 of 2009, Management of Respite Services in the ACT*

- 1.13 Of particular interest to the Committee were the audit's findings relating to:
- quality assurance of services and compliance with the National Disability Service Standards (NDSS);
 - staff qualifications and training; and
 - assessment of unmet demand and unknown need.
- 1.14 The findings of the audit are discussed throughout this report.

The policy context

- 1.15 The delivery of human services in the ACT, including the provision of respite care services, is underpinned by national policies and agreements targeting specific population groups.
- 1.16 The National Disability Agreement (NDA), which replaced the Commonwealth State and Territory Disability Agreement (CSTDA), provides the national framework for the provision of government support and services for people with a disability. State and territory governments are responsible for the delivery of specialist disability services under the agreement.
- 1.17 The ACT Government's policy framework, released in September 2009, *Future Directions: Towards Challenge 2014* guides the priority areas for disability policy and service delivery through to 2014.
- 1.18 The *ACT Mental Health Services Plan 2009–2014* guides the strategic directions for mental health services in the ACT and the *National Action Plan on Mental Health* provides the national framework and reform agenda for people living with a mental illness and their carers. As part of the national plan, the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) funds the *Mental Health Respite Program* (MHRP) that provides a range of flexible respite options for carers of people with severe mental illness/psychiatric disability and carers of people with intellectual disability.⁷

⁷ Intellectual disability is included as a target group in recognition of the gaps in service provision in some current programs for intellectual disability, especially for complex cases with dual diagnosis or severe behavioural problems. (FaHCSIA), viewed 30 September 2010,

- 1.19 The MHRP has two components: a brokerage service model to procure respite on behalf of targeted carers; and a direct funding model to increase the availability of appropriate respite services where demand exceeds supply.⁸
- 1.20 The Australian National Healthcare Agreement guides the provision of aged care services. Residential aged care facilities (RACFs) set aside approximately two per cent of their beds for planned or emergency respite care.⁹ However, the majority of respite for the frail aged and/or those suffering from dementia is provided in the community through the Home and Community Care (HACC) program and community run day care programs.
- 1.21 Funding and administrative responsibilities for respite care in the ACT is shared between the Australian and ACT Governments and the Department of Disability, Housing and Community Services (DHCS) and ACT Health.¹⁰ The major sources of government funding are:
- DHCS (Disability ACT, Therapy ACT, Carers Recognition Grants);
 - ACT Health (ACT Mental Health);
 - Home and Community Care (HACC) program (jointly funded by the ACT and Australian Governments);
 - Australian Government Department of Families Housing, Community Services and Indigenous Affairs (FaHCSIA); and
 - Australian Government Department of Health and Ageing (DoHA).
- 1.22 The Committee also notes the current national inquires that could have major policy implications for the future delivery of services for carers and care recipients. These include:

<http://www.fahcsia.gov.au/sa/mentalhealth/pubs/GuidelinesServiceProviders/Documents/NRDF_Guidelines/sec3.htm>

⁸ FaHCSIA, *Mental Health Respite Program*, viewed 22 September 2010,

http://www.facs.gov.au/sa/mentalhealth/pubs/mhrp_bchgc/Documents/default.htm

⁹ Australian Institute of Health and Welfare, *Residential aged-care in Australia 2006–07*, p 23

¹⁰ A list of respite services in the ACT is provided at Appendix C.

- The Productivity Commission *Disability Care and Support* inquiry examining a range of options and approaches for a national disability long-term care and support scheme;¹¹
- The Productivity Commission *Caring for Older Australians* inquiry examining the development of options for structural reform of the aged care system to meet the challenges facing an ageing population;¹²
- The National Carer Recognition Framework which includes the National Carers Strategy and the Carers Recognition Bill that was passed in the Senate in October 2010;¹³ and
- The Senate Community Affairs Reference Committee inquiry into *Planning Options and Services for People Ageing with a Disability* looking at options and services to assist people with a disability and their carers to plan for the future.¹⁴

Structure of this report

- 1.23 This report addresses a wide range of issues raised throughout the inquiry. The majority of the evidence received related to the respite needs of people with a disability and their carers and this is reflected in the report. However, the report has incorporated the respite needs of those living with a mental illness and the elderly where appropriate. This is in no way intended to emphasise the needs of one group above another.
- 1.24 Chapter two provides an overview of the meaning of respite care and discusses the importance of respite care for carers and care recipients.

¹¹ Productivity Commission, *Disability Care and Support*, viewed 25 November 2010, <http://www.pc.gov.au/projects/inquiry/disability-support>

¹² Productivity Commission, *Caring for Older Australians*, viewed 25 November 2010, <http://www.pc.gov.au/projects/inquiry/aged-care>

¹³ Australian Government Department of Health and Ageing, *National Carer Strategy*, viewed 25 November 2010, <http://www.health.gov.au/nationalcarerstrategy>

¹⁴ Senate Community Affairs Reference Committee, *Inquiry into Planning Options and Services for People Ageing with a Disability*, viewed 25 November 2010, http://www.aph.gov.au/senate/committee/clac_ctte/planning_options_people_ageing_with_disability_43/index.htm

- 1.25 Chapter three examines the common characteristics of the needs of care recipients and carers. Special consideration is given to the unique needs of Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse backgrounds, older carers and young carers.
- 1.26 Chapter four examines the current state of service provision in the ACT with particular emphasis on whether current policy is meeting its objectives. This chapter also considers quality assurance and the complaints management process.
- 1.27 Chapter five examines the needs and working conditions of paid carers including the shortage of qualified staff, training needs, implications of the portable long service scheme and minimum standards for workers.
- 1.28 Chapter six explores the interconnection between government and non-government service providers with a particular focus on community partnerships, access to information and case management.
- 1.29 Chapter seven examines the current and future needs of respite care services in the ACT and considers the Government's model for assessing and addressing unmet need.
- 1.30 The final chapter provides some concluding remarks.

2 WHAT IS RESPITE?

- 2.1 Carers and care recipients are as diverse as the Australian population. While circumstances and individual support needs will vary greatly, respite care stands out as a common link for all carers and the need for access to good quality, affordable, flexible respite care, to help sustain the caring relationship, has been well documented.¹⁵
- 2.2 Respite care is provided for people with a disability, people with mental illness, and the frail aged or people suffering from dementia, and can include:
 - part or full day respite in day care centres;
 - in-home respite services, including overnight care and personal care services;
 - recreational respite; and
 - overnight respite in community or government respite houses.
- 2.3 The Macquarie Dictionary describes respite as 'a delay or cessation for a time, especially of anything distressing or trying' or 'an interval of relief'.
- 2.4 The Australian Bureau of Statistics (ABS) defines formal respite care as a support service that allows carers time away from the care recipient to pursue other activities. The ACT Government's definition of respite care aligns with that of the ABS.¹⁶
- 2.5 This definition tends to favour the needs of carers above the needs of the care recipient. While the main aim of respite is to relieve the carer of their caring responsibility for a period of time (hours, days or weeks) respite care also has a responsibility to cater to the needs of care recipients. The needs of carers and care recipients are discussed in chapter three.

¹⁵ See for example, The Parliament of the Commonwealth of Australia, House of Representatives Standing Committee on Family, Community, Housing and Youth *Who Cares...?*, April 2009, p 13, and National People with Disabilities and Carer Council, *Shut Out: The Experience of People with Disabilities and their Families in Australia*, 2009, 55–56

¹⁶ Submission 42, ACT Government, p 2

- 2.6 While it is well documented that respite is an important service, the meaning and use of respite care varies among carers, depending on individual needs. For many it is much more than time apart, as one mother caring for a child with Autism explained:

... respite is not just about going to the shops alone. It is about waking up in the morning knowing you don't have to have a battle, coerce, cajole, beg, bribe or encourage your child to go through the usual routines of a morning and a day. It is about peaceful mealtimes, participating in community activities, perhaps a restaurant, spontaneity, relaxing evenings without having to wake and toilet a sleeping child. It's about not having to allow for transitions to go wrong all day long. We can't get these things from a short burst of respite lasting a few hours, we need full days and overnights to recover our energy and will for the ongoing stresses of raising a child with autism.¹⁷

- 2.7 Another carer noted:

We use respite to work and spend a couple of hours each fortnight with our other child. Respite, however, does not mean time out for us, as individuals or a couple - which is what we desperately need to maintain health, happiness and ability to cope with a difficult path ahead.¹⁸

- 2.8 In its submission, National Disability Services ACT pointed out that respite services play an important role in providing preventative solutions to families and individuals, stating:

Providing carers with adequate access to respite, whether for planned or unplanned activities, can offer significant benefit in terms of reducing stress and accumulated tension. Carers can continue to provide essential support for much longer if they can be confident of having a break when they need it.¹⁹

- 2.9 A 2009 inquiry into better support for carers conducted by the House of Representatives Standing Committee on Family, Community, Housing and

¹⁷ Submission 27, Name withheld

¹⁸ Carer quoted in Submission 25, Carers ACT, p 12

¹⁹ Submission no 1, National Disability Service ACT, p 1

Youth received over 1000 submissions from carers across Australia. The inquiry found that lack of access to appropriate respite care:

... increased levels of stress for carers, their families and those being cared for, reduced economic and social participation and reduced levels of health and wellbeing.²⁰

- 2.10 While the meaning of respite has evolved significantly from the traditional sense (described earlier), Ms Anita Phillips, Public Advocate of the ACT, told the Committee that:

... clarification and dialogue about the meaning of respite and what it entails is essential in facilitating access to services which are relevant and match needs.²¹

- 2.11 In its submission, the PA ACT supported a shift in terminology from respite care to one of short breaks, as the term respite care can be stigmatising, causing some carers, particularly older carers, to feel that accepting respite was a sign of failure in themselves, therefore avoiding utilising available services.²²
- 2.12 The Committee acknowledges the concern around the term respite and the potential impact of this on some carers. The Committee was also concerned about the lack of understanding of respite services and considers that clarification of the purpose and role of respite services would be of benefit to carers.
- 2.13 For example, the ACT Government reported an increase in community access hours for people with a disability and a decrease in the number of centre-based respite nights in 2009–10. The reason cited for this was the increasing preference for community access services as a respite alternative.²³
- 2.14 While community access programs do provide carers with a break, they are not respite and have a specific function to 'provide opportunities for people with a disability to gain and use their abilities to enjoy their full potential for

²⁰ The Parliament of the Commonwealth of Australia, House of Representatives Standing Committee on Family, Community, Housing and Youth *Who Cares...?*, April 2009, p 175

²¹ Submission no 43, PA ACT, p 2

²² Submission no 43, PA ACT

²³ ACT Government 2010–11 Budget Paper No. 4, p 375

social independence'.²⁴ The Committee is pleased that community access hours have increased, as this is an important service, but the Government should be cautious to read this as preference away from overnight respite, the importance of which is discussed in chapter three.

- 2.15 National Disability Service ACT also noted the linkages between respite care services and community access programs as a form of respite, but cautioned that:

... the potential for cost shifting and distortion of estimates of demand are linked to the interconnectedness of disability services.²⁵

- 2.16 The Mental Health Foundation also considered it important to be specific about the definition of a respite service, and noted in their submission that crisis, medium or long term accommodation services should not be considered respite services, as they have different functions.²⁶

- 2.17 Although respite services are listed on the DHCS website, there is little information about the role and purpose of respite and the potential benefits for carers and their families. The Committee is of the view that the information provided on the website could be significantly enhanced and include relevant links to government funded organisations and to the Commonwealth Respite & Carelink Centre (run by Carers ACT) that is specifically funded to assist people with all respite enquiries and also provides local information on community aged care and disability services.²⁷

- 2.18 The Committee found no information about mental health respite on the ACT Health website or in its directory of Mental Health Services. The Committee understands that respite is not directly provided by Mental Health ACT, but discussion and links to appropriate services on its website would be beneficial to carers who turn to the ACT Health website for information.

²⁴ ACT Government 2010–11 Budget Paper No. 4, p 375

²⁵ Submission 1, NDS ACT, p 1

²⁶ Submission 5, Mental Health Foundation, p 3

²⁷ Carers ACT, Commonwealth Respite & Carelink Centre, viewed 19 November 2010, <http://www.carersact.asn.au/>

- 2.19 Furthermore, defining the role and purpose of respite may also assist in removing the stigma that prevents some families from accessing services that would support them in their caring role. The Committee considers that respite care services must be responsive to the needs of carers and care recipients and this should be explicitly stated in any documentation regarding respite care services.

RECOMMENDATION 1

- 2.20 **The Committee recommends that the Department of Disability, Housing and Community Services (DHCS) and ACT Health develop a common definition of respite that includes the role, purpose and benefits of respite care for the carer and care recipient and promote the information on their websites and in relevant policy documents.**

14 STANDING COMMITTEE ON HEALTH, COMMUNITY AND SOCIAL
SERVICES

3 NEEDS OF CARE RECIPIENTS AND CARERS

- 3.1 The needs of care recipients and carers are interconnected. The nature of the relationship renders the care recipient reliant on their carer and the dual role held by many carers, such as spouse, parent or child, can make it impossible to move out of the caring role. The relationship between carer and care recipient can also make it difficult for some people to see themselves as carers and therefore not realise their eligibility for support from available services.
- 3.2 The majority of care is provided by informal carers, at a significant saving to the public purse.²⁸ The well-being of the carer as well as the care recipient is of paramount importance in maintaining the caring relationship for as long as is appropriate.
- 3.3 A care recipient can be defined as a person who is receiving care and support, either in the community, in their own home or in a residential aged care facility. Care may include support to take part in social activities, help with physical tasks, personal and medical care. Care recipients can be any age and the degree of support required will vary.
- 3.4 A carer can be defined as a person who provides, or has provided, unpaid care and support to a person who has needs associated with disability, ageing, ongoing physical or mental illness or substance use.²⁹
- 3.5 Anyone can be a carer, including parents, life-long partners, husbands, wives, brothers, sisters, children, extended family members and friends. Providing ongoing care to a family member can place enormous stresses not only on the primary carer but all family members.

²⁸ Australia's family carers provide 1.2 billion hours of unpaid care annually, the replacement value of which is estimated at over \$30.5 billion. Access Economics, *The Economic Value of Informal Care*, prepared for Carers Australia, Canberra, 2005

²⁹ DHCS, *The Caring for Carers Policy*, 2003, p 2

- 3.6 While there is a community expectation that families should be providing care to their family members in need, there is also an understanding that support from outside the family is required.³⁰ Despite the best intentions, families are not always able to meet all of the care recipients needs. As one parent told the Committee, *'love has its limits'*.³¹ As noted in the Chair's foreword, the Committee chose this phrase as the title for its report as it describes the difficult situation facing many carers.

Needs of carers

- 3.7 The Survey of Disability, Ageing and Carers (SDAC) 2003 identified 32 400 carers in the ACT, down from the 1998 SDAC that identified over 43 000 carers. More recently, the 2006 Census identified close to 26 000 carers in the ACT.³² Carers ACT estimates that there are over 40 000 families living in the ACT who provide ongoing care for people with disability, mental illness, chronic conditions, palliative care needs, or who are aged and frail.³³
- 3.8 The needs of carers will vary depending on individual circumstances such as age and ethnicity and the nature of the care recipients' needs. Despite the diversity, a common goal of most carers is to achieve a quality of life for themselves and the person they care for.
- 3.9 The Kings Fund, a prominent UK Charity, has developed the Carers Compass that identifies eight common characteristics of need for all carers. These are:
- access to full information;
 - recognition and carers health and wellbeing taken into account;
 - a life of their own – quality services for the carer and the person cared for;
 - time off from their caring responsibility;
 - emotional support;
 - training and support to care;

³⁰ DHCS, *The Caring for Carers Policy*, 2003, p 2

³¹ Ms Karna O'Dea, *Transcript of Evidence*, 14 April 2010, p 9

³² Allen Consulting Group, *Review of Caring for Carers Policy*, p 2

³³ Submission 25, Carers ACT, p 3

- financial security; and
- a voice.³⁴

3.10 While all of these needs are interrelated and important, 'time off' from the caring role is one of the greatest needs of carers, and the topic of this report. It has been well documented that without access to high quality, safe, affordable respite, carers would not be able to continue in the caring role as long as they do.³⁵

3.11 Carers must also be confident that the substitute care provided is appropriate and that care recipients' physical, medical, emotional and social needs are being met. As one carer noted:

There is no point if you put your child into respite and you go away and you worry, is he going to be injured, because it is not respite.³⁶

3.12 Another carer commented:

The preparation required for a period in respite took a substantial effort and our son's emotional state post-respite meant that sometimes centre-based respite just did not seem worth it.³⁷

3.13 While the majority of submissions received by the Committee were from families caring for a child with a disability, many of the issues identified were relevant to all carers. Major issues raised included:

- lack of access to weekend respite;³⁸
- lack of access to safe, appropriate, respite;³⁹

³⁴ The Kings Fund, *Carers Compass*, viewed 30 September 2010, <http://www.kingsfund.org.uk/>

³⁵ See for example, The Parliament of the Commonwealth of Australia, House of Representatives Standing Committee on Family, Community, Housing and Youth *Who Cares...?*, April 2009, p 13, and National People with Disabilities and Carer Council, *Shut Out: The Experience of People with Disabilities and their Families in Australia*, 2009

³⁶ NSW Legislative Council, Standing Committee on Social Issues, *Making it Happen, Final report on Disability Services*, 2002, p 20

³⁷ Submission 22, Name withheld

³⁸ See Submission 2, Autism ACT, Submission 8, Mental Health Community Coalition, Submissions 18, 27 and 29 Name withheld. This was also raised in confidential submissions received by the Committee and in public hearings.

³⁹ See Submission 9, 17, 22, Name withheld, Submission 25, Carers ACT, Submission 30, Ms McKenzie, Submission 37, Community Living Project

- lack of reliable, long term care workers;
- the impact of caring on family relationships (including siblings and spouses);⁴⁰
- confidence in the substitute care being provided;
- inflexible service delivery;
- the quality of care provided; and
- lack of choice in workforce and education participation (primarily due to shortages of respite or alternative care options).⁴¹

3.14 Lack of access to out of school hours care and holiday care was also raised as a significant concern by families caring for school age children.⁴² This extended to concerns about post school placements for young adults with a disability.⁴³ While this is not a respite service, the lack of appropriate alternative care options is placing increased demand on respite care services. This is considered later in this chapter.

3.15 For carers of children and young people with a disability, the school years not only contribute to the child's education but provide stability, in terms of structured time apart, that benefit both carer and recipient. The period following school years are of particular concern to many families caring for young people, particularly those with high needs who are not likely to gain employment or move into further education. With limited post school options available in the ACT the Committee supports the recommendations made by the Standing Committee on Education, Young People and Training in its recently released report into the needs of ACT students with a disability.⁴⁴

⁴⁰ See Submission 2, Autism, Submission 4, Communities@Work, Submission 8 Mental Health Community Coalition, Submission 9, 17, 22, and 29 Name withheld, Submission 35, Canberra and Queanbeyan ADD Support Group

⁴¹ See Submission 10, and 13 Name withheld, Submission 14 St Margaret's Aged and Disability Services Committee

⁴² See submissions 2, Autism ACT, Submission 7, Noah's Ark, Submission 9, 10, 27, 29 name withheld, *Transcript of Evidence* 3 September 2010, p 147, Also raised in confidential submissions.

⁴³ *Transcript of Evidence*, 3 September 2010, p 147, Submission 27

⁴⁴ ACT Legislative Assembly, Standing Committee on Education, Training and Young People, *Needs of ACT students with a disability*, Report no 5, 2010, pp 60–64

3.16 Carers in the ACT have been supported by the ACT Government through the 2003 *Caring for Carers Policy* and the *Caring for Carers in the ACT – a plan for action 2004-2007*. While becoming a carer is not usually a choice, the policy recognised that:

... carers should have choices, receive support to make decisions about the caring role and have their own needs recognised by human services; people requiring care should not be solely dependent on the resources and goodwill of their immediate family or social network; and a range of supports provided by the community should be available to offer choice and any assistance necessary to achieve a quality of life that is in accordance with community standards.⁴⁵

3.17 Many carers presenting to the Committee did not feel that choices were available to them. In particular, respite services were inflexible and care recipients were required to fit in with the program rather than the service catering to the care recipient's individual needs. This is discussed further in chapter four.

3.18 A 2008 review of the *Caring for Carers* policy, conducted by the Allen Consulting Group found that the majority of actions from the Action Plan had been addressed 'to some extent'.⁴⁶ The review also identified the following two areas of high need, within the scope of the ACT Government:

- greater recognition of the role of carers, including increased self-identification of carers; and
- streamlined access to services, including more services and a greater variety.⁴⁷

3.19 A further requirement of the review was to develop an alternative model to support carers in the ACT, following the completion of the Action Plan in 2007–08.⁴⁸ The alternative model proposed, built on the *Caring for Carer* policy

⁴⁵ DHCS, *The Caring for Carers Policy*, 2003, p 4

⁴⁶ Allen Consulting Group, *Review of Caring for Carers Policy*, p vi

⁴⁷ Allen Consulting Group, *Review of Caring for Carers Policy*, p vii

⁴⁸ Allen Consulting Group, *Review of Caring for Carers Policy*, p v

and principles with a greater emphasis on reporting, to be achieved through an outcomes based reporting approach with key performance indicators.⁴⁹

- 3.20 The needs of carers have been well considered in a plethora of policies, statements and legislation at the state, territory and commonwealth level. Examples include the ACT *Caring for Carers Policy, Future Directions: Towards Challenge 2014*, the Queensland *Carer Recognition Policy*⁵⁰, the Queensland *Carers Recognition Act*, and the NSW *Carer Action Plan 2007–2010*⁵¹.
- 3.21 Further to legislative rights already in place in the ACT for carers, the ACT Government is currently consulting with carers on the development of a Carers Charter. The aim of the Charter is to 'provide an accessible and easy to understand document that outlines what carers should expect from ACT Government agencies and government funded community organisations that provide support services to carers'. The Charter is due for completion in April 2011⁵²
- 3.22 The *Carers Recognition Bill*, part of the National Carers Strategy, passed in the Senate in October 2010, also aims to recognise the contribution of carers in Australia and to provide a legislative framework for including the consideration of carers in public policy and programming.
- 3.23 The Bill includes a *Statement for Australia's Carers* that articulates principles for dealing with carers in a policy, program or service delivery setting. These principles are not dissimilar to those in the ACT's *Caring for Carers* policy introduced in 2003. While the *Statement for Australia's Carers* will not create rights, it will establish key principles on how public service care agencies and associated providers should treat carers when developing, implementing, providing and evaluating care supports.⁵³

⁴⁹ Allen Consulting Group, *Review of Caring for Carers Policy*, p viii

⁵⁰ viewed 7 October 2010, <<http://www.disability.qld.gov.au/support-services/carers/support-initiatives/carers-recognition-policy.html>>

⁵¹ viewed 7 October, <http://www.health.nsw.gov.au/policies/pd/2007/PD2007_018.html>

⁵² Minister for Disability, Housing and Community Services, correspondence to the Committee received 16 November 2010

⁵³ Australian Government, Carers Recognition Bill, http://parlinfo.aph.gov.au/parlInfo/download/legislation/bills/r4342_first/toc_pdf/10069b01.pdf;fileType%3Dapplication%2Fpdf

- 3.24 Despite the best intentions of these policies, plans, strategies, frameworks and Acts, carers are still struggling to have their needs met. As the father of a 25 year old son with a severe intellectual disability commented:
- ... [we] have considerable experience with reading literally hundreds of grandiose and ostentatious statements regarding the objective, ideals and plans from countless disability bureaucrats in, again, literally thousands of expensive, glossy pamphlets, booklets and reports.⁵⁴
- 3.25 Other carers questioned the value of yet another inquiry, feeling that for all the feedback provided little real change had occurred.⁵⁵ Another submitter thanked the Committee for the opportunity to provide input adding 'lets hope this time it makes a difference!'⁵⁶
- 3.26 The Committee notes that carers have had enough rhetoric. The challenge for the Government is meeting the needs of all carers and care recipients. Unless the support services are there to match the policy aims and objectives, words are of little value to carers who are struggling to meet their day to day caring responsibilities.
- 3.27 The Committee understands the importance of having in place appropriate policies, plans and strategies to guide the delivery of human services, but is concerned that without adequate planning and resourcing, it could be difficult to achieve the intended goals. For example, 10 of the 42 action items of *Future Direction: Towards Challenge 2014 Implementation Plan 2009–10* involved the development of policy frameworks, plans and strategies, and *Future Directions: Towards Challenge 2014, Implementation Plan 2010–14*, released in December 2010, is tasked with their implementation. These are significant documents and while key partners, including community service providers, are identified in the plan, there is no detail as to specific community organisations and resourcing implications of enhanced service delivery. The Committee considers that the inclusion of detailed information about how aims and

⁵⁴ Mr Robinson, *Transcript of Evidence*, 3 September 2010, p 161

⁵⁵ Ms Gordon, *Transcript of Evidence*, 1 September 2010, p 103

⁵⁶ Submission 27 Name withheld, p 2

objectives will be achieved in all implementation documents will provide assurance to the target audience that intended goals will be met.

RECOMMENDATION 2

- 3.28 **The Committee recommends that the ACT Government provide more information about how the aims and objectives of all ACT Government policies, strategies and action plans relating to carers and respite care services will be met, and to ensure that there are adequate services to fulfil the intended goals of all such documents.**

Needs of care recipients

- 3.29 The needs of care recipients are less well defined, as the majority of policy responses are aimed at the needs of the carer, as described above.
- 3.30 Care recipients, like everybody else, have a range of physical, emotional and intellectual needs that must be met. With limited independence, in many cases, care recipients rely on their primary carers, family members, friends and support services to meet those needs to enhance the quality of their lives.
- 3.31 The needs of care recipients will vary depending on individual circumstances and the nature of the caring relationship, and will change over time. Families and carers are not always able to meet the care recipients needs.
- 3.32 Respite care services are one option available to care recipients to expand their horizons and gain confidence and independence, as appropriate. Overnight respite is an important part of developing independent living skills. Care recipients are often not afforded the same opportunities as the general population such as children's sleepovers or holidays with friends, that accustom people to being away from the family home/primary carer. In the case of ageing parents, this is even more important as overnight respite helps to prepare an adult child for transition from the family home. The needs of older carers and adult children are discussed later in this chapter.
- 3.33 Centre-based overnight respite also provides a source of social interactions outside of the immediate family and opportunities to develop friendships, particularly important as the care recipient becomes a young adult.

3.34 As noted earlier, the ACT Government recorded a reduction in centre based respite nights in 2010–11 reasoning this as a preference towards community access options.⁵⁷ This is of concern to the Committee as significant evidence was presented during the inquiry regarding the need for overnight respite. The Committee was told that families had removed their child from overnight respite, not because they no longer required the service, but because of a range of concerns, including:

- lack of age appropriate activities;⁵⁸
- safety concerns for their child from other residents;⁵⁹
- lack of internet access for residents;⁶⁰
- lack of therapeutic responses for residents;⁶¹ and
- inadequate facilities.⁶²

3.35 Care recipients accessing overnight respite services require supervision and/or structured activities for the duration of their stay. Care recipients may need guidance in their social interactions with their peers, assistance with their daily living skills and access to stimulating activities to keep them engaged. However, the Committee was concerned that these needs were not always being met. One mother told the Committee:

I organise his week so that he is out of the house as much as possible while he is staying at respite; otherwise, I know he would be sitting watching television and doing nothing else. So it is up to me to make sure that his week at respite has varied activities for him to do.⁶³

3.36 The ACT Government is the major provider of centre-based respite services for people with a disability, operating four houses in the ACT. The results of the 2007 client satisfaction survey conducted by Disability ACT showed an overall satisfaction rating of 86 per cent. However, when assessing satisfaction with

⁵⁷ ACT Government 2010-11 Budget Paper No. 4, p 375

⁵⁸ Submission 34, Name withheld

⁵⁹ Submission 22, Name withheld

⁶⁰ Submission 22, Name withheld

⁶¹ Submission 38, Mr Robinson, p 1

⁶² Submission 38, Mr Robinson, p 1

⁶³ Ms Frazer, *Transcript of Evidence*, 14 April 2010, p 11

the range of activities provided during respite stays, the satisfaction rating was significantly lower at 54 per cent.⁶⁴

- 3.37 The disparity between the services delivered to people with disabilities in respite homes and those offered to elderly people utilising respite services in aged care facilities, was brought to the Committee's attention. Mr Trevor Robinson, a carer/parent was of the view that residents in aged care facilities had greater access to therapists and recreational facilities and was particularly keen to see the inclusion of diversional therapy⁶⁵ and other therapeutic programs for people in overnight respite centres.⁶⁶ In evidence to the Committee, Mr Robinson suggested that external providers could be engaged by the Government to provide diversional and therapeutic programs to residents of respite homes.⁶⁷
- 3.38 The Committee notes the Budget commitment of \$250 000 for a feasibility study looking at options for the replacement of the four Government respite houses.⁶⁸ While the facilities are important, the Committee considers that it is also timely to invest some capital into the programs and structured activities provided by the government respite services. Buying in services of trained therapists such as music or art therapists, yoga instructors or craft teachers to engage with residents in a structured way, would be an inexpensive way of engaging residents.

RECOMMENDATION 3

- 3.39 **The Committee recommends that Disability ACT conduct a review of the programs and activities at the four ACT Government centre based respite houses with a view to engaging external expertise to provide therapeutic and creative outlets for the residents.**

⁶⁴ Auditor-General's Report *Management of Respite Care Services* Report No. 3 / 2009, p 74

⁶⁵ Diversional therapy is a client centred practice that recognises leisure and recreational experiences as the right of all individuals. Diversional Therapists work with people of all ages and abilities to design and facilitate leisure and recreation programs. Diversional Therapy Australia, viewed 20 October 2010, <<http://www.diversionaltherapy.org.au/>>

⁶⁶ Submission 38, Mr Robinson, p 1

⁶⁷ Mr Robinson, *Transcript of Evidence*, 3 September 2010, p 168

⁶⁸ ACT Government, 2010–11 Budget Paper 3, p 167

The need to work

- 3.40 Carers face significant disadvantage in participating fully in the workforce due to their caring commitments and in many cases give up income by providing care rather than participating in paid employment.
- 3.41 The ACT Government recognised this in its 2003 *Caring for Carers Policy* stating that carers often experience difficulties:
- ... balancing work or study demands with caring responsibilities, which can lead to loss of earnings or employment, poor grades or withdrawal from school [for young carers].⁶⁹
- 3.42 The Australian Bureau of Statistics (ABS) cites the reduced opportunity for parents to work as an indirect cost of having a child with a disability. In 2003, around 51 per cent of couple families who had a child with a disability had both parents employed, compared with 61 per cent of couple families where no child had a disability. If the child's disability was profound/severe, the proportion having both parents employed was 42 per cent.⁷⁰
- 3.43 Data from the Australian Institute of Health and Welfare (AIHW) indicates that among carers of prime working age (25–54), approximately 47 per cent of male primary carers were employed full-time compared with 80 per cent of men who were not primary carers. For female primary carers aged 25–54 years 18 per cent were in full-time paid employment compared with 39 per cent of women who were not primary carers.⁷¹
- 3.44 Further to the rate of employment, research by the Taskforce on Care Costs (TOCC) in 2007, found that nearly half (44 per cent) of working carers had selected a role at work below their skill level because it provided the flexibility they needed to balance their work and caring responsibilities.⁷²

⁶⁹ DHCS, *Caring for Carers Policy*, 2003, p 3

⁷⁰ Australian Bureau of Statistics, Australian Social Trends 2008, *Families with a young child with a disability*, viewed on 22 September 2010, <<http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4102.0Chapter4002008>>

⁷¹ Australian Institute of Health and Welfare (2004), cited Carers Australia, *About Carers*, viewed 30 September 2010, <http://www.carersweek.com.au/10/carers.html>

⁷² Taskforce on Care Costs, *The hidden face of care: Combining work and caring responsibilities for the, aged and people with a disability*, 2007, p 5, viewed 5 October 2010,

3.45 Limiting the ability for carers to participate fully in paid employment and/or working below their skill level impacts negatively on the carer, their families, their employer and the economy.⁷³

3.46 The Committee is concerned that there are carers in the ACT unable to work when the ACT is experiencing a skill shortage. Attracting skilled workers to the ACT is still a priority for the ACT Government, with the Chief Minister recently stating:

Skill shortages continue to persist across a range of sectors in Canberra, and although unemployment remains at almost historic lows, it is important that we continue to attract a steady stream of skilled workers to meet the ongoing demand.⁷⁴

3.47 The need for out of school hours and holiday care was cited by carers with school aged children as one of the main problems preventing carers from full participation in the workforce or taking less skilled positions to fit in with their caring responsibilities. As one parent explained:

I am forced to take employment that does not recognize my skills and talents and underpays me for what I can bring to the role, simply because I can only work part-time. My inclusion in the workforce is limited and any career aspirations and prospects I once had, go unfulfilled.⁷⁵

3.48 The Committee heard many other examples of carers forced to give up employment⁷⁶ and further education⁷⁷ or work part-time to accommodate their caring responsibilities.⁷⁸

<[http://www.tocc.org.au/media/Final TOCC 2007 Report The Hidden Face of Care 16 Nov 2007.pdf](http://www.tocc.org.au/media/Final_TOCC_2007_Report_The_Hidden_Face_of_Care_16_Nov_2007.pdf)>

⁷³ Carers Australia, *About Carers*, viewed 30 September 2010, <http://www.carersweek.com.au/10/carers.html>

⁷⁴ J Stanhope (Chief Minister), *ACT targets skilled workers in Sydney*, media release, 6 August 2010, available at, <<http://www.chiefminister.act.gov.au/media.php?v=9838&s=3>>

⁷⁵ Submission no 27, Name withheld, p 2

⁷⁶ Submission 10, Name withheld, Submission 16, Name withheld, Submission 44, Ms Anna Kieltyka, Submission 14, St Margaret's Aged and Disability committee, Mr Trewhella, *Transcript of Evidence*, 14 April 2010, p 16

⁷⁷ Submission 20, Name withheld

⁷⁸ Submission 10, Name withheld,

- 3.49 Apart from the obvious economic benefits of paid employment, the social aspects are equally important. As one mother of a child with autism told the Committee, 'I go to work at Tax to get some respite'.⁷⁹
- 3.50 Lack of appropriate care for school age children also places enormous pressure on respite services, such as Tandem, that are utilised by carers to fill the gap for working parents. While this does not fall into the technical definition of respite care, carers are increasingly relying on respite care services to enable their participation in the workforce and/or education. However, one parent noted that she was unable to 'rely on respite care as means of maintaining other aspects of my life, such as my job' due to the unreliability of carers.⁸⁰
- 3.51 The House of Representatives inquiry into better support for carers also identified access to alternative, suitable and affordable care for care recipients as essential in enabling carers to participate in employment and recommended:
- That the [Australian Government] Minister for Families, Housing, Community Services and Indigenous Affairs through the Health, Community and Disability Services Ministerial Council encourage states and territories to provide additional funding for disability support workers in long day care, out of hours care and school holiday care to improve access for employed carers.⁸¹
- 3.52 The Committee strongly supports this recommendation as this is a significant area of need for ACT carers of school aged children and teenagers.⁸²
- 3.53 The Australian Government funds the *Outside School Hours Care for Teenagers with Disability* to provide flexible before school, after school and/or school

⁷⁹ Ms O'Dea, *Transcript of Evidence*, 14 April 2010, p 2

⁸⁰ Submission 10, Name withheld

⁸¹ House of Representatives Standing Committee on Family, Community, Housing and Youth, *Who cares...? Report on the inquiry into better support for carers*, April 2009, recommendation 38, p 204

⁸² The Australian Government agreed to this recommendation as part of achieving the outcomes of the NDA, noting however, that under the NDA, the Australian Government does not specify budget allocations and state and territory governments are free to deliver services flexibly in line with agreed outcomes. (Government response *Who cares...? Report on the inquiry into better support for carers*, p 44)

holiday care.⁸³ The only service in the ACT to receive funding through this program is the Marymead 'wheelies' program which caters for teenagers in a wheelchair. Options for high school aged children with a disability or other support needs are limited.⁸⁴

- 3.54 The Committee understands that DHCS agreed to provide non-recurrent funding to Noah's Ark for 2010–11 financial year. However, the September 2010 school holiday program was cancelled due to lack of funding, leaving many working parents to make alternative arrangements at short notice.⁸⁵
- 3.55 The Committee is of the view that the most sensible approach to deal with this would be to establish after school hours care at the four special schools (Black Mountain, The Woden School, Cranleigh School and Malkara School) in the ACT, open to all children.
- 3.56 The needs of working carers has been recognised by the Australian Government through its Employed Carers Respite Initiative, under its National Respite for Carers Program, to increase respite services to support carers who are caring for a person 65 years and over or who has early stage dementia. Carers ACT is funded to provide this service in the ACT.⁸⁶
- 3.57 The House of Representatives inquiry into better support for carers recommended an expansion of this program to include those who provide care to people with disability or mental illness who are under the age of 65.⁸⁷
- 3.58 The Australian Government rejected this recommendation on the basis that the *Fresh Ideas for Work and Family* program, launched in March 2009, is designed to assist employers to establish family friendly businesses by providing grants

⁸³ Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, *Outside School Hours Care for Teenagers with Disability*, viewed 22 September 2010, <<http://www.facs.gov.au/sa/disability/funding/outsidethatcare/Pages/default.aspx#providers>>

⁸⁴ The four options include Noah's Ark, located in Rivett, Gungahlin Youth Program, Woden Community Services youth program and Fun4Youth, operated by Communities@Work in Tuggeranong.

⁸⁵ Letter from Noah's Ark, advising of this, provided to the Committee from a parent.

⁸⁶ Carers ACT, Employed Carers Program, viewed 22 September 2010, <<http://www.carersact.asn.au/employed-carers-program.html>>

⁸⁷ House of Representatives Standing Committee on Family, Community, Housing and Youth, *Who cares...? Report on the inquiry into better support for carers*, April 2009, recommendation 39, p 206

of up to \$15 000 to assist small businesses to implement practices that help employees balance their work and family obligations and improve employee retention and productivity.⁸⁸

- 3.59 With many carers in the ACT unable to work as much as they would like or work below their skill level the Committee considers that more should be done to assist those carers to participate in the workforce. Providing appropriate out of school hours care is one way to begin to address this imbalance.

RECOMMENDATION 4

- 3.60 **The Committee recommends that the ACT Government seek to establish after-school care programs at the four ACT Government special schools, The Woden School, Black Mountain School, Cranleigh School and Malkara School to ease the pressure on respite care services and working carers.**

Impact on family members

- 3.61 Caring for a family member with special needs places significant stress on all family members and access to appropriate respite care services plays an important role in maintaining 'normal' family relations. Without adequate support, it was suggested that the strain of caring for a child with a disability could lead to marriage breakdown.⁸⁹

- 3.62 In the words of one family:

We are in a position where we have to use respite services because we wouldn't survive as a family without them.⁹⁰

- 3.63 For another family:

Respite care for us is primarily to enjoy social occasions as a couple without children...We believe that time spent together as a couple

⁸⁸ Australian Government Department of Education, Employment and Workplace Relations, *Work and Family Fresh Ideas*, viewed 22 September 2010, <<http://www.deewr.gov.au/WorkplaceRelations/FreshIdeas/Pages/default.aspx>>

⁸⁹ See for example Submission 20 Name withheld, Submission 25, Carers ACT, Submission 30, Carol McKenzie, this was also raised in confidential submissions

⁹⁰ Submission 15, Name withheld, p 2

benefits the well-being of our family and the relationships we have with our regular children as well as our disabled daughter.⁹¹

- 3.64 In caring families, siblings often miss out on the attention of their parents and the chance to spend quality time together. This was raised by a number of families⁹² with Communities@Work noting that 'siblings need respite too'.⁹³ The things that many families take for granted are simply not available to families providing care for a loved one with special needs. As one mother explained:

I do not plan ahead for anything and my son is missing out on events and doing things that are just normal, going to the park, beach or parties. Being a family with a severely disabled child and having to ensure her safety and health over other things can be very stressful and tiring. Trying to get a balance, to ensure my son's needs are met is hard.⁹⁴

- 3.65 Another family explained:

We also use respite care for occasional family outings where it is not appropriate to bring our disabled child (for example, a film which she would not enjoy, and at which she may be noisy).⁹⁵

- 3.66 Siblings are also young carers. While they may not be the primary carer, the caring responsibilities placed on the family may require them to take on greater responsibilities for household duties than what might be expected of a person of a similar age or direct caring responsibilities for their sibling, particularly when their parents are not available such as after school hours.

Young carers

- 3.67 Young carers are children and young people up to 25 years of age who may be the primary carer or provide additional help with the care of a sibling or

⁹¹ Submission 29, Name withheld, p 2

⁹² See for example, Submission 2, Autism ACT, Submission 14, St Margaret's Aged and Disability Committee, Submission 35, ADD Support Group, Submissions 9, 13, 15, 17, Name withheld

⁹³ Submission 4, Communities@Work

⁹⁴ Submission 13, Name withheld

⁹⁵ Submission 29, Name withheld, p 2

parent with a chronic illness, disability, mental illness or an alcohol or other drug problem.⁹⁶

- 3.68 Due to the unique nature of the caring relationship, the needs of young carers were highlighted by Carers ACT as an area of specific concern.⁹⁷
- 3.69 The caring responsibilities, particularly for the young primary carer such as additional domestic duties and assisting the care recipient with medication, therapy and medical appointments makes it harder to access education and employment opportunities. For example:
- 60 per cent of young primary carers aged 15–25 are unemployed or not in the labour force, compared with 38 per cent for the general population in the same group; and
 - only four per cent of young primary carers aged 15–25 are still at school, compared with 23 per cent of the general population in the same age group.⁹⁸
- 3.70 Access to responsive and adequate respite has been identified by young carers and their families as their most important and pressing need. However, without a family-responsive focus, accessing respite for young carers is not easy. For example, if a young carer was caring for a single parent, that person would not be able to access a residential respite facility if it meant that the young carer was not supervised or supported while they were away.⁹⁹
- 3.71 As most respite services cater for the care recipient, that is, the care recipient attends the facility, it can be difficult for young carers to get a break if the person being cared for does not accept support.¹⁰⁰
- 3.72 Mark's Place, a relatively new respite service offered in Canberra by the Mental Health Foundation (ACT), supports carers of adults living with a mental illness. The service caters for carers and care recipients who can utilise

⁹⁶ Carers ACT, Young Carers Program, viewed 15 October 2010, <<http://www.carersact.asn.au/programs/young-carers-program/>>

⁹⁷ Submission 25, Carers ACT, pp 14–15

⁹⁸ (ABS unpublished data) cited Carers Australia, *About Carers*, viewed 30 September 2010, <http://www.carersweek.com.au/10/carers.html>

⁹⁹ Submission 25, Carers ACT, p 14

¹⁰⁰ Submission 25, Carers ACT, p 14

Mark's Place individually or together. Individual recovery plans helps Mark's Place to support the goals of the carer and the care recipient.¹⁰¹

- 3.73 The service focus of Mark's Place is unique in the ACT and has the potential to benefit young carers who may be experiencing difficulty in accessing respite care for the people they are caring for.
- 3.74 The Young Carers Respite and Information Services Program, delivered through the Commonwealth Respite and Carelink Centre, assists young carers who need support to complete their secondary education or vocational equivalent due to the demands of their caring role. Carers ACT provide this service, mainly through brokering in-home support to enable young carers to attend school camps or access to study time.¹⁰²
- 3.75 Cyclops, funded by the ACT Government is the main service provider in the ACT supporting young carers and their families. The Committee understands that Cyclops is running to capacity and is not able to meet the demand on the service. *Vinnies Youth* also provides young carer camps and activities for people aged 9–16, with no Government funding. The Committee is supportive of programs aimed at assisting young carers and considers that funding to match need is required to enhance the capacity of services currently supporting young carers.

RECOMMENDATION 5

- 3.76 **The Committee recommends that the ACT Government determine the level of need for young carers and provide additional funding as required to young carers programs to ensure that young carers have access to appropriate support when required.**

¹⁰¹ Mental Health Foundations, Mark's Place, viewed 13 October 2010, <<http://www.mhf.org.au/mhf/ServicesandPrograms.aspx?a=21&s=40&c=205>>

¹⁰² FaHCSIA, Young Carers Respite and Information Services Program, viewed 6 October 2010, <<http://www.facsia.gov.au/sa/carers/progserv/Pages/YoungCarersRespiteProgram.aspx>>

Older carers

- 3.77 The increased life expectancy of people living with disability is resulting in adult children with an intellectual disability or mental illness outliving their elderly parents. This is a distressing situation for the carer and care recipient to come to terms with and unless planning for the future and transition arrangements have been made, there will be significant problems for the care recipient when the primary carer is no longer able to continue in the caring role. These families must be supported to ensure that forward planning and transitional arrangements have been established before this occurs.
- 3.78 It is the view of Professor Christine Bigby, Director, Postgraduate Program, School of Social Work and Social Policy, La Trobe University, that the situation for older carers has been created by lack of policy implementation at earlier parts of the life course, and further exacerbated by 'continuing unmet need for alternative accommodation and housing support'.¹⁰³
- 3.79 Lack of alternative accommodation options was also highlighted in the Australian Government report into the experience of people with a disability, which stated:
- The desperation of ageing parents haunted by the thought of what will happen to their children when they are no longer able to provide a high level of care and support was a sad recurring theme in submissions. The crisis in accommodation means that few are able to plan effectively, and transitions out of the family home are therefore often traumatic rather than seamless.¹⁰⁴
- 3.80 Older carers have been prioritised under the NDA and have been the focus of federal policy initiatives in recent years such as the *Mature Aged Carers Program* and the *Employed Carers Program*. However, Professor Bigby explained that increasing respite as the solution fails to address the underlying issue:

¹⁰³ Professor Bigby, *Transcript of Evidence*, 21 July 2010, p 86

¹⁰⁴ Australian Government, *Shut Out: the Experience of People with Disabilities and their Families*, p 29
<http://www.fahcsia.gov.au/sa/disability/pubs/policy/community_consult/Documents/NDS_report.pdf>

... which is the need for people to make the transition from parental care and find alternative supported accommodation or go and live in group homes or whatever suits them.¹⁰⁵

- 3.81 However, respite care services do play an important role for this group of older carers by supporting ageing parental carers to continue in their role and ensuring a smooth transition for middle-aged adults with intellectual disability to non-parental care, particularly those who have independently cared for their disabled adult child in the family home. Professor Bigby explained that the respite programs she had researched were used:

... as a means to begin that separation and to begin things like doing life-story work with the adult so that their story of their life and who has been important to them and the things they have done is documented. It is there for when the parents are no longer around; otherwise, nobody is going to know their history if they are not able to communicate that. There are a whole range of tasks around the planning issues, beginning to engage parents in planning and the preparation for the future.¹⁰⁶

- 3.82 The importance of support for ageing parents cannot be overstated, as it is inevitable that the time will come when the parents are going to die or become incapacitated, when that transition from parental care is going to have to happen. Respite care services play an important part in preparing people for future transitions. As Professor Bigby explained:

Respite care and respite programs can be used as a way of avoiding that future crisis, of avoiding having an unplanned transition to inappropriate accommodation.¹⁰⁷

- 3.83 St Margaret's Uniting Church runs the Stepping Stones for Life Program, funded by Disability ACT to support parents over the age of 60 to plan for the future accommodation needs of their adult child with a disability once they are no longer able to continue in the primary caring role. The service is contracted to provide intensive assistance to 10 families and less intensive support to a

¹⁰⁵ Professor Bigby, *Transcript of Evidence*, 21 July 2010, p 86

¹⁰⁶ Professor Bigby, *Transcript of Evidence*, 21 July 2010, p 91

¹⁰⁷ Professor Bigby, *Transcript of Evidence*, 21 July 2010, p 88

further 10 families. The Committee was advised however, that the demand for the service is increasing, but as Mr Baker, Chair, St Margaret's Aged and Disability Committee explained:

We can only manage those to the extent that we are staffed to do so. I believe there is certainly a need for a much wider type of service similar to what we are trying to provide.¹⁰⁸

- 3.84 With at least 25 000 carers in the ACT, the Committee is concerned that the ACT Government does not have an accurate picture of the number of carers who are over the age of 60. Furthermore, as Professor Bigby explained, this group of carers has chosen to take on this role and often do not see themselves as carers, and are the least likely to seek support.¹⁰⁹
- 3.85 Professor Bigby advised the Committee about a model of local government in the UK that has developed registers of older carers. They know how many older carers there are and are able to keep in touch with most of them in a very low-level way. This helps local government predict current and future needs and respond if there are hospitalisations or other emergencies. This type of model has the potential to be emulated in the ACT.¹¹⁰
- 3.86 Planning and support to ensure a smooth transition from the caring relationship is essential for both the carer and care recipient. The Committee notes the excellent service provided by the Stepping Stones for Life Program and would like to see it expanded to ensure all families in this situation have access to the support they require.

RECOMMENDATION 6

- 3.87 **The Committee recommends that the ACT Government determine the number of older carers, over the age of 60, providing primary care for an adult child with a disability and/or a mental illness in the ACT, and based on the findings increase the capacity of the Stepping Stones for Life Program or establish a similar service.**

¹⁰⁸ Mr Baker, *Transcript of Evidence*, 3 September 2010, p 180

¹⁰⁹ Professor Bigby, *Transcript of Evidence*, 21 July 2010, p 89

¹¹⁰ Professor Bigby, *Transcript of Evidence*, 21 July 2010, p 93

- 3.88 Another group of older carers are those providing primary care for their spouse or other family member in their own home. The PATH Through Life Survey¹¹¹ found a high-occurrence of carers in the 65–69 year age group in this situation. Care was being provided to those with a physical disability or chronic illness (57.8 per cent), those with a mental illness (13.3 per cent) and memory or other cognitive problems (10.2 per cent).¹¹²
- 3.89 Carers in this age group, when compared to non caregivers, were more likely:
...to be women, to report physical impairment, to be reliant on welfare payments, to have experienced financial hardship and to have greater responsibility for household management. Carers were also more likely to suffer from mental health issues such as anxiety and depression.¹¹³
- 3.90 The Committee is concerned that this group of carers may not be having their needs fully addressed.

Aboriginal and Torres Strait Islander people

- 3.91 Aboriginal and Torres Strait Islander (ATSI) people have significantly higher rates of profound or severe core activity limitation than non-indigenous people.¹¹⁴
- 3.92 Despite an open door policy, the evidence still indicates that many Aboriginal people want and prefer Aboriginal services to mainstream services.¹¹⁵ The Canberra Social Plan, for example, notes the difficulty ATSI people experience

¹¹¹ Conducted by the ANU, the Personality and Total Health (PATH) Through Life Project is a 20-year longitudinal cohort study of 7,485 young (aged 20 – 24 at baseline), midlife (aged 40 – 44 at baseline) and older (aged 60 – 64 at baseline) adults randomly sampled from the Electoral Rolls of the Australian Capital Territory and the nearby city of Queanbeyan, viewed 30 September 2010, <<http://cmhr.anu.edu.au/path/>>

¹¹² ACT Government, *Population Ageing in the ACT Issues and Analysis*, July 2010, p 31

¹¹³ ACT Government, *Population Ageing in the ACT Issues and Analysis*, July 2010, p 32

¹¹⁴ Steering Committee for the Review of Government Service Provision, *Report on Government Services 2010*, Volume 2, p 14.12

¹¹⁵ Working with Aboriginal and Torres Strait Islanders and their Communities, *Practice implications: Self-determination*, viewed 5 October 2010, <http://www.workingwithatsi.info/content/PI_selfdetermination.htm>

in accessing mainstream health services due to limited understanding of cultural and health issues.¹¹⁶

- 3.93 The ACT Government has further acknowledged the need for ATSI specific services with the investment in the Aboriginal Healing Farm and the development of a policy framework for ATSI people 'to enhance the responsiveness of supports and services to Indigenous people with disability and their families'.¹¹⁷
- 3.94 As part of the *Caring for Carers in the ACT – A plan for action 2004–2007*, a feasibility study was commissioned to 'develop a new model of respite care that better recognises and supports Aboriginal and Torres Strait Islander peoples' preference for kinship and family care'. The study was conducted by the Echidna Group – Indigenous Research and Development Consultancy, in 2008.¹¹⁸
- 3.95 The report found ATSI people in the ACT region were not accessing respite services due to poor help-seeking knowledge and skills, lack of knowledge about services, lack of advocacy, lack of Aboriginal specific respite and care support services.¹¹⁹ The report also found that attitude to mainstream services was of significant concern, stating:
- Many participants reported a preference for Aboriginal-specific services, and even a reluctance to access mainstream services. Reasons for this were based around perceived and experienced levels of cultural competence of these services, historical competence, and fear that asking for respite may invite scrutiny, or be seen as a sign of not coping, and could even result in the removal of a child with a disability.¹²⁰

¹¹⁶ ACT Government, *Building Our Community, The Canberra Social Plan*,

¹¹⁷ DHCS, *Future Directions: Towards Challenge 2014, Implementation Plan 2009–2010*, Action 12, p 3

¹¹⁸ The Echidna Group, *Feasibility Study for Respite Care for Aboriginal & Torres Strait Islander Peoples*, February 2009, http://www.dhcs.act.gov.au/_data/assets/pdf_file/0008/89315/ACT_ATSI_Respite_Feasibility_Report.pdf

¹¹⁹ The Echidna Group, *Feasibility Study for Respite Care for Aboriginal & Torres Strait Islander Peoples*, February 2009, pp 33–36

¹²⁰ The Echidna Group, *Feasibility Study for Respite Care for Aboriginal & Torres Strait Islander Peoples*, February 2009, p 34

3.96 The report further noted:

The cultural inappropriateness of respite care service provision, and the cultural incompetence of staff was unanimously noted by all participants as an obstacle to Aboriginal and Torres Strait Islander access to respite care services.¹²¹

3.97 The Committee was advised that ACT Health and the Australian Government Department of Health and Ageing, through their Aboriginal and Torres Strait Islander health section, are looking at opportunities to develop an ATSI specific respite facility.¹²²

3.98 With no Aboriginal specific aged care respite in the ACT the Committee was told of the difficulty this presented. Mrs Agnes Shea, a senior Ngunnawal elder explained:

I had to put my mother in a nursing home for respite care and if I had told her she was going into a nursing home she would never have gone there. I told her that she was going to a special hospital. The people there were fantastic with her, I must say, but she always felt that she was the odd one out because she was the only Aborigine there.¹²³

3.99 The Committee was also advised of the nature of co-caring in the Aboriginal community. Mrs Shea, who is nearly 80 years old, provides the primary care for her 50 year old son who is confined to a wheelchair. He travels to New South Wales to stay with nieces and nephews to provide a break for Mrs Shea. She told the Committee:

He is coming back this weekend, but he said the last time he went away, about a month ago: "I'm getting too old to travel. What are we going to do if something happens to you? Who's going to look after us?"¹²⁴

3.100 The Committee heard that there was widespread support for the development of a specific ATSI aged care village in the ACT.¹²⁵ The Rose Mumbler Village,

¹²¹ The Echidna Group, *Feasibility Study for Respite Care for Aboriginal & Torres Strait Islander Peoples*, February 2009, p 35

¹²² Ms Gehrig, *Transcript of Evidence*, 28 April 2010, p 43

¹²³ Mrs Shea, *Transcript of Evidence*, 14 April 2010, p 36

¹²⁴ Mrs Shea, *Transcript of Evidence*, 14 April 2010, p 37

located in Nowra NSW, was provided as an example of an Aboriginal aged care retirement village that also catered for overnight or weekend respite stays.¹²⁶

- 3.101 The Echidna Group made 15 recommendations, specific to respite care services for ATSI people in the ACT, under the following four headings: Consultation / Communication; Delivery of Respite; Workforce Development / Training / Mentoring; and Care Support Other Than Respite.¹²⁷
- 3.102 ATSI specific services in the ACT currently include the Carers ACT *Indigenous Carers Program*¹²⁸ and the Ngunnawal Aboriginal Corporation. The Committee notes that ATSI people are prioritised under the HACC program and the National Respite Program for Carers but is concerned that ATSI people do not have equitable access to respite care services in the ACT.

RECOMMENDATION 7

- 3.103 **The Committee recommends that the Minister for Disability, Housing and Community Services table, in the Assembly, by March 2011, the Government's response to the recommendations made by The Echidna Group in its *Feasibility Study for Respite Care for Aboriginal & Torres Strait Islander Peoples* and state the Government's intention in relation to an Aboriginal and Torres Strait Islander specific respite facility in the ACT and the timeframe intended to complete this.**

Culturally and linguistically diverse people

- 3.104 People from culturally and linguistically diverse (CALD) communities are often disadvantaged and can experience social isolation, particularly those with limited English language skills. Research conducted by Sarah Maslen for the Women's Centre for Health Matters found that women from CALD

¹²⁵ Ms Roslyn Brown, *Transcript of Evidence*, 14 April 2010, p 31

¹²⁶ Ms Roslyn Brown, *Transcript of Evidence*, 14 April 2010, p 33

¹²⁷ The Echidna Group, *Feasibility Study for Respite Care for Aboriginal & Torres Strait Islander Peoples*, February 2009, pp 54–57

¹²⁸ Carers ACT, Indigenous Carers Program, viewed 30 October 2010, <http://www.carersact.asn.au/programs/indigenous-carer-program/>

backgrounds are one of the most disadvantaged and vulnerable groups who consistently experience isolation and marginalisation in the ACT.¹²⁹ This isolation can impact on their ability to access support services.

3.105 The Multicultural Women's Advocacy (MWA) Inc is the ACT peak advocacy, advisory, and lobby group representing the needs of women from CALD backgrounds. The following issues were identified in their submission to the Committee:

- lack of awareness and knowledge of respite care services and the type of services they deliver;
- the understanding that the primary care of aged family members and children with disabilities is provided through kinship networks not mainstream services;
- the stigma people face within their own communities when they seek assistance outside the kinship networks;
- the expectation on older female siblings to take on the caring responsibility for younger siblings, siblings with a disability or grandparents when both parents are working;
- problems among young CALD carers such as truancy, teenage pregnancy and/or alcohol and drug abuse; and
- lack of support groups for care recipients and caregivers from CALD backgrounds.¹³⁰

3.106 There are a number of services in the ACT that cater specifically to the needs of CALD communities. These include the:

- Carers ACT, CALD Carers Program that provides support and facilitates access to services for carers from non English speaking backgrounds including 15 support groups, hosted by a bilingual group leader;¹³¹

¹²⁹ Sarah Maslen, cited in Submission 40, Multicultural Women's Advocacy Inc, p 1

¹³⁰ Submission 40, Multicultural Women's Advocacy Inc, p2

¹³¹ Carers ACT, Culturally and Linguistically Diverse Carers Program, viewed 6 October 2010, <<http://www.carersact.asn.au/cald-carer-groups.html>>

- Baptist Community Services NSW/ACT, runs the Culturally and Linguistically Diverse Occasional Respite (CALDOR) program that provides in home respite;
- Community Options CALD Case Manger program for clients from non-English speaking background; and
- Carers kits provided by the Australian Government in a number of languages to cater to the needs of CALD carers.

- 3.107 The culturally specific support groups for CALD carers are a useful resource but do not cater for all cultural communities.
- 3.108 While there are services that can assist CALD people it appears that there are many in the community that do not have knowledge of the available services and do not understand the valuable role that respite services and other support services can have in supporting family members, as discussed in chapter two.
- 3.109 The Committee notes the range of bilingual information available through brochures and information kits. However, not all cultures are catered for in translated materials and the available translated material tends to favour the more established communities such as Greek, Italian, Spanish and Vietnamese. These communities also tend to have more structured supports in place.
- 3.110 Increasing people's awareness, knowledge and understanding of disability and mental illness and the benefits of respite services, for carers and care recipients, with the assistance of bilingual support workers, has the potential to breakdown the stigma that prevents CALD people from seeking support outside their own communities.

RECOMMENDATION 8

- 3.111 **The Committee recommends that the ACT Government develop bilingual programs for new and emerging communities in the ACT aimed at de-stigmatising disability and mental illness and raising awareness about respite care services and other support services, with a particular emphasis on the benefits for both carer and care recipient.**

Attention Deficit Hyperactivity Disorder

- 3.112 The Committee received representation from a group of carers who felt their needs were not being addressed. The submission from the Canberra and Queanbeyan ADD Support Group called for greater recognition of carers of children and young people with Attention Deficit Hyperactivity Disorder (ADHD). The impact of caring for a child with ADHD has similarities to caring for a child with another type of disability, as discussed in chapter two. However, according to the ADD Support Group, the problems for children with ADHD are exacerbated through the ACT school system that does not recognise their condition as a disability that requires special needs assistance.¹³²
- 3.113 The Committee understands that there are limited supports available for this group of carers. For example, Carers ACT can provide support and assistance but requires a medical diagnosis, or Tandem which will take referrals of children with ADHD. The Committee understands however, that all new referrals to Tandem are placed on the waiting list according to level of need, so a person assessed as having a low level of need (which may include a child with ADHD) can be superseded by new referrals, therefore extending their time on the waiting list. The waiting list can be up to two years and there is no guarantee of a service.¹³³
- 3.114 Overnight respite options for children and young people with ADHD may be available through the ACT Government respite houses, however, the Committee was advised this is not an appropriate model as 'ADHD children do not like to be co-located with other physically disabled children as they do not see themselves in that same way'.¹³⁴
- 3.115 The ADD Support Group's submission calls for greater access to respite care services, stating:

¹³² Standing Committee on Education, Training and Youth Affairs, *The needs of ACT students with a disability*, 201, p 23

¹³³ Information provided by Tandem in-take line, 25 September 2010

¹³⁴ Submission 35, Canberra and Queanbeyan ADD Support Group inc, p 2

A night or weekend respite for their ADHD child so that the siblings can have quality time with the parents/carers is an under-recognised need, as is a weekend away from family to de-stress or to attend seminars so as to better educate themselves on ADHD.¹³⁵

- 3.116 The ADD Support Group's submission also stated that ADHD families feel 'isolated' and the Committee is concerned that this group has been overlooked in the provision of respite care services and considers that more should be done to enable these carers and care recipients access to the benefits of respite, as previously discussed.

¹³⁵ Submission 35, Canberra and Queanbeyan ADD Support Group inc, p 2

4 RANGE, AVAILABILITY AND SUITABILITY OF RESPITE SERVICES

- 4.1 The majority of respite care in the ACT is provided through the community sector in a variety of settings for the elderly, people living with a mental illness and people with a disability. The Australian Government National Respite for Carers Program (NRCP) funds a range of service models and the ACT Government also funds a range of services through DHCS and ACT Health.
- 4.2 The Home and Community Care (HACC) program, jointly funded by the ACT and Australian Governments, is the major provider of essential community care services to frail aged people and younger people with disabilities, and their carers. The main objective of the program is to promote and enhance the independence of people in these client groups. For the 2008–09 financial year there were 30 active HACC funded services operating in the ACT that provided care to 11 292 clients in the ACT, of which 25 per cent reported having a carer.¹³⁶
- 4.3 The major types of respite services available in the ACT include overnight respite (government and community based), own home respite, day care for older persons and recreational respite.¹³⁷ However, meeting the diversity of need is not always easy.

Flexible respite

- 4.4 Carers and care recipients need access to flexible respite tailored to the needs of individuals and their families. This is reflected in one of the core principles of the *ACT Caring for Carers* policy, that states:

¹³⁶ Australian Government Department of Health and Ageing, *Home and Community Care Minimum Data Set 2008–09 Annual Bulletin*, viewed 25 September 2010, Table A9, <[http://www.health.gov.au/internet/main/publishing.nsf/Content/28557CCBE3618FADCA2576CE001D9397/\\$File/2008-09_HACC_Annual_Bulletin_final.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/28557CCBE3618FADCA2576CE001D9397/$File/2008-09_HACC_Annual_Bulletin_final.pdf)>

¹³⁷ A full list of service providers is at Appendix C.

The health and wellbeing of carers is supported through services and programs that are flexible and responsive to individual needs and circumstances.¹³⁸

4.5 To meet this need, one of the strategies of the *Plan for Action* was to:

Improve access to flexible and timely respite care and other forms of short-term care that provide carers with opportunities for other activities and breaks.¹³⁹

4.6 The Committee heard from many families that this was not their experience and that the limited options of respite in the ACT required families to fit in with what is available. However, this was not always possible. The Committee heard the following examples:

- A family with three disabled children sought in-home respite for six weekends per year. While they have been offered a weekly allocation of hours through a community organisation, the hours could be not be utilised. At the time of writing, despite the best intentions of Disability ACT, their need had not yet been accommodated.¹⁴⁰
- The only option available to a care recipient requiring respite for eight weeks while his primary carer attended to her health needs was in a residential aged care facility (RACF). This was not appropriate and the only resolution for this family was to pay for a full-time nurse, an expensive option that would not be available to many families.¹⁴¹

4.7 Carers need respite at a time of their choosing. Of particular concern to many families was the reduction in weekend respite hours provided through Tandem. Tandem is the largest community based provider of respite care services, catering to people with a disability, people with a mental illness and the frail aged.¹⁴² The Committee heard that the loss of weekend respite hours impacted heavily on families, particularly for siblings who used this to spend

¹³⁸ DHCS, *Caring for Carers Policy*, 2003, p 5

¹³⁹ DHCS, *Caring for Carers Policy A Plan for Action*, p 10

¹⁴⁰ Mr and Mrs Mowbray, *Transcript of Evidence*, 1 September 2010, p 114

¹⁴¹ Mr Trewhella, *Transcript of Evidence*, 14 April 2010, pp 18–19

¹⁴² Tandem, viewed 30 September 2010, <http://www.tandem.org.au/site/index.php>

some quality time with their parents. While families were offered substitute weekday respite, this was not convenient, and another example that required more flexibility from the family than the service.¹⁴³

- 4.8 The Committee understands that the decision taken by Tandem to reduce access to weekend hours was a business decision based on the availability of funding. As Ms Cheryl Pollard, Chief Executive Officer of Tandem, explained:

One of the challenges is the financial need to apply a ceiling to weekend service provision due to a combination of funding being provided on a weekday unit cost basis and the imperative to meet funded hour allocations. So with our funding from HACC, Disability ACT and mental health we have to provide a certain number of outputs, we have a certain number of dollars to do that with and we have to then put the hours out. The reality is that we identified last year that we were not able to sustain the level of weekend support that we were providing, mainly in the children's program.¹⁴⁴

- 4.9 The Committee understands that since this inquiry began, Tandem has secured additional funding through the ACT Government to enable the reintroduction of weekend respite hours.

RECOMMENDATION 9

- 4.10 **The Committee recommends that the ACT Government continue to support Tandem to ensure that the provision of weekend respite for people with a disability and those living with a mental illness is sustainable in the long term.**

Lack of other support services

- 4.11 Respite care is one type of service provided across the spectrum of disability, mental health and aged care services and should not be examined in isolation. The Committee heard that respite care was being used less in the traditional sense, as a break, with more carers relying on respite care services to meet

¹⁴³ See for example Submission 17, Name withheld and Submission 18, Name withheld

¹⁴⁴ Ms Pollard, *Transcript of Evidence*, 14 April 2010, p 24

their daily living requirements, as discussed in chapter three. As one care recipient noted the demand for respite comes from fragmented services and lack of support for people with disabilities, families and carers.¹⁴⁵

4.12 The Committee also received evidence that respite was being used more frequently as a gap filler, to prop up the disability sector, where other support programs are not available, particularly out of school hours care, school holidays care and post school options, as discussed in chapter three.

4.13 Shortage of supported accommodation options was identified as a particular area of concern.¹⁴⁶ In their submission, National Disability Services ACT considered it important for respite services to be considered in the context of increasing demand for supported accommodation. They stated:

If the current demand on supported accommodation increases and cannot be met, many individuals with disability may need to remain in the family home. This will have a flow on impact regarding demand for respite service to support those individuals and families.¹⁴⁷

4.14 The longer that people remain living in the family home the greater demand will be on respite care services. However, for young people with a disability it is desirable for them to leave home if they are going to live a more normal life. As Ms Margaret Verick, Director of Focus ACT, pointed out:

Families would actually want their person, when they attain adulthood, like everybody else in the community, to go on to develop a life of their own, which would mean moving into community living or some other arrangement.¹⁴⁸

4.15 The situation of a young man with Autism was described by his mother who, like any parent, wanted the best for her son. She told the Committee her son should be entitled to:

¹⁴⁵ Mr Trehwella, *Transcript of Evidence*, 14 April 2010, p 15

¹⁴⁶ Submission 1, National Disability Services, p1, Submission 8, Mental Health Community Coalition, pp 2–3, Submission 14, St Margaret's Aged and Disability Services Committee, Professor Bigby, *Transcript of Evidence*, 21 July 2010, pp 86–87

¹⁴⁷ Submission 1, National Disability Services, p1

¹⁴⁸ Ms Verick, *Transcript of Evidence*, 1 September 2010, p 137

... a reasonable life that every other 21-year-old has... he does not have a sustainable work life and he does not want to live with his parents forever...We are boring. He is 21. He needs to have a life.¹⁴⁹

- 4.16 The Committee understands that the majority of care recipients in the ACT are living in the family home, many of whom are happy with the current arrangement. At this stage, however, it is unclear how many people are seeking alternative accommodation and circumstances will change, particularly as children grow into young adults.
- 4.17 The Community Living Project (CLP) is a group of families who have come together in the ACT seeking supported accommodation for a family member with a disability. The group exists because of the lack of adequate options and considers that greater access to respite care, in-home support and disability services would reduce the need for supported accommodation in the short term.¹⁵⁰
- 4.18 CLP is currently conducting a feasibility study for the establishment of an 'urban village' living environment that would provide supported accommodation, training, employment and lifestyle options for people with moderate to severe intellectual disability. This option has the support of CLP families, and in light of limited supported accommodation options, the Committee considers this model warrants further investigation.¹⁵¹

RECOMMENDATION 10

- 4.19 **The Committee recommends that the ACT Government give serious consideration to organisations such as the Community Living Project's proposed 'urban village' model of supported accommodation for people with a disability, given the shortage of supported accommodation options in the ACT and the significant support this model has among families caring for a child/adult with a disability.**

¹⁴⁹ *Transcript of Evidence*, 14 April 2010, p 10

¹⁵⁰ Submission 37, Community Living Project, p 5

¹⁵¹ ACT Community Living Project, The Urban Village Concept, viewed 18 October 2010, <<http://communitylivingproject.org.au/the-village>>

- 4.20 Focus ACT is an ACT Government funded community based organisation that provides accommodation support services to around 70 people with a mild to moderate intellectual disability. Over 50 per cent of Focus's clients are over 45 years of age, many of whom have been with the service for over 17 years. With limited funding, Focus is not able to take on new clients. Ms Verick advised that Focus did not have a waiting list as there was no point. She further told the Committee that:

The funding has just been increased after two years of negotiations so that we can better meet the needs of the people that we have who have been involved with us for 17 or more years, who are ageing and developing complex medical needs and so on.¹⁵²

- 4.21 Professor Bigby advised the Committee that unless the lack of supported accommodation options was addressed there will be a continuing issue about older carers of people with disabilities and mental illness, as discussed in chapter three.¹⁵³
- 4.22 The Committee notes the work conducted by the ACT Government into accommodation and support options for people with high and complex needs for specifically designed properties.¹⁵⁴ While special purpose planning is important, more work needs to be done to assess and plan for the future housing needs of people with a disability and mental illness. Accommodation options must also include the provision of support that residents will require.
- 4.23 As Focus ACT noted in its submission to the ACT Government Budget Consultation, good estimates of the number of people in the ACT who require supported accommodation assistance now and in the future is required.¹⁵⁵

RECOMMENDATION 11

- 4.24 **The Committee recommends that the ACT Government identify the number of people that require supported accommodation and take appropriate action to meet the current and future housing needs for**

¹⁵² Ms Verick, *Transcript of Evidence*, 1 September 2010, p 137

¹⁵³ Professor Bigby, *Transcript of Evidence*, 21 July 2010, p 87

¹⁵⁴ DHCS Annual Report 2010–11, p 29

¹⁵⁵ Focus ACT, ACT Budget Consultation, 2009,

people with a disability and/or mental illness including the identification of alternative housing models.

Alternative models of respite

- 4.25 There are a wide range of respite models being delivered across Australia, many of them providing flexible options that are not currently available in the ACT.
- 4.26 The Committee's attention was drawn to the Interchange Illawarra, a not-for-profit, community-based organisation offering a range of flexible respite support to suit the individual needs of people with developmental disabilities and their families/carers. The Committee was told of one family's experience with the Host Family Program that was able to cater to their specific respite needs.¹⁵⁶ Since moving to the ACT, this family has been unable to have its need for respite met, despite the best intentions of Disability ACT.¹⁵⁷
- 4.27 The Host Family Program is operated by volunteers who are remunerated for their time and out of pocket expenses. Volunteer families undergo mandatory training and must obtain a first aid certificate; criminal record clearance; working with children check; and specific training regarding the care recipients needs (such as epilepsy or gastric tube feeding). Family homes are also assessed for suitability and safety.¹⁵⁸
- 4.28 The Committee understands that overnight in-home respite is available in the ACT, though Tandem, but the cost can be prohibitive to some families, particularly when more than one night is required.¹⁵⁹ The volunteer base of host families makes the Illawarra Interchange program sustainable.¹⁶⁰
- 4.29 The Committee notes the reference to the development of new service options for respite, such as host family respite and shared care arrangements in the

¹⁵⁶ Submission 18, Name withheld, p 2

¹⁵⁷ Mrs Mowbray, *Transcript of Evidence*, 1 September 2010, p 111

¹⁵⁸ Information obtained through discussion with staff at Interchange Illawarra, 13 October 2010

¹⁵⁹ Tandem clients pay a subsidised hourly rate based on annual family income. The cost for overnight in-home respite is 24 times the hourly rate.

¹⁶⁰ Interchange Illawarra, viewed 13 October 2010, <<http://www.interchangeillawarra.org/>>

*2009 Policy Framework for Children and Young People with a Disability and Their Families*¹⁶¹ and feels that much could be gained by examining the model of host family respite provide by the Illawarra Interchange.

- 4.30 While it is optimal for families to utilise informal networks, not all families feel they are able to ask for help from friends or family, or do so intermittently, or only in times of crisis. As one family caring for their daughter with high needs explained:

... we do not like to impose on our friends' and family's lives or ask for assistance. We would not like them to feel taken for granted or obligated.¹⁶²

- 4.31 For this family having the ability to offer remuneration to family and friends would relieve some of the pressure of asking for help. Continuity of care is also an important feature of the caring arrangement for this family, who commented:

We would rather see him [our son] paid to care for our daughter than a stranger, who does not know her or her history, or who understands what she is trying to communicate. This could be paid work for him rather than adding to demands of our family by us driving him to work at a shop in the Mall, for example.¹⁶³

- 4.32 The Committee noted that the Interchange Illawarra have a program that supports families to better utilise their informal networks through the provision of remuneration for extended family members (including siblings) and friends.¹⁶⁴

- 4.33 Illawarra Interchange also runs a number of other programs that combine flexible respite options with social opportunities for care recipients operating on weekends, such as:

¹⁶¹ ACT Government, *Policy Framework for Children and Young People with a Disability and There Families*, 2009, p 9

¹⁶² Submission 29, Name withheld, p 3

¹⁶³ Submission 29, Name Withheld p 3

¹⁶⁴ Information obtained through discussion with staff at Interchange Illawarra, 13 October 2010

- a Saturday play group for children with Autism;¹⁶⁵ and
 - the Peer and Social Support program that includes the Saturday Club for people between 10 and 16 years of age.¹⁶⁶
- 4.34 Respite camps are another model that provides respite for both the carer and care recipient. The PA ACT drew the Committee's attention to Leap Frog Adventures,¹⁶⁷ a community based group in the ACT that provided adventure camps for people with disability.¹⁶⁸ The Committee understands this program no longer exists due to lack of funding.
- 4.35 The Committee notes that respite camps for children and young people with a disability are available in other states and considers this an interesting respite option. Examples of respite camps include:
- Villa Maria, a not-for-profit values-based organisation provides day programs and camps for older people and people with a disability;¹⁶⁹ and
 - Kids Camps, a WA charity organisation provides camps for children aged 5-18 that can walk unassisted with an intellectual disability during school holidays and weekends¹⁷⁰
- 4.36 Karingal Community Living is a mental health service in Victoria that provides a range of community-based services and programs designed to support people with mental illness take steps towards recovery. Of particular interest is the respite house that not only provides educational and life skills opportunities for residents, but runs as a 'drop-in' program that allows people to visit for a coffee, company and/or informal support at regular, dedicated

¹⁶⁵ Interchange Illawarra, *Saturplay*, viewed 30 September 2010, <<http://www.interchangeillawarra.org/services/saturplay.html>>

¹⁶⁶ Interchange Illawarra, Peer and Social Support Program, viewed 30 September 2010, <<http://www.interchangeillawarra.org/services/peer-a-social-support.html>>

¹⁶⁷ Leap Frog Adventures, viewed 13 October 2010, <http://www.leapfrogadventures.com/trips.htm>

¹⁶⁸ Submission 43, PA ACT, p 5

¹⁶⁹ <http://www.villamaria.com.au/services/disability-services/flexible-respite.html>

¹⁷⁰ <http://www.kidscamps.org.au/index.php>

times throughout the week.¹⁷¹ The need for a drop-in centre for people living with a mental illness in the ACT was also raised as part of this inquiry.¹⁷²

RECOMMENDATION 12

- 4.37 **The Committee recommends that the ACT Government investigate flexible respite options to meet the diversity of needs, with a view to establishing new models of respite services in the ACT that are truly responsive to the needs of carers and care recipients.**

Quality assurance

- 4.38 Robust quality assurance processes are essential to provide carers with the confidence to relinquish caring responsibility of their loved one, even for a short period of time, to substitute carers.
- 4.39 Residential aged care facilities, that also provide respite nights, must be accredited in order to receive funding from the Australian Government through residential care subsidies. The Aged Care Standards and Accreditation Agency is appointed by the Department of Health and Ageing as the accreditation body under the *Aged Care Act 1997*.¹⁷³
- 4.40 Services funded under the Mental Health Respite Program, including services purchased through the brokerage component of the program, are expected to meet all standards and legislative requirements of the Centre Guidelines and must meet the National Respite for Carers Program National Service Standards, as well as all state or legislative requirements relevant to the service.¹⁷⁴
- 4.41 Under the NDA disability services are required to comply with the National Disability Service Standards (NDSS). However, with no formal accreditation process Disability ACT funded services are required to complete an annual

¹⁷¹ Karingal Community Living, viewed 13 October, 2010, <<http://kcl.karingal.org.au/karingal-community-living/home/mental-health-support/393/default.aspx>>

¹⁷² Submission 41, Mr Wilkinson, p 2

¹⁷³ The Aged Care Standards and Accreditation Agency, viewed 30 September 2010, <http://www.accreditation.org.au/>

¹⁷⁴ http://www.facs.gov.au/sa/mentalhealth/pubs/mhrp_bchgc/Documents/part06.htm

- 4.42 Further to self-assessment, Disability ACT aims to conduct five service audits per year. However, the Auditor-General found that quality assurance through annual self-assessment by service providers was not effective and that it would take eight years to review all service providers through the current regime of external audits.¹⁷⁵
- 4.43 A brief review of the current process of self-assessment to monitor performance of service providers conducted by the Auditor-General found no evidence of review and follow-up action by Disability ACT since 2006.¹⁷⁶
- 4.44 The Community Living Project regarded this situation as 'extremely high risk and...of real concern to CLP families'.¹⁷⁷
- 4.45 The PA ACT was also of the view that monitoring of respite services and care standards needs to be prioritised, stating that 'if insufficient attention is given to this area there may be adverse outcomes regarding the care, safety and wellbeing of clients'.¹⁷⁸
- 4.46 The Auditor-General further found that at the time of the performance audit the government respite centres had not been subject to any recent internal or independent review to assess their compliance with the NDSS.¹⁷⁹ The audit also noted that while staff working in the Government respite houses were generally aware of the NDSS, there was a perception that the standards were not relevant to the services provided to people with a disability. The Auditor-General noted:

This indicated that there was a gap in the expectations between management and support staff in relation to the application and implementation of the service standards in accordance with the NDSS.¹⁸⁰

¹⁷⁵Auditor-General's Report, *Management of Respite Care Services*, Report No. 3 / 2009, p 46

¹⁷⁶Auditor-General's Report, *Management of Respite Care Services*, Report No. 3 / 2009, p 60

¹⁷⁷ Submission 37, Community Living Project, p 3

¹⁷⁸ Submission 42, Public Advocate of the ACT, 7

¹⁷⁹Auditor-General's Report, *Management of Respite Care Services*, Report No. 3 / 2009, p 59

¹⁸⁰Auditor-General's Report, *Management of Respite Care Services*, Report No. 3 / 2009, pp 32–32

4.47 The Committee notes the recommendation made by the Auditor-General that Disability ACT:

- should conduct an independent review of service providers performance and quality of services based on risk;
- effectively manage the annual self-assessment process; and
- undertake a review of its own services (such as respite care) to ensure they comply with industry standards or the NDSS.¹⁸¹

4.48 The ACT Government agreed with this recommendation, and in its submission to the Committee advised that the recommendation had been completed, stating:

- Disability ACT commenced an internal review of its services to ensure that they comply with the NDSS;
- A communication and compliance strategy has been developed for community service providers as part of the contract management function; and
- Disability ACT has incorporated the review of government and community service provision into the Quality Management Framework.¹⁸²

4.49 The Committee is concerned about the ability of Disability ACT to ensure that government and non-government services are complying with the NDSS and considers a full review of all ACT Government funded services providing respite care is long overdue.

RECOMMENDATION 13

4.50 **The Committee recommends that the Minister for Disability, Housing and Community Services table in the Assembly, by the last sitting day in March 2011: 1) the outcomes of the internal review assessing Disability ACT services compliance with the National Disability Service Standards (particularly the respite care houses); and 2) details**

¹⁸¹ Auditor-General, *Management of Respite Care Services, Report No. 3 / 2009*, recommendation 11, p 62

¹⁸² Submission 42, ACT Government, Attachment A1, *ACT Government Implementation of Recommendations of Auditor-General's report, No. 3 of 2009, Management of Respite Services in the ACT*, p 8

of the communication and compliance strategy for community service providers.

RECOMMENDATION 14

- 4.51 **The Committee recommends that DHCS increase its current capacity of conducting five service audits per year, by engaging an external auditor to review all ACT Government funded organisations providing respite care services by the end of 2011, to ensure they are in compliance with the National Disability Service Standards, as many services have not had an external review since 2006.**
- 4.52 The Committee notes that the NDSS are being revised as part of the development of a National Quality Framework for Disability Services in Australia (NQF), a key priority of the National Disability Agreement (NDA).¹⁸³
- 4.53 The Committee further notes that one of the core features of the *Interim National Quality Framework for Disability Services in Australia* recently released requires that:
- All service providers are externally monitored for compliance against the National Standards for Disability Services.¹⁸⁴
- 4.54 The Committee is pleased to note the introduction of this level of monitoring but is concerned how this will be implemented in the ACT as this has not been the practice of Disability ACT. The Committee is further concerned that the additional resources required to conduct this level of monitoring could impact negatively of the delivery of disability services.

¹⁸³ State Government of Victoria, Department of Human Services, *Revision of the National Standards for Disability Services, Discussion Paper*, April 2010, viewed 13 September 2010, http://www.dhs.vic.gov.au/_data/assets/pdf_file/0010/422686/quality_natstand_discuspaper_0410.pdf

¹⁸⁴ State Government of Victoria, Department of Human Services, *Interim National Quality Framework for Disability Services*, viewed 13 September 2010, http://www.dhs.vic.gov.au/_data/assets/pdf_file/0010/378433/quality_interimnationalqfdisinaust_1109.pdf

RECOMMENDATION 15

- 4.55 **The Committee recommends that the Minister for Disability, Housing and Community Services report to the Assembly how the external monitoring for compliance against the National Quality Framework for Disability Services in Australia will be conducted and what additional resources will be required and the timeframe for implementation.**
- 4.56 The Committee notes that the prequalification framework being developed for DHCS (to be trialled in 2010) is expected to provide 'an added layer of reassurance in relation to services meeting a whole range of criteria before they are even able to get, in this case, DHCS funding'.¹⁸⁵
- 4.57 However, until such time as greater checks and balances are in place the Committee is seeking assurance from the Minister for Disability, Housing and Community Services that all government and government funded disability services are compliant with the NDSS.

Official visitor scheme

- 4.58 Official visitor schemes or programs have been developed nationally and internationally to promote the rights and monitor the wellbeing of different population groups in residential or inpatient facilities, foster homes, secure sites and accommodation services, including respite services. Although the aims of schemes and programs vary, common purposes are improving outcomes for population groups, enhancing the voice of the consumer via first hand information and identifying systemic issues to be addressed.
- 4.59 There are a variety of schemes operating in Australia. Every state and territory has an official scheme, mandated in legislation, operating for people with mental illness and most appear to have something in place for children and young people and for people in prison. NSW, Victoria and Queensland also have programs for people with disabilities, with Queensland being the only jurisdiction that includes the aged care facilities.

¹⁸⁵ Ms Ford, *Transcript of Evidence*, pp 73–74

- 4.60 The ACT has a comprehensive Official Visitor Scheme covering children and young people, people in mental health facilities and people in prison. There is no Official Visitor Scheme for people with a disability.
- 4.61 The ACT Government committed to establishing a Disability Services Commissioner and Official Visitors for disability in response to the 2002 *Board of Inquiry Report*, that found:
- ... the rights and interests of people with disabilities had not been adequately or effectively protected by the policies and systems operating in the ACT. It identified significant failures in relation to the monitoring and accountability of service delivery, and that there was not sufficient scrutiny of the management of disability services and programs.¹⁸⁶
- 4.62 While the Committee is pleased to note the establishment of a Disability and Community Services Commissioner, the Committee notes that an Official Visitor Scheme for people with a disability has not yet been established.
- 4.63 The PA ACT told the Committee that she supported the establishment of an Official Visitor Scheme for people with a disability in the ACT.¹⁸⁷ In 2004, the ACT Government issued a position paper on the *System of Statutory Oversight in the ACT* acknowledging the need for accessible complaints mechanisms and supported widening the scope of the function of Official Visitors in relation to mental health and the introduction of Official Visitors for disability.¹⁸⁸
- 4.64 The Government also supported the relocation of the Official Visitors for mental health, child protection and youth justice to the Office of the Public Advocate of the ACT.¹⁸⁹
- 4.65 The Office of the Public Advocate manages the Community Visitors Scheme in Victoria. Under this scheme, community visitors are volunteers empowered by law to visit Victorian accommodation facilities for people with a disability or mental illness at any time, unannounced. They monitor and report on the adequacy of services provided, in the interests of residents and patients.

¹⁸⁶ ACT Government *Position Paper on the System of Statutory Oversight in the ACT*, p 11

¹⁸⁷ Ms Phillips, *Transcript of Evidence*, 8 September 2010, p 188

¹⁸⁸ ACT Government *Position Paper on the System of Statutory Oversight in the ACT*, p 27

¹⁸⁹ ACT Government *Position Paper on the System of Statutory Oversight in the ACT*, p 27

Appointed by the Victorian Governor in Council, Community Visitors are created under the *Mental Health Act 1986*, the *Health Services Act 1988*, and the *Disability Act 2006*.¹⁹⁰

- 4.66 The Committee supports the establishment of an Official Visitor Scheme in the ACT for people with a disability.

RECOMMENDATION 16

- 4.67 **The Committee recommends that the ACT Government establish an Official Visitor Scheme for disability services located within the Office of the Public Advocate of the ACT.**

Managing complaints

- 4.68 The appropriate management of complaints and access to mechanisms to make complaints are an important part of monitoring service provision.
- 4.69 The Disability Services Commissioner, Ms Mary Durkin is mandated to receive complaints regarding disability services. She told the Committee that the number of complaints in relation to disability services continued to rise steadily each year, but in her view 'it is in no way a true representation of the volume of issues'¹⁹¹ and that complaints received did not 'reflect the breadth or gravity of the issues that exist within many disability services'.¹⁹²
- 4.70 The evidence received by the Committee supports this view. Carers told the Committee they were reluctant to go through the complaints process for a number of reasons, including lodging complaints with the Disability and Community Services Commissioner.¹⁹³ Lack of confidence in the complaints process was also identified as an area of concern. One mother commented:

I just do not have time to spend the hours writing to and telephoning people with my complaints. Because the system is so fragmented, we are

¹⁹⁰ Public Advocate Victoria, viewed 22 September 2010
<<http://www.publicadvocate.vic.gov.au/services/107/>>

¹⁹¹ Ms Durkin, *Transcript of Evidence*, 3 September 2010, p 150

¹⁹² Ms Durkin, *Transcript of Evidence*, 3 September 2010, p 149

¹⁹³ CLP, *Transcript of Evidence*, 1 September 2010, p 121

dealing with a huge array of services. You would need to do it full time. And does it get you anywhere? Does it improve the quality of service in the end?¹⁹⁴

4.71 Another parent commented:

I would say that we have some of the most beautifully crafted complaints processes in the world in the ACT. The simple problem is that they do not work. It is nothing to do with the process, because they are beautifully crafted and we have some wonderful brochures; they are delightful. It is an attitudinal problem.¹⁹⁵

4.72 Lack of avenues for making anonymous complaints was also raised as an area of concern.¹⁹⁶ This was also evident with many carers reluctant to appear before the Committee in a public hearing or requesting their submissions be kept confidential. These families felt they could not freely express their concerns in relation to respite care services without fear of repercussion.

4.73 Ms Durkin told the Committee that she had not received any feedback regarding repercussions in any of the complaints handled by the Commission, however, she did acknowledge the fear experienced by some families, stating:

... people are often reliant on disability service providers for a long time or a lifetime and there is a fear of repercussions if they put in complaints. Again, we encourage people to come to us and we will work through those issues with them.¹⁹⁷

4.74 Ms Durkin told the Committee that in her view the complaints-handling model was flexible and informal with responses able to be tailored to people's needs.¹⁹⁸ The Committee is concerned that more complaints are not reported to the Disability and Community Services Commissioner and would like to see greater promotion of the role of the Commissioner in handling complaints relating to disability, mental health and aged care services.

¹⁹⁴ Mrs Frazer, *Transcript of Evidence*, 14 April 2010, p 9

¹⁹⁵ Mr Vardanega, *Transcript of Evidence*, 14 April 2010, p 10, Mr Robinson, *Transcript of Evidence*, 3 September 2010, pp 167

¹⁹⁶ Submission 33, Name withheld

¹⁹⁷ Ms Durkin, *Transcript of Evidence*, 3 September 2010, p 152

¹⁹⁸ Ms Durkin, *Transcript of Evidence*, 3 September 2010, p 152

RECOMMENDATION 17

- 4.75 **The Committee recommends that the ACT Government promote the role of the Commissioner for Disability and Community Services in handling complaints through websites and community outlets.**
- 4.76 The Committee understands that community organisations funded by Disability ACT are required to maintain a mechanism for client feedback including information on how to make a complaint. The Committee would like to see this requirement extended to require all funded organisations to clearly display their complaints policy on the organisation website with a link to the DHCS Compliments and Complaints webpage that details the ways that people can feedback to the department.¹⁹⁹
- 4.77 The Committee understands that Disability ACT is trialling a new Client Feedback System to operate as the complaints and grievance process for clients and their families in relation to government provided and funded services. The Committee is concerned however, that there are many people in the community who are not aware that they can make complaints to DHCS regarding community services.

RECOMMENDATION 18

- 4.78 **The Committee recommends that community organisations funded by the ACT Government to provide respite care services be required to promote their complaints policy and procedures on their websites with a direct link to the Department of Disability, Housing and Community Service's Compliments and Complaints webpage.**

¹⁹⁹ DHCS, *Compliments and Complaints*, viewed on 10 September 2010, http://www.dhcs.act.gov.au/complaints_and_advocacy

5 DISABILITY, MENTAL HEALTH AND COMMUNITY CARE WORKERS

- 5.1 Paid carers work in a dynamic and challenging environment. Client's needs will vary depending on age, physical, intellectual and mental health circumstances and meeting those needs requires a range of skills, qualifications and personal attributes. In some circumstances, specialised training will be also be required to enable appropriate care.
- 5.2 Carers rely on respite workers for planned and unplanned respite sessions. While the Committee heard praise for the efforts of respite staff working in centre-based facilities and community based respite, the shortage of reliable, qualified staff was raised as a significant concern.²⁰⁰ Evidence to the Committee highlighted the following issues:
- lack of training and qualifications;
 - paid carers not turning up for planned sessions leaving carers unable to attend appointments or social activities;
 - high turnover of staff placing additional stress on carers and care recipients with complex needs that benefited from continuity of care;
 - lack of confidence in the substitute care; and
 - dissatisfaction with the quality of the care.
- 5.3 The provision of quality services cannot be achieved without a quality workforce and many submissions called for greater recognition of workers though increased pay and better conditions.²⁰¹
- 5.4 St Margaret's Aged and Disability Committee referred to Social Role Valorisation (SRV) that provides people with a valued role in society. While

²⁰⁰ See also House of Representatives Standing Committee on Family, Community, Housing and Youth *Who Cares...?*, April 2009, pp 188–190

²⁰¹ Submission 14, St Margaret's Aged and Disability Committee, p 3, Submission no 9, Submission 19, Ms Scott, Submission 25, Carers ACT, Submission no 30, Ms McKenzie, Submission 36, Tandem

this is usually applied to a devalued member of society, and often a person with a disability, St Margaret's was of the view:

It should also apply to the staff who provide care. They provide a very valuable role and this should be recognised by way of training, remuneration, status, expectations placed upon them to be trustworthy, responsible and professional.²⁰²

- 5.5 Respite services for people with disability, a mental health illness or the frail aged are provided by government and community organisations. Most accommodation services are provided by government, which is a major employer of disability support officers (DSOs). The community sector, with funding from Disability ACT, ACT Health and the Australian Government, is responsible for the majority of community support, community access and respite services. Community organisations vary in size and the range of services they provide and many depend on the support of volunteers.²⁰³
- 5.6 The community sector as a whole has had difficulty in attracting and retaining staff for sometime. In 2004, the ACT Government established the Community Sector Taskforce to, among other things, investigate measures to increase staff retention and sectoral capacity.²⁰⁴ The 2006 Taskforce report identified pay disparity of up to \$20 000 between community sector and public sector workers, including lower leave and other entitlements.²⁰⁵ Other factors specific to the community sector include: high proportion of volunteers; high proportion of casual or part-time workers; ageing community sector workforce; staff shortages due to growth in the sector; difficulties resourcing training; and lack of career development opportunities.²⁰⁶

²⁰² Submission 14, St Margaret's Aged and Disability Committee, p 3

²⁰³ A Disability Workforce Strategy For The ACT Disability Sector May 2007, <http://www.dhcs.act.gov.au/_data/assets/pdf_file/0004/27976/ACT_Disability_Workforce_Strategy.pdf>

²⁰⁴ *Towards a sustainable community services sector in the ACT* p 10

²⁰⁵ *Towards a sustainable community services sector in the ACT*, p 7

²⁰⁶ Mental Health Community Coalition, *Building Capacity in the ACT Community Mental Health Sector*, p 29

- 5.7 A 2007 report on building capacity in the ACT community mental health sector stated:

Poor salaries and conditions, relative to the public and private sectors, result in a struggle to recruit and retain quality staff. The lack of opportunity for career development has given rise to a tendency for skilled workers to leave the community sector in favour of government or other services.²⁰⁷

- 5.8 To address the shortage of workers in the disability sector, in 2007, Disability ACT commissioned Coote Practice Pty Limited to develop a disability workforce strategy for the ACT Disability Sector.

- 5.9 The report, *Disability Workforce Strategy for the ACT Disability Sector*, built on the analysis and discussion of disability workforce issues undertaken over previous years, and many of the recommendations reflected initiatives previously discussed in the ACT. The report concluded:

That the ACT disability sector needs to implement a coordinated set of workforce initiatives across government and non-government sectors.²⁰⁸

- 5.10 The latest Disability ACT workforce strategy, *Workforce Directions 2010-2014* was released in September 2010 and aims to 'develop and sustain a skilled, valued and committed workforce'. The new strategy notes the work already undertaken and lists some of the achievements against the previous strategy. The implementation of the strategy and annual action plan will be overseen by the ACT Disability Workforce Working Group (WWG).²⁰⁹

- 5.11 Increasing the community sector workforce is also being considered at the national level. As part of the NDA, FaHCSIA commissioned the Community Services and Health Industry Skills Council to develop a National Disability Workforce Plan. The project aimed to develop and establish: an agreed 15–20 year workforce plan; shared stakeholder views for entry benchmarks and

²⁰⁷ Mental Health Community Coalition, *Building Capacity in the ACT Community Mental Health Sector*, p 31

²⁰⁸ A Disability Workforce Strategy for the ACT Disability Sector, May 2007, p 4

²⁰⁹ DHCS, *Workforce Directions 2010-2014A workforce strategy for the ACT Disability Sector*, viewed 22 October 2010, <http://www.dhcs.act.gov.au/_data/assets/pdf_file/0006/159117/Workforce_Directions_2010.pdf>

industrial review; strategies for increased uptake of traineeships and other VET programs; career map (including skills audit strategy for enterprises and workers); and new qualifications, competencies and/or skill sets to support new disability roles and careers. The final report *An Examination of Workforce Capacity Issues in the Disability Service Workforce: Increasing Workforce Capacity* has been delivered to FaHCSIA, and at the time of writing, has not yet been publically released.²¹⁰

- 5.12 The Australian Government is also implementing a number of initiatives to encourage new workers into the community care workforce and to retain trained workers in the sector. These include the Productivity Places Program²¹¹ and monitoring the award modernisation process for industries that employ carers.²¹²

Shortage of qualified staff

- 5.13 One of the major concerns highlighted to the Committee is the shortage of qualified staff. While the community sector struggles to attract and retain staff on the national level, the situation in the ACT is exacerbated by employment opportunities in two levels of government and a competitive private sector that offers skilled and qualified workers significantly higher salaries.
- 5.14 To improve pay conditions of community sector workers, the Australian Services Union has lodged the first test case for Equal Pay for Equal Work under the *Fair Work Act*.
- 5.15 The case will examine the pay and conditions of comparable work in a bid to achieve pay parity for community workers, arguing that wages have been set and kept low as the work of the sector has been traditionally considered as

²¹⁰ Community Services and Health Industry Skills Council, Disability Workforce Project, viewed 29 October 2010, <http://www.cshisc.com.au/index.php?option=com_content&task=view&id=263&Itemid=162>

²¹¹ Productivity Places Program (provides training opportunities to new and existing workers wanting to gain or upgrade their skills), viewed 29 October 2010, <<http://www.deewr.gov.au/Skills/Programs/SkillTraining/ProductivityPlaces/Pages/default.aspx>>

²¹² Who cares recommendation 37, *to build capacity in the community care workforce, particularly initiatives to encourage retention of trained workers in the sector*

women's work.²¹³ Women make up just over 87 per cent of the community services workforce²¹⁴

- 5.16 The Equal Pay Case has been given the seal of approval by the Australian Government in the signing of a Heads of Agreement with the Australian Services Union in 2009. The Heads of Agreement outlines the Government's in principle support for the running of the case, but does not make any reference to funding the outcome of the case.²¹⁵
- 5.17 Workers in the community sector have been covered by the Social and Community Services (SACS) (ACT) Award 2001. Award Modernisation is the process of rationalising 47 existing state and federal awards to create a system of 'modern awards' that will operate within the Australian workplace relations system. The new modern award *Social, Community, Home Care and Disability Services Industry Award 2010*²¹⁶ replaced the SACS award on 1 January 2010, however, key aspects of its implementation will not take place until 1 July 2011.²¹⁷
- 5.18 While the Award protects workers and provides appropriate working conditions the financial impact of revised working conditions and pay parity (pending the outcome of the Equal Pay case expected in July 2011), was raised as a concern. Ms Cheryl Pollard, Chief Executive Officer of Tandem, provided the following example:

... we currently provide one hour of support and they (the Award) have said that the minimum is a three-hour shift. How do we cover that? Do we pay the support worker three hours but only one hour is required? Providing the individual response that we do, they might not be able to get three consecutive hours. So that is a significant challenge, let alone

²¹³ Australian Services Union, *Equal Work Equal Pay*, viewed 18 October 2010, <<http://www.asumembers.org.au/equalpay>>

²¹⁴ Australian Institute of Health and Welfare, *Health and community services labour force 2006, 2009*, p 17

²¹⁵ Heads of Agreement between the Australian Government and the Australian Services Union, viewed 18 October 2010, <<http://www.asumembers.org.au/downloads/SACS/Heads-of-Agreement-signed.pdf>>

²¹⁶ Social, Community, Home Care and Disability Services Industry Award 2010, viewed 18 October 2010, <<http://www.airc.gov.au/awardmod/awards/social.pdf>>

²¹⁷ ACTCOSS, Factsheet Award Modernisation, viewed 18 October 2010, <<http://www.actcoss.org.au/flyer/Factsheet-AwardModernisation-Dec09.pdf>>

that it is going to the Industrial Relations Commission and we might be required to increase wages. I believe everyone in the sector should have an increased wage, but how is it going to be funded?²¹⁸

5.19 Another concern regarding the shortage of qualified staff related to the employment of a highly transient workforce. The Auditor-General reported that the turnover rate in the disability sector had ranged from 25–30 per cent in recent years, but the staff turnover in the respite houses was less at 17 per cent. However, this was higher than the average turnover rate of 11 per cent for Disability ACT as whole.²¹⁹

5.20 For families caring for those with high and complex needs the high turn over of staff often left them without a suitable carer to provide their allocated respite hours and also could impacted negatively on the care recipient. The retraining of new workers also presented significant problems.²²⁰ As one mother of a 14 year old daughter explained:

My daughter has had about 15 to 20 carers in the last 8 years. This is not healthy mentally for us or our daughter. It means we have to keep "training" new carers and it also exposes my daughter to way too many people who are taking care of her personal needs which reduces her ability to protect herself from abuse as the concept of "stranger" has no meaning anymore.²²¹

5.21 While there were some concerns with the transient workforce, the Committee was advised that the part-time workforce was well suited to the respite programs offered by Communities@Work, as stated in their submission:

The majority of our paid labour force are generally university students studying 2nd or 3rd year psychology or social work... These students are regularly available to work for short periods on a casual basis, with particular availability afternoons/evenings and on weekends.²²²

²¹⁸ Ms Pollard, *Transcript of Evidence*, 14 April 2010, p 24

²¹⁹ Auditor-General's Report, *Management of respite services Report No. 3 / 2009*, pp 54–55

²²⁰ See for example; Submission 9, Name withheld; Submission 10, Name withheld; Submission 27 Name withheld; Submission 29 Name withheld

²²¹ Submission no 17, Name withheld

²²² Submission 4B, Communities@Work, pp 3–4

Staff training needs

- 5.22 Lack of training was also raised as an area of significant concern, with many submitters reluctant to relinquish care to unqualified staff. The PA ACT told the Committee that the nature of the sector meant that some agencies were unable to deliver services due to the shortage of suitably qualified workers, or were employing 'who they could get'.²²³
- 5.23 Without adequate training paid carers are not able to do their job, and should not be expected to do so. Data from the 2006 Census showed that just over half (53.9 per cent) of aged and / or disabled care workers held a formal qualification, with the majority (67 per cent) at a certificate level.²²⁴
- 5.24 The ACT Government is responsible for the training needs of government employed workers and community organisations are responsible for the provision of training for their own staff.
- 5.25 The ACT Government provides training to its new and experienced disability support officers (DSO) through the Disability ACT Training Unit. In 2009–10 training included: induction programs for new staff; mandatory refresher modules for existing staff; induction programs for agency relief staff; health related modules for specific health needs; and team leader training programs.²²⁵ The Committee understands that Therapy ACT provides training for respite carers to inform their understanding of developmental, behavioural and social needs.²²⁶
- 5.26 The ACT Government also funds government workers and community agency staff to complete the Certificate IV in Disability Work through the Canberra Institute of Technology (CIT). Disability support officer level 3 positions require a formal qualification equivalent to the Certificate IV in Disability

²²³ PA ACT, *Transcript of Evidence*, 8 September 2010, p 188

²²⁴ Australian Institute of Health and Welfare, *Health and Community Services Workforce*, p 24

²²⁵ DHCS Annual Report 2009–10, p 38

²²⁶ Submission 43, ACT Government, p 5

Work.²²⁷ Seven ACT Government staff and five community agency staff commenced the training in 2010.²²⁸

- 5.27 The Committee considers that this program could be expanded to include more workers wishing to upgrade their skills in both the disability and mental health sectors.

RECOMMENDATION 19

- 5.28 **The Committee recommends that the ACT Government expands its funding program to enable a greater number of government and non-government workers to complete the Certificate IV in Disability Work and to include Certificate III in Community Studies for mental health workers.**
- 5.29 The Auditor-General raised a number of concerns regarding the systems and processes in managing staff training and professional development, and in particular tracking training records of staff employed by Disability ACT. The ACT Government has responded to the recommendation to enhance training and development and advised that education and training for Disability ACT staff has been incorporated into the DHCS Learning and Community Education.²²⁹
- 5.30 Other concerns raised by the Auditor-General included individual respite plans not being completed and incidents not being reported on RiskMan.²³⁰ The Community Living Project was also concerned about the lack of information regarding client files and considered that 'inconsistencies in record-keeping practices between the four government respite houses is a critical problem for staff moving between respite houses...and this puts the clients at risk'.²³¹ The Committee notes that the Government agreed with the recommendation made by the Auditor-General to improve record keeping and has established a strategy to insure that individual respite plans are

²²⁷ Auditor General Report, *Management of respite services Report No. 3 / 2009*, p 55

²²⁸ Submission 43, ACT Government, p 5

²²⁹ Submission 43, ACT Government, Appendix A, Recommendation 9, p 7

²³⁰ RiskMan is (among other thing) a management information system used by Disability ACT to record incidents of risk that occur during a person's stay at a respite house.

²³¹ Submission 37, Community Living Project, p 2

completed, and that staff are fully trained and aware of their responsibilities to record incidents on RiskMan.²³²

Minimum standards for workers

- 5.31 The Committee was concerned that there were no set minimum standards for community care workers, and particularly for the disability sector. The Committee understands that organisations funded through DHCS to provide disability services are required to comply with the NDSS. Standard 8 refers to people with disability receiving services from appropriately skilled and competent staff. The Auditor-General's report into the *Management of Respite Care Services* refers to a 2008 DHCS report that Disability ACT has adopted the WA Disability Service Commission Service Standards that include two additional standards, specifically Standard 9 relating to staff recruitment, employment and training.²³³
- 5.32 As discussed in chapter four (paragraph 4.42), however, the Auditor-General found that the process for assessing compliance with the NDSS was limited.
- 5.33 A National Disability Quality Framework with a National Quality Assurance system for disability services is being developed to introduce a national approach to quality assurance and the continuous improvement of disability services. *The Interim National Quality Framework for Disability Services in Australia*, discussed earlier, refers to a skilled and competent workforce. National Quality Indicator 7 states:
- Service providers have in place systems and processes to ensure that employees and volunteers have, appropriate to their role, relevant qualifications, knowledge, values, personal skills, attributes and cultural competence to effectively deliver quality services to people with a disability.²³⁴

²³² Submission 43, ACT Government, Appendix A, Recommendation 9, p 7

²³³ Auditor-General's Report, *Management of Respite Care Services*, Report No. 3 / 2009, p 60

²³⁴ http://www.dhs.vic.gov.au/disability/improving_supports/national-quality-framework

- 5.34 While this provides a clear guide on what the expected standard is, unless systems are in place to monitor and assess compliance, it offers little assurance to service users.
- 5.35 Imposing minimum standards on disability support workers was recommended by the 2007 Disability Workforce Strategy. At that time, there was agreement that entry level qualifications were desirable, however, many providers questioned the viability of mandating standards, as it was already difficult to attract new staff.²³⁵ Other concerns raised included the perceived unwillingness of staff to obtain a mandatory qualification due to literacy competency, high casual labour force (attracting penalty rates for weekend and overnight work); already having experience in the sector; cost to organisations; and availability of appropriate training.²³⁶
- 5.36 On the other hand, compulsory training 'acknowledges the complexity, demands and the responsibility of disability work' and has the potential to enhance the perception of the sector as a career option and improve retention rates.²³⁷ As stated in the 2007 Strategy, lack of:
- ... formal qualifications and educational standards reinforces a common but incorrect assessment that disability work means only basic care or 'unskilled minding'. This view undermines the attractiveness of the industry.²³⁸
- 5.37 The national peak body for disability services, National Disability Services (NDS), also supports the development of a 'skilled and committed disability workforce and encourages the achievement of qualifications as a pathway to this goal', while recognising that few disability service providers have the capacity to absorb additional costs arising from mandatory qualifications. NDS has recommended the development of a core induction program, based on nationally recognised competencies specific to the disability sector, and that 'governments build the cost of training and assessment for the core induction

²³⁵ *A Disability Workforce Strategy for the ACT Disability Sector*, May 2007, pp 13–18

²³⁶ *A Disability Workforce Strategy for the ACT Disability Sector*, May 2007, pp 14–15

²³⁷ *A Disability Workforce Strategy for the ACT Disability Sector*, May 2007, p 15

²³⁸ *A Disability Workforce Strategy for the ACT Disability Sector*, May 2007, p 15

program into their unit price (staff on-cost) for the purchase of quality service delivery'.²³⁹

- 5.38 The Committee is disappointed that the 2010 ACT Government disability workforce strategy does not advance the discussion on entry level qualifications, and cites no mandatory qualifications in the disability sector as a strength to attracting people to the sector, and less so as a risk.²⁴⁰
- 5.39 The provision of high quality care requires competent staff with training and qualifications, personal aptitude and a commitment to working with people with a disability. While this discussion is based on the disability workforce, it is no less relevant to community workers in the mental health and aged care sectors.
- 5.40 The Committee acknowledges the difficulties and costs of imposing minimum standards, but considers the investment in staff, caring for the most vulnerable people, many of who cannot speak for themselves, is essential. The extra assurance afforded to carers, with the introduction of mandatory minimum qualifications, has the potential to ease some of their concerns when relinquishing the responsibility for the care of their loved ones.

RECOMMENDATION 20

- 5.41 **The Committee recommends that the ACT Government work with the disability sector to establish a minimum mandatory qualification for all paid disability support workers in government and non-government services and develop a framework to ensure that all volunteers be appropriately trained.**
- 5.42 HACC funded services are required to meet the HACC National Standards which are reflected in their operational policy and procedures. To ensure compliance, all HACC services are subject to self assessment and validation by the funding body against the National Service Standards.

²³⁹ National Disability Services, NDS Position on Minimum Qualification, provided by Ms Jane Strang CEO of NDS ACT

²⁴⁰ ACT Government, *Workforce Directions 2010–2014 A workforce strategy for the ACT Disability Sector*, Section 5 Our Strengths

- 5.43 Service providers funded under the Mental Health Respite Program are required to provide high quality services and to comply with all relevant legislation and standards, including a set of core principles.²⁴¹
- 5.44 While there is no mandatory specification for employee qualifications, due in part to the shortage of qualified mental health workers, there is an expectation that funded services will only employ suitably qualified staff. Mental health awareness training and mental health first aid are considered to be the minimum standards, but as mentioned, not mandated.²⁴²

Portable long service leave

- 5.45 The future of the community sector and its ability to attract and retain staff has been an ongoing concern. Reflecting the mobility of workers in the sector, in 2006, the ACT Community Sector Taskforce recommended the introduction of a mandatory portable long service leave for community sector employees.²⁴³ The Community Sector Long Service Leave commenced operation in July 2010 in accordance with the provisions of the *Long Service Leave (Portable Schemes) Act 2009* which was passed by the ACT Legislative Assembly in December 2009.²⁴⁴
- 5.46 While the Committee supports the community sector long service leave scheme, as one strategy, to make working in the community sector more attractive, there is concern that this could increase the costs on community organisations and ultimately impact on service delivery. Noting support for the scheme in the sector, Ms Cheryl Pollard told the Committee:

... it needs to be funded and we need to look at how much it is really going to cost. Putting it back on the government, HACC and so on, to

²⁴¹FaHCSIA, Mental Health Respite Program, viewed 20 October 2010, <http://www.fahcsia.gov.au/sa/mentalhealth/pubs/GuidelinesServiceProviders/Documents/NRDF_Guidelines/sec2.htm#t4>

²⁴² Oral information received through the Department of Families, Housing, Community Services and Indigenous Affairs, 21 October 2010.

²⁴³ The Community Sector Taskforce, *Towards a sustainable community services sector in the ACT*, July 2006

²⁴⁴ ACT Long Service Leave Authority, viewed 23 September 2010, <<http://www.actslsb.act.gov.au/>>

negotiate with the agencies will not be the right answer because I think it needs to be a whole of government response.²⁴⁵

- 5.47 The cost pressure of the portable long service leave scheme on non-government organisations (NGOs) in the disability sector was also raised in the 2010–11 Estimates inquiry.²⁴⁶

RECOMMENDATION 21

- 5.48 **The Committee recommends that the ACT Government factor the cost of the Portable Long Service Leave Scheme into service funding agreements to ensure that community organisations are not financially disadvantaged.**

RECOMMENDATION 22

- 5.49 **The Committee recommends that the ACT Government conduct an education campaign detailing the provisions and requirements of the Portable Long Service Leave Scheme for the community sector to ensure that community services are aware of their obligations under the scheme.**

²⁴⁵ Ms Pollard, *Transcript of Evidence*, 14 April 2010, p 24

²⁴⁶ ACT Legislative Assembly, Select Committee on Estimates, *Inquiry into the Appropriation Bill 2009–2010*, pp 1068–1078

6 NAVIGATING THE SYSTEM (INTERACTION BETWEEN GOVERNMENT AND NON- GOVERNMENT PROVIDERS)

- 6.1 The multiple entry points into the community care system present difficulties for carers and consumers. As discussed earlier, cross departmental responsibilities, funding from the Australian and ACT Governments, and a variety of programs and initiatives delivered through a wide range of services in the ACT, often add to the stress of families seeking support.
- 6.2 While respite care services are provided under three distinct policy areas, they are not unique. People with disability age, mental illness affects people of all ages, and many people live with a dual diagnosis. Navigating the system between the sectors adds to the complication, making it harder to access the right information at the right time.
- 6.3 One of the aims of the *ACT Caring for Carers Action Plan* was to improve access to information and resources for carers.²⁴⁷ While many of the initiatives in the action plan have been implemented, the Allen review found that there had been limited impact on the coordination of initiatives across government and non-government agencies.²⁴⁸
- 6.4 This is not surprising, given the complexity of the system. In recognition, the Australian Government has committed to streamlining the provision of respite services through the National Respite for Carers Program 'to create a more sensible system for carers'.²⁴⁹

²⁴⁷ ACT Government, *Caring for Carers - A Plan for Action*, viewed 13 October 2010, p 6
http://www.dhcs.act.gov.au/_data/assets/pdf_file/0013/7240/DHCS_Carers_Plan.pdf

²⁴⁸ The Allen Consulting Group, *Caring for Carers Review and Future Model*, April 2008, p vi

²⁴⁹ Australian Government, *Government Response to the House of Representatives Standing Committee on Family, Community, Housing and Youth report: Who Cares ...? Report on the inquiry into better support for carers*, 2009, p 38

- 6.5 Service delivery is often fragmented with many carers engaging with multiple systems. Each service has its own focus and may not see the bigger context of the person with a disability and the carer. For example, a person with a disability may be accessing a day program provided by a community organisation, receiving home help through a HACC service, and accessing a residential respite facility through Disability ACT, making it difficult to provide family-focused responses. In terms of older carers, the fragmented services may not consider the needs of the family as a whole and what is going to happen in the future when the carer cannot care anymore, or the carer has to go to hospital. As Professor Bigby explained:

You often end up with a situation where families have got multiple people coming in but nobody seeing the whole picture or working with them around the whole picture.²⁵⁰

Access to information

- 6.6 The most important aspect of navigating a complex system such as the community care sector is the ability to access accurate, comprehensive information about all available services, to ensure that care recipients and their carers are able to access all available services.
- 6.7 The Committee heard considerable evidence to suggest that information was not reaching those that needed it most, with many people supporting a central access point for information regarding available services and eligibility to those services.²⁵¹
- 6.8 However, Ms Therese Gehrig, Manager of the Aged and Community Care Policy Unit at ACT Health, told the Committee that there are a number of opportunities for individuals to access information in the ACT. For example, Carers ACT is seen to be a significant portal as it caters to the needs of the different target groups of carers and has the ability to refer individuals to a range of carer supports.²⁵² Further to this, Carers ACT is funded by the

²⁵⁰ Professor Bigby, *Transcript of Evidence*, 21 July 2010, p 93

²⁵¹ See Submission 13, Name withheld, Ms McGrath, *Transcript of Evidence*, 28 April 2001, p 81

²⁵² Ms Gehrig, *Transcript of Evidence*, 28 April 2010, p 41

Australian Government to provide information on community aged care and disability services including respite care services in the ACT, through the Commonwealth Carers Respite and Carelink Centre.²⁵³ It should be noted that Carers ACT does not receive specific funding through HACC or the ACT Government to act as an information referral service.

- 6.9 People can also access information through the Disability ACT Information Line, which provides a central access point for information regarding disability services. However, the Auditor-General found that the operations of the Disability ACT Information Line were not efficient and 'the process for the collection and management of data was not effective'. The Auditor-General also noted that the number of inquiries to the information line more than doubled from 1,059 in 2006–07 to 2,644 in 2007–08.²⁵⁴
- 6.10 Disability ACT also funds the Citizen's Advice Bureau to provide CanAccess, a web based directory for disability services.²⁵⁵ Unless people know about this service, it is of little value.
- 6.11 Increasing knowledge about what resources are available to carers is foremost to improving access. Despite the availability of information, the Committee is concerned that there are still many people unable to access the information that they require and is of the view that better promotion of the information sources could improve the situation.
- 6.12 Strategic priority 4 of *Future Directions: Towards Challenge 2014* addresses access to information through the development of a marketing and communications plan to:
 - strengthen and market central points of information access across the ACT Government to people with disability;

²⁵³ Australian Government, Commonwealth Respite and Care link Centre, viewed 30 September 2010, <<http://www9.health.gov.au/ccsd/index.cfm#3>>

²⁵⁴ Auditor-General's Report, *Management of Respite Care Services*, Report No. 3 / 2009, p 35

²⁵⁵ Citizen's Advice Bureau, *CanAccess*, Disability Information directory, Viewed 22 October , 2010, <<http://search.canaccess.org.au/bin/dd.dll/Lincs?xpsSrch&MBR=DIDACT&GID=1755&SRCH=%22Accommodation%22>>

- enhance access to information for example for people with disability from culturally and linguistically diverse backgrounds; and
- clearly articulate what individuals, families and carers can expect from services they access.²⁵⁶

6.13 The Committee supports this marketing plan for disability services but considers that it could be extended to promote access points in the community for those caring for the frail aged and for people living with a mental illness.

RECOMMENDATION 23

6.14 **The Committee recommends that DHCS work with ACT Health to extend its disability marketing and communication plan to promote information access points in the community sector, to people with a mental illness and the frail aged and their carers.**

Case management

6.15 Case management has the potential to ease the burden for families caring for people with high and complex needs who receive services through a range of service providers or those caring for more than one child with a disability. The Committee understands that case management is an option provided through Therapy ACT, but heard that there are additional families in the ACT who could benefit from a case manager.

6.16 Ms Dee McGrath, CEO, Carers ACT told the Committee:

There does not seem to be a lot of support in funding rounds for case management. Some families probably need that to help get them get around the system and get the services in place.²⁵⁷

6.17 Tandem provides intensive case management through its AFFIRM program, for families caring for a child with a disability, but is only able to work with half a dozen families at any one time. As Ms Pollard stated:

²⁵⁶ Department of Disability, Housing and Community Services, *Future Directions: Towards Challenge 2014, Implementation Plan 2009–2010*, p 8

²⁵⁷ Ms McGrath, *Transcript of Evidence*, 28 April 2010, p 81

It is very intensive but much needed—the need for case management in general to be able to help families work through the system to find a better life.²⁵⁸

6.18 The Committee was advised that the need for case management was much greater than Tandem was able to provide. Another concern identified by Ms Pollard was the 'lack of knowledge about effective and person-centred case management, emphasised by lack of training, supervision and support of those in case management roles'.²⁵⁹

6.19 While case management is particularly useful for those with the most complex needs, not all case management has to be intensive, and can play an important role working with families to prevent situations developing into crisis, that can be traumatic for the carer and care recipient and more expensive to manage.

6.20 As Ms Pollard noted:

I think we need additional case management that will work closely with the family and maybe just drop in and out of their lives across a period of time.²⁶⁰

6.21 Professor Bigby also argued that ageing carers could benefit from low level preventative programs to stop people ending up in a crisis.²⁶¹

6.22 The Committee considers that greater access to case management, such as that provided by the AFFIRM Program, would be of benefit to families with complex needs.

RECOMMENDATION 24

6.23 **The Committee recommends that the ACT Government increase its capacity to provide case management and / or case coordination for people of all ages whose needs require them to access and negotiate a complex range of health and other services.**

²⁵⁸ Ms Pollard, *Transcript of Evidence*, 14 April 2010, p 23

²⁵⁹ Submission 36, Tandem, p 3

²⁶⁰ Ms Pollard, *Transcript of Evidence*, 14 April 2010, p 26

²⁶¹ Professor Bigby, *Transcript of Evidence*, 21 July 2010, p 95

Community partnerships

- 6.24 In such a comprehensive and complex service delivery environment improved coordination across services would ease the burden on families, particularly for those who are required to access a range of services.
- 6.25 The Government submission draws the Committee's attention to the Social Compact that enables a partnership between government and community agencies 'to achieve a better, more equitable and supportive community'.²⁶²
- 6.26 The ACT component of the *Building Capacity in Community Mental Health Family Support and Carer Recognition*²⁶³ project brought together six community partners, with different and complementary service delivery experiences, to synchronise service delivery. The concept of the model, developed by Dr Leanne Craze:
- ... was to set up a system of working together that would include common intake. After that a case manager would work with the family, coordinating the partners and working out what was needed from other services. It was building the capacity of what was already there, and where necessary looking for where service options were needed.²⁶⁴
- 6.27 The Committee understands that this model did not attract additional funding from the Australian Government for respite care services in the ACT, but did 'succeed in establishing the blueprint for innovative partnerships across community sector organisations in the ACT'.²⁶⁵
- 6.28 The Committee considers that this model is worthy of further consideration by the ACT Government, given the amount of background work conducted and the alignment with strategic priority 5 of Future Directions, *I want to tell my story once*.

²⁶² Submission 43, *ACT Government*, p 9

²⁶³ The *Building Capacity in Community Mental Health and Family Support and Carer Respite* project was funded by the Australian Government to provide a structure to bring people and organisations together to develop new and innovative support services for families and carers of people with a mental illness.

²⁶⁴ Partners in Respite, *Building Capacity in Community Mental Health Family Support and Carer Recognition*, 2001, p 75

²⁶⁵ Submission 8, *Mental Health Community Coalition of the ACT*, p 2

RECOMMENDATION 25

- 6.29 **The Committee recommends that the ACT Government examine the community partnership model developed by Dr Leanne Craze as part of the *Building Capacity in Community Mental Health Family Support and Carer Recognition* project with a view to supporting its implementation across government and non-government service providers.**
- 6.30 The Committee notes that a current review of the community mental health sector, commissioned by ACT Health, aimed at identifying gaps in service provision, researching and identifying evidence-based practice, and assisting with the development of a coordinated approach to service delivery, has the capacity to improve community partnerships. Results and recommendations from the review are expected in December 2010.²⁶⁶

RECOMMENDATION 26

- 6.31 **The Committee recommends that the Minister for Health, table in the Assembly, by the last sitting day in March 2011, the results of the community sector mental health services review.**

'No wrong door'

- 6.32 Despite considerable support for a central access point for information, the Committee was advised that DHCS favours a 'no wrong door' model of service delivery. This model would allow people to come into the system at a point of their choosing, and not only receive information about that particular service but also comprehensive information about other available services.
- 6.33 The Minister for Disability, Housing and Community Services acknowledged the complexity of navigating the system and told the Committee that in her view the best way to address this would be through strengthening the community partner linkages and develop a 'no wrong door' model of service delivery. Ms Lois Ford, Executive Director of Disability ACT, agreed, telling the Committee that the research was out on the central access point being the

²⁶⁶ ACT Health, Annual Report 2009–10, p 135

best model 'because people more commonly need the information wherever their point of access is'.²⁶⁷

6.34 Ms McGrath was not supportive of a 'no-wrong door' model pointing out that this model is better suited in areas of wider geographical spread. In her view, for a relatively small population base like the ACT a central access point would be more appropriate.²⁶⁸

6.35 In its submission the Mental Health Community Coalition noted:

...fragmentation of funding sources and providers makes the market for respite care services unacceptably difficult for potential clients to navigate. Workers in other services seeking to refer a client to a respite service often do not have sufficient knowledge of services available to make the best referral either.²⁶⁹

6.36 A major challenge of the 'no wrong door' approach is ensuring that all practitioners working with families understand and are aware of the range of supports available and how clients access these at the local level. Further, it relies on practitioners developing understanding, trust and value in other services to feel confident referring clients to other agencies.²⁷⁰ This would require significant information and training regarding services.

6.37 A web-based personal information collection tool has been developed by Disability ACT to support the 'no wrong door' approach to service delivery. A trial of the personal information tool was scheduled for September 2010.²⁷¹

6.38 The 'no wrong door' approach has been implemented across a number of jurisdictions and has shown to be successful in the area of health and dual diagnosis where people present at a service with multiple issues. This model could apply to the disability/mental health sector.

²⁶⁷ Ms Ford, *Transcript of Evidence*, 28 April 2010, pp 69–70

²⁶⁸ Ms McGrath, *Transcript of Evidence*, 28 April 2010, p 80

²⁶⁹ Submission no 8, Mental Health, Community Coalition, p 4

²⁷⁰ Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, FRSA response to FSP consultation, viewed 10 September 2010, http://www.fahcsia.gov.au/sa/families/progserv/familysupport/FRSA/Pages/4_service.aspx

²⁷¹ Estimates 2010–11, Question on Notice no 431

- 6.39 Properly implemented the 'no wrong door' approach to service access has the potential to benefit carers and care recipients and further increase the links between community agencies and government departments. The Committee supports the introduction of a well planned and fully resourced 'no wrong door' model of service delivery that connects government and non-government services. However, the concern expressed by service providers and organisations must be acknowledged and planning and resourcing will be essential to ensure this approach works.
- 6.40 The Committee notes that Mental Health ACT has also adopted a 'no wrong door' approach to improve responsiveness of its services and has provided specific training to staff to enable the facilitation between the government and non-government sector.²⁷²

RECOMMENDATION 27

- 6.41 **The Committee recommends that the ACT Government ensure that the development of the 'no wrong door' model of service delivery is well planned and fully resourced and extends across the disability and mental health sectors.**

Experience of service users

- 6.42 There is a wide range of services available in the ACT catering for the needs of people with a disability, a mental illness, the frail aged, those with dementia and their carers. The experience of families accessing those government and non-government services varies considerably.
- 6.43 For example, the Mental Health Foundation reported positive experiences from consumers accessing their respite houses resulting in 'long term positive effects on the caring relationship'.²⁷³ St Margaret's Aged and Disability Committee also reported positive experiences of families accessing their

²⁷² ACT Health Annual Report 2009–10, p 135

²⁷³ Submission 5, Mental Health Foundation, pp 4–5

Stepping Stones for Life Program and an excellent partnership arrangement with Disability ACT.²⁷⁴

- 6.44 While there are many families that are happy with the services they receive there are many that are not. Chapter three of this report discusses the problems experienced by many service users. Much of the dissatisfaction stems from the difficulty of accessing services and the delivery of those services by an under resourced and limited workforce. In other words, people appear to be generally happy if they can get the services, but there is certainly many improvements that can be made to enhance service delivery.
- 6.45 Respite effect is the term used to describe the positive experience respite can have for the carer and care recipient. However, the respite experience is not always positive for the care recipient or the carer and is an area for improvement. For example, the Auditor-General in her audit concluded that the government respite houses met clients' 'basic needs for safety and respite care'.²⁷⁵ Positive respite effect is not achieved through the provision of basic services.

²⁷⁴ Submission 14, St Margaret's Aged and Disability Committee, p 5

²⁷⁵ Auditor-General's Report, *Management of Respite Care Services*, Report No. 3 / 2009, p 4

7 CURRENT AND FUTURE NEED

- 7.1 For people with a disability, mental health illness or the frail aged being eligible for a service does not guarantee access to that service. In the current climate of limited services, access is based on relative need.
- 7.2 For example, in disability services the Auditor-General found that access to services was reasonable and most respite services were provided to those with the greatest need. However, the audit concluded that 'compared to the national average, access to respite services in the ACT had not increased proportionately to meet the growth in demand... and [DHCS] was unable to provide support for all those requesting it due to increased demand and limited funding'.²⁷⁶
- 7.3 The demand for services is evidenced by the high numbers of people accessing support services in the ACT. For example, Carers ACT provides direct support to over 5 000 families through counselling, information, respite support, education, social support and case co-ordination,²⁷⁷ while Tandem provides support to over 600 families with caring responsibilities.²⁷⁸ The ACT Government provides disability respite support for 300 clients per year and the estimated growth in the number of people accessing disability services in the ACT is expected to increase from 3 477 in 2009–10 to 4 050 in 2013–14.²⁷⁹
- 7.4 Based on the evidence received by the Committee the demand for respite care services is exceeding the supply, due in part, to lack of other support services, particularly supported accommodation options (discussed in chapter four) and will continue to increase as the population ages.

²⁷⁶ Auditor-General's Report, *Management of Respite Care Services*, Report No. 3 / 2009, p 5

²⁷⁷ Submission 25, Carers ACT, p 3

²⁷⁸ Submission 36, Tandem, p 1

²⁷⁹ ACT Government, Budget Estimates, Paper No. 4, p 370

The ageing population

- 7.5 Over the next 50 years people over the age of 65 living in the ACT are projected to double from approximately 10 per cent to 20 per cent of the population, in line with projections elsewhere in Australia and the rest of the western world.²⁸⁰
- 7.6 The ageing population will increase demand for aged care services including a wider range of aged care options and an increased workforce to meet the demand.²⁸¹
- 7.7 The future needs of older Australians are currently being considered by the Productivity Commission in its inquiry, *Caring for Older Australians*. The Commission will be developing options for structural reform of the aged care system to meet the challenges facing an ageing population. As part of its inquiry, the Commissions will be, among other things, developing regulatory and funding options for residential and community aged care including the HACC program and examining future workforce requirement of the aged care sector. The final report is due in April 2011.²⁸²
- 7.8 The increased preference for people to live in their own homes for as long as possible, with the support of family and community care will impact on demand for community support services. Many people with dementia are cared for in their own homes, often by a spouse or other family members. Support for these carers is primarily provided through HACC funded services which are estimated to increase nationally from around 966 710 in 2010 to 2.7 million in 2050.²⁸³
- 7.9 Of recent concern is the anticipated increase in the number of people with dementia, expected to more than double over the next 20 years and the impact

²⁸⁰ ACT Government, *ACT Population Projections 2007 to 2056*, <http://www.cmd.act.gov.au/_data/assets/pdf_file/0010/119719/act-population-projections-2007-2056.pdf>

²⁸¹ The Productivity Commission Issues Paper *Caring for Older Australians*, p 1

²⁸² Productivity Commission, *Caring for Older Australians*, viewed 20 October 2010, <<http://www.pc.gov.au/projects/inquiry/aged-care>>

²⁸³ Access Economics, *Caring Places: Planning for Aged Care and Dementia 2010–2050*, Alzheimer's Australia, p i, viewed 25 September 2010, <<http://www.alzheimers.org.au/index.cfm>>

- ²⁸⁴ The term dementia encompasses a range of conditions characterised by impairment of brain functions, including language, memory, perception, personality and cognitive skills. It is estimated that there are currently over 200 000 Australians who have dementia with around 3 000 people suffering from dementia related illness in the ACT, with that number projected to grow to over 14 000 by 2050.²⁸⁵
- 7.10 An Access Economics report commissioned by Alzheimer's Australia found the aged care system would require major reform to keep up with the demand for community and residential care, with the increased prevalence of dementia and the associated need for high levels of support and care.²⁸⁶
- 7.11 Residential aged care is the responsibility of the Australian Government with around two per cent of residential aged care places used to provide respite care to people living in the community.²⁸⁷ Eligibility to respite care in a residential aged care facility is determined through an aged care assessment. ACT Health funds 15 respite beds at the Burrangiri Crisis, Respite and Day Care Centre for the Aged that is not subject to an aged care assessment.²⁸⁸
- 7.12 The Committee notes the recently released *Population Ageing in the ACT* examining the effects of ageing in the ACT and some of the policy implications. While the document discusses the needs of carers, particularly those in the 60–65 year age group it offers little analysis of the current demand for support for carers and future projections.²⁸⁹
- 7.13 The policy implications for an ageing carer population will have significant impact on areas such as social and community housing and must be considered by the ACT Government in future policy directions.

²⁸⁴ Australian Institute of Health and Welfare, *Australia's health 2010 - in brief*, p 23, viewed 10 October 2010, <<http://www.aihw.gov.au/publications/aus/ah10inbrief/ah10inbrief.pdf>>

²⁸⁵ Access Economics, *Caring Places: Planning for Aged Care and Dementia 2010–2050*, Alzheimer's Australia, viewed 25 September 2010, Table 1.3, p 16

²⁸⁶ Access Economics, *Caring Places: Planning for Aged Care and Dementia 2010–2050*, Alzheimer's Australia, viewed 25 September 2010, p i, <<http://www.alzheimers.org.au/index.cfm>>

²⁸⁷ Australian Government Department of Health and Ageing 2009

²⁸⁸ Submission 42, ACT Government, p 8

²⁸⁹ ACT Government, *Population Ageing in the ACT Issues and Analysis*, pp 31–32

Managing current demand

- 7.14 As discussed earlier, the Committee received significant evidence suggesting that the current demand for respite was not being met and that there was little flexibility in the services offered.²⁹⁰ This included families who required more hours than allocated, families who were unable to utilise allocated hours, lack of in-home and overnight support, or carers not turning up for a planned session. For community based respite, the session was often contingent on the availability of appropriate staff.
- 7.15 The House of Representatives inquiry into better support for carers also found nationally that respite services were not meeting current demand and that 'the shortage was one of the key issues facing carers'.²⁹¹
- 7.16 According to the 2010 *Report on Government Services* less than 10 per cent of the estimated potential population of respite users in the ACT accessed CSTDA funded respite services between 2003–2008, below the national average of 12.8 per cent.²⁹² This figure supports the evidence presented to the Committee suggesting the need for greater access to respite services in the disability sector.
- 7.17 The Auditor-General also found that the available funding for all disability services was not sufficient to meet demand reporting a shortfall of \$8.3 million on funding applications in 2007–08.²⁹³
- 7.18 The 2010–2011 Estimate's Committee also expressed concern that the level of increase in growth in disability services was not being matched by funding and questioned the sustainability for disability services over the long term. The Estimates Committee considered that annual growth funding, as applied to

²⁹⁰ Submission 43, Public Advocate of the ACT, p 4

²⁹¹ The Parliament of the Commonwealth of Australia, House of Representatives Standing Committee on Family, Community, Housing and Youth *Who Cares...?*, April 2009, pp 176–177

²⁹² Steering Committee for the Review of Government Services, *Report on Government Services*, Volume 2, p 14.29

²⁹³ Auditor-General *Management of Respite Care Services*, See also Submission 14, St Margaret's Aged and Disability Committee, p 5

²⁹³ Auditor-General's Report, *Management of Respite Care Services*, Report No. 3 / 2009, p 65

health care services, should be made available to disability services, recommending:

...a formula for growth funding be developed for disability services, as per health funding, and that this formula be applied to the 2011–2012 Budget process.²⁹⁴

- 7.19 The Government response cited any future planning was contingent on the work being undertaken at the national level on future arrangements for disability services.²⁹⁵
- 7.20 The Committee understands that funding allocations for disability services need to be considered in the context of competing priorities across all government services, but is concerned that the current level of funding is not meeting the need. Furthermore, outcomes of the work being conducted by the Productivity Commission as well as work under the NDA may not be implemented for some time. In the interim, the Committee supports the development of a formula, as recommended by the Estimates Committee, for growth funding to be applied to disability services commencing in the 2011–12 budget and calls on the ACT Government to reconsider its response to the recommendation.²⁹⁶

RECOMMENDATION 28

- 7.21 **The Committee recommends that a formula for growth funding be developed for disability services, as per health funding, and that this formula be applied to the 2011–2012 Budget process, as recommended by the Select Committee on Estimates 2010–2011.**
- 7.22 The Committee also heard evidence suggesting that the current demand for mental health respite was not being met. The Mental Health Community Coalition reported that its members providing respite services:
- ... consistently express frustration that demand for their mental health respite services exceeds their capacity to deliver, but some agencies also

²⁹⁴ Select Committee on Estimates 2010–2011, *Appropriation Bill 2010–11*, pp 1057–1063, recommendation 36

²⁹⁵ Government Response, Estimates Committee 2010–2011

²⁹⁶ Government Response, Estimates Committee 2010–2011

acknowledge that this is not the case for all respite care services in the ACT, whether because of over-supply, too restrictive criteria for access to certain programs, or simply because potential clients are not aware of the existence of a particular service provider.²⁹⁷

- 7.23 The Committee was also told that there were limited places for overnight respite for people living with a mental illness.²⁹⁸ As discussed in chapter three the need for overnight respite is important for carers and their families and the Committee is concerned that access to overnight respite in both the mental health and disability sector will get harder as the population ages.
- 7.24 Determining the demand for services is difficult. The Committee is concerned that the current measures are limited in their ability to determine the extent of demand for respite for the elderly, for people living with a mental illness and people with a disability. The Committee considers that determining the potential population of service users, through demographic research, would provide a more accurate assessment of the current and future need, including those hidden carers who are currently not accessing services.

Future demand

- 7.25 Planning for future respite needs of people in the ACT, particularly in light of the ageing population, is more important than ever, as demand is expected to increase for people with a disability, people living with a mental illness and the frail aged and those suffering from dementia, as previously discussed.
- 7.26 Disability ACT has a formula for determining future funding to meet the demand for disability services, based on:
- current service levels for accommodation support, community support, community access and respite;

²⁹⁷ Submission 8, Mental Health Community Coalition, p 3

²⁹⁸ Submission 5, Mental Health Foundation, p 3 (Mental health overnight respite options include Mark's Place, the Lodge, Inna House and Warren 'I Anson Respite House)

- forward demand drivers, including ageing of current users; young people leaving the education system; children with disabilities entering the service system; acquired disabilities; breakdown of natural supports; and mortality;
- forward cost drivers for each service type and expenditure category; and
- current known unmet demand for each service type and the inclusion of additional funding over a five year period to progressively meet this demand level.²⁹⁹

7.27 With unmet demand only taking into consideration people who had requested services, but did not get them, a number of submissions were concerned that Disability ACT was not addressing the unmet needs of people who did not request services, and therefore distorting the future projections by not reflecting the true demand for services.³⁰⁰

7.28 Also impacting on unmet need, are carers who do not see themselves as carers and are therefore unlikely to receive or seek out support services to assist them in their caring role. As discussed in chapter two, the stigma associated with the term respite and feelings of guilt can restrict carers from accessing much need services. It is very important, as identified in the Allen Review, that people are able to identify what they do as caring, to ensure they access the supports they require.³⁰¹

7.29 Following the Auditor-General's findings, that the estimated gross level of unmet need for disability services was not being addressed³⁰², Disability ACT in 2009, updated its funding model on population projections for the demand for disability services. The Disability Policy and Research Working Group is undertaking modelling of unmet need and demand at the national level as one of the eight priority areas under the NDA.³⁰³ But as Ms Ford noted 'predicting

²⁹⁹ DHCS, *Precis of the Disability Funding*, viewed 20 October 2010, Model <http://www.dhcs.act.gov.au/disability_act/publications/funding_model>

³⁰⁰ For example see Submission 25, Carers ACT, Submission 30 Ms Carol McKenzie, Submission 31, Name withheld and Submission 37 Community Living Project

³⁰¹ The Allen Consulting Group, *Caring for Carers Review and Future Model*, April 2008, p vii

³⁰² Auditor-General's Report, *Management of Respite Care Services, Report No. 3 / 2009*, p 79

³⁰³ DHCS Annual Report, 2009–10, p 31

demand into the future is a very complex piece of work, and we continue to work away at that with Treasury'.³⁰⁴

7.30 In 2007–08, 11.8 per cent of the adult ACT population reported having a mental disorder that had been diagnosed by a doctor, slightly higher than the national average on 11.2 per cent.³⁰⁵ According to the Mental Health Community Coalition, however, the current data collection for mental health respite services is not reliable,³⁰⁶ making it difficult to determine the future demand.

7.31 The *National Respite for Mental Health Program* was an initiative of the National Action Plan on Mental Health, developed by the Council of Australian Government in 2006, in response to mental illness becoming the largest cause of disability in the Australia.³⁰⁷

7.32 As a relatively new area of service for carers of people living with a mental illness, particularly older carers, it is likely that, as more carers become familiar with the availability of respite services the demand will increase.

³⁰⁴ Ms Ford, *Transcript of Evidence*, 28 April 2010, p 67

³⁰⁵ ACT Health, Chief Health Officer, 2010 Report, p 25

³⁰⁶ Submission 8, Mental Health Community Coalition, p 3

³⁰⁷ http://www.facs.gov.au/sa/mentalhealth/pubs/mhrp_bchgc/Documents/part02.htm

8 CONCLUSION

- 8.1 The caring responsibility places enormous stresses on carers who are also susceptible to economic and social disadvantage because of their caring role. While the needs of carers and care recipients are interconnected, 'time off' from the caring role is essential for carers, to support them to continue in their caring role and to foster balanced family relationships with other family members such as partners, siblings and other children.
- 8.2 Respite care is a discrete service, with the specific aim of relieving carers of their caring responsibility for a period of time, in a variety of settings. This should not be confused with other support services, which also provide time apart, but have specific aims and objectives of their own, such as community access programs aimed at enhancing the quality of life for the care recipient.
- 8.3 Lack of other support services, particularly in the disability sector, place greater pressure on respite services, as carers become reliant on respite services to conduct, what most people would consider normal daily business, such as going to work, the doctor or the supermarket.
- 8.4 The availability of flexible respite in the ACT has not been demonstrated to the Committee during the course of its inquiry. The limited options for respite are further hampered by inflexible service delivery models that fail to cater for the individual needs of families.
- 8.5 People's needs vary significantly and catering to the diversity of respite need is a challenge for any government. However, greater choice of respite options, particularly at the time of the family's choosing, such as weekends, can begin to address this shortcoming.
- 8.6 Simplifying the community care system also has the potential to improve access to services while relieving some of the stress of navigating between departments and sectors, particularly for those with the greatest need. Clearer links between government and non-government organisations strengthened through the 'no wrong door' model of service delivery and enhanced web presence between the sectors may go some way to addressing this.

- 8.7 The Committee notes that there are no short term answers, but for the families that shared their experiences with the Committee, and many more families in the community, the need is immediate, and it is up to the ACT Government to provide services and appropriate funding to ensure that families caring for a loved one have access to the supports that they need.
- 8.8 The Committee has made 28 recommendations with a focus on practical solutions to improve people's access to respite care services in the ACT.
- 8.9 The Committee thanks the participants to the inquiry who provided submissions and/or oral evidence.

Steve Doszpot MLA

Chair

3 December 2010

APPENDIX A: Submissions

No	Organisation/individual
1	National Disability Services ACT
2	Autism Asperger ACT
3	Confidential
4	Communities@Work
4B	Communities@Work
5	Mental Health Foundation
6	Catholic Care
7	Noah's Ark
8	Mental Health Community Coalition
9	Name withheld
10	Name withheld
11	Name withheld
12	Confidential
13	Name withheld
14	St Margaret's Aged and Disability Committee
15	Name withheld
16	Name withheld
17	Name withheld
18	Name withheld
19	Ms Evelyn Scott
20	Name withheld
21	Confidential
22	Name withheld
23	Confidential
24	Confidential
25	Carers ACT
26	Confidential
27	Name withheld
28	Confidential
29	Name withheld
30	Ms Carol McKenzie
31	Name withheld
32	Mr Ian Trehwella
33	Name withheld
34	Name withheld
35	ADD Support Group
36	Tandem
37	Community Living Project
38	Mr Trevor Robinson
39	Ms Ildiko Auer

40	Multicultural Women's Advocacy
41	Mr John Wilkinson
42	ACT Government
43	Public Advocate of the ACT
44	Ms Anna Kieltyka

APPENDIX B: Public Hearings

Wednesday 14 April 2010

Ms Francis Frazer, parent/carer

Mr Max Vardenega, parent/carer

Ms Karna O'Dea, parent/carer

Mr Ian Trewhella, care recipient

Ms Cheryl Pollard, CEO, Tandem

Ms Roslyn Brown, Aboriginal and Torres Strait Islander Elected Body

Ms Agnes Shea, Ngunnawal Elder

Wednesday 28 April 2010

Ms Katy Gallagher MLA, Minister for Health

Mr Ross O'Donoghue, Executive Director, Policy, ACT Health

Ms Therese Gehrig, Manager, Aged Care Policy Unit, ACT Health

Mr Simon Viereck, Mental Health Community Coalition

Ms Tu Pham, Auditor-General

Mr Rod Nicholas, Director, Performance Audits and Corporate Services

Mr Michael Lai, Senior Manager Performance Audits

Ms Joy Burch MLA, Minister for Disability, Housing and Community Services

Ms Lois Ford, Executive Director, Disability ACT

Ms Bronwen Overton-Clarke, Executive Director, Policy and Organisational Services

Ms Dee McGrath, CEO, Carers ACT

Ms Leslea Geary, Respite Assistant, Carers ACT

Wednesday 21 July 2010

Professor Christine Bigby, Director of Postgraduate Programs, School of Social Work and Social Policy, La Trobe University

Wednesday 1 September 2010

Ms Anita Gordon, carer/care recipient

Mrs Patricia and Mr Glen Mowbray, parent/carers

Ms Esther Woodbury, President, Community Living Project

Ms Alison McGregor, Coordinator, Community Living Project

Ms Maureen Cain, CEO, Communities@Work

Ms Camilla Rowland, Executive Director Community Services, Communities@Work

Ms Margaret Verick, Board Member, Focus ACT

Friday 3 September 2010

Mr Bob Buckley, parent/carers

Ms Mary Durkin, Commissioner for Disability and Community Services

Ms Kelly Swan, Disability Adviser

Mr Trevor Robinson, parent/carers

Ms Jane Strang, Manager, National Disability Service (NDS) ACT

Ms Cheryl Pollard, Board Member NDS and CEO of Tandem

Mr Keith Baker, Chair, St Margaret's Aged and Disability Committee

Mr Jeff Bishop, Board Member and Carer, St Margaret's Aged and Disability Committee

Wednesday 8 September 2010

Ms Anita Phillips, Public Advocate for the ACT

Ms Patricia Mackey, Principal Advocate

APPENDIX C: Respite care services in the ACT

Model of Care: Children and Young People with a Disability		
Provider	Description of Service	Funding Source
Communities @ Work	- Day care - Living skills and leisure activities for Young People With a Disability	HACC
Tandem	Own home respite*	DACT
Communities @ Work	Fun for Youth (F4Y) – respite for young people with a disability	HACC
Marymead	Host family respite/peer support respite*	DACT
Tandem	- Children and young people program 1, respite - Children and young people program 2, social support	HACC
Marymead	Flexible respite*	DACT
Marymead	Kids companion program, respite Kids companion program, social support	HACC
Disability ACT (Kese, Teen)	Two houses providing respite care to children aged, 5 – 12, teenagers.	DACT
Kincare	Young Carers Respite	HACC
Model of Care: Adults with a Disability		
Tandem	- Integrated in – home respite support for adults - Integrated in – home social support for adults	HACC
Baptist Community Services	Own home respite.	DACT
Tandem	Flexible respite Flexible respite*	DACT
Community Connections	Flexible respite*	DACT
Carers ACT	Centre-based respite/respite homes	DACT
CatholicCare	Centre based respite	DACT
Community Connections	Centre based respite*	DACT
Disability ACT (Symonston)	Respite service for adult individuals with a dual disability, and high and complex needs, who are often clients of the Intensive Treatment and Support (ITS) Service with high and complex needs.	DACT
Hartley Lifecare	Centre based respite/respite homes	DACT
Carers ACT	Flexible respite	DACT
Disability ACT	Two houses providing respite care to adults with high physical support needs and adults who may require a secure setting.	DACT
Koomarri	Flexible respite*	DACT
Carers ACT	Palliative care for people living at home: respite and carers support (ATSI people and people under 65, including children)	ACT Health, through a grant from DoHA

* Purchased by an individual using ISP funding

Model of Care: Older Persons		
Provider	Description of Service	Funding Source
Kincare	Integrated in-home support for older persons	HACC
Aged Care and Rehab Service (ACT Health)	Day care for older persons	HACC
Belconnen Community Services	Day care for older persons	HACC
Canberra Senior's Centre	Respite for older persons	HACC
Goodwin Aged Care Services	Day care for older persons, More Than Armchair Aerobics	HACC
Gungahlin Regional Community Services	Day care for older persons	HACC
Mirinjani	Day care for older persons	HACC
North Belconnen Day Centre	Day care for older persons	HACC
Northside Community Services	Day care for older persons	HACC
Sharing Places	Day care for older persons	HACC
Tandem	• Living skills / Respite for older persons • Living skills / Social support for older persons • Leisure link / Social support for older persons	HACC
Salvation Army	Burrangiri Respite Centre: 15 bed unit in Rivett providing convalescent and residential respite care.	ACT Health
Model of Care: Culturally and Linguistically Diverse (CALD) Carers		
Carers ACT	Building a caring community for CALD carers, social support	HACC
Southside Community Services	• CALD programs especially Chinese and Spanish • Day care • Rhythm for life – Day care for older persons	HACC
Model of Care: People with a Mental Health Diagnosis		
CatholicCare	Residential in home, on-on-one respite for adults with mental illness	ACT Mental Health
Barnardos	Day and school holiday camps for children with mental illness and / or children with parents with mental illness	ACT Mental Health
CatholicCare	Residential respite for adults with mental illness post discharged from in-patient unit/s	ACT Mental Health
INANNA Women's Service	Adults with mental illness, females only	ACT Mental Health
Tandem	Recreational, in-home, one-on-one respite for families where parents and/or children are carer/s of a family member/s with mental illness	ACT Mental Health
Carers ACT	Residential respite and in-home respite	ACT Mental Health

Model of Care: Flexible Family Support	
Community Connections Community Options Carers ACT	Flexible family support provides respite services for: • Children, Young People and Adults with Disability; • Older Persons; • People from a Culturally and Linguistically Diverse Background; • Indigenous People; and • People with a Mental Health Diagnosis

Projects funded by the Australian Government under National Respite for Carers Program	
Carers ACT	▪ Commonwealth Respite and Carelink Centre ▪ Dementia Education and Training for Carers ▪ Home From Home and Host Family Respite ▪ Employed Carers Support Project
Community Options	Community Options Flexible Respite
Uniting Care	Mirinjani Day Care Centre
Alzheimer's Australia ACT	ACT Respite Links Mobile Respite Response Team
Baptist Community Services	ACT Sundowner's Program ACT Host Home Day Care Day Break Comprehensive Support for Working Carers
Villaggio Italiano	Extended Respite Care Service
Illawarra Retirement Trust	High Care Community Respite

Information provided by the ACT Government (see submission 42 Attachment A 2 and Attachment A 3).