



Inquiry into Respite Services in the ACT

Submitted to Standing Committee on Health, Community and Social Services

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Carers ACT acknowledges that modern day Canberra has been built on the traditional lands of the Ngunnawal people. We recognize the displacement and disadvantage they have suffered since European settlement. We offer our respects to their Elders and celebrate the continuation of the Ngunnawal people's living culture.

Carers ACT sincerely thanks all Carers who have contributed to the research and consultation activities which inform our policy and representation work.

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Who is Carers ACT?

Carers ACT is a non-profit, community-based, incorporated association and registered charity dedicated to improving the lives of the estimated 43,000 caring families living in the Australian Capital Territory. These families provide ongoing care for people with disabilities, mental illness, chronic conditions, who have palliative care needs, or who are aged and frail. Carers ACT currently provides direct support to over 5,000 families through our counseling, information, respite support, education, social support and case co-ordination services. Our services meet HACC and NCCP accreditation standards and were assessed in 2009 as being at a level of excellence.

Carers ACT has a constitutional mandate to represent the voices of Carers to government and the wider community. We actively consult with a wide diversity of caring families on an ongoing basis to enable improved understanding of their needs and to provide better inclusion for them and the people they care for. Policy work in consultation, research and representation is kept separate from service delivery to ensure that the privacy of individual service recipients is respected. All Carer participation in policy work is voluntary.

Carers ACT is a member of the National Network of Carers Associations and works actively with other States and Territories to share knowledge and facilitate improved health and wellbeing outcomes for caring families.

Contents:

1	<i>Introduction</i>	5
2	<i>Needs of Care Recipients and their Carers in the ACT.....</i>	6
3	<i>Needs of Respite Care Services Staff.....</i>	8
4	<i>Range, availability and suitability of respite care services.....</i>	9
5	<i>Government and Non-government Respite Care Provider Interactions....</i>	11
6	<i>Experience of Respite Care Service Users</i>	12
7	<i>Practical and Financial Support Needs.....</i>	13
8	<i>Respite Needs for Young Carers and Their Families</i>	14
9	<i>Bibliography</i>	17

1 Introduction

On behalf of Carers living in the ACT, Carers ACT is pleased to contribute this submission to the Standing Committee on Health, Community and Social Services' Inquiry into Respite Services.

Anyone can become a Carer at anytime. It is in everyone's interest to provide support to allow Carers to continue caring. From a societal perspective, Carers allow for a greater sense of community as people prefer to be cared for in the familiarity of their own home. There have been shifts from institutional care to community-based, person-centered care that is meeting this preference. From a financial aspect, Carers' work is essential for the wellbeing of the economy. If the government were to replace informal care with formal care, the cost to the local government would be \$524.6 million per annum¹.

To many Carers, particularly those living in complex care situations, respite is essential to their capacity to continue in their role as Carer. In evidence presented to the Federal Government's Inquiry into Better Supports for Carers, respite care and in-home assistance were repeatedly mentioned as being of critical importance to Carers². Carers ACT has received the same message locally in the ACT. In our *'Have Your Say'* report in which we surveyed 280 Carers, affordable, accessible, safe, flexible, good quality respite options were found to be one of the top 3 needs of Carers³. When respite is provided in a safe, affordable way, Carers report tremendous benefits to them and to others around them, including the recipients of their care.

With the recent tabling of the National Carer Recognition Bill, Carers ACT is pleased that the journey to a place where the community shares care equitably has begun. Carers ACT looks forward to the anticipated improvements in policy and service delivery arising from the passing of this bill and the National Carers Recognition Framework of which it is a part. A Charter of Rights based in legislation is the most effective means of enabling systematic reform of a service structure and ensuring compliance from departments and service providers.

¹ Figure calculated by Carers ACT, using a model developed in Access Economics (2005) The economic value of informal care. Canberra: Carers Australia, and applied to SDAC data.

² House of Representatives Standing Committee on Family, Community and Youth (2009) Who Cares...? Report on the inquiry into better support for Carers Canberra: Commonwealth of Australia

³ Ashton A, McGrath, D. (2008)'Have Your Say' ACT Election Survey Report. Canberra: Carers ACT

It is worrying to note that the Auditor General's report says that respite in the ACT has not kept pace with other States. Statements from Carers to Carers ACT supports the Auditor General's finding that the current system is at or past capacity. With the population ageing at unprecedented levels and insufficient replacement numbers born in younger cohorts, the number of people available to provide care is already low and will greatly be reduced in coming decades.

In the absence of action, this situation is likely to worsen as the population ages.

Carers ACT welcomes efforts to improve this unacceptable situation and to that end provides the following submission, addressing the terms of reference, to the inquiry to respite services.

2 Needs of Care Recipients and their Carers in the ACT

Although Carers are a diverse group of the population, they have similar categories of needs resulting from their caring role. The combination of supports that each individual caring unit needs to be sustainable however, can be quite varied. Carers need to be consulted and listened to as the experts in their own needs. Carers in the ACT have told us that they need flexible and responsive supports. By increasing their understanding of the differing nature of Carers' needs and by shaping supports accordingly to assist Carers to meet these needs, government and the community can share the responsibility of Caring.

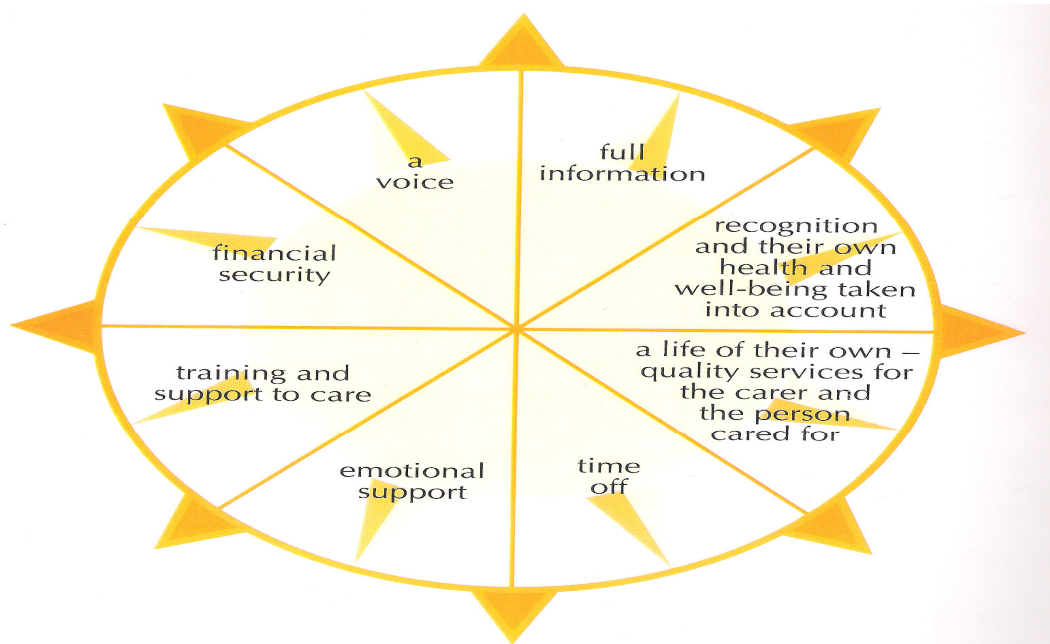
The Carers Compass

One way to envisage the diversity of the needs of Carers is to use the internationally recognized Carers Compass. The Carers Compass was developed by The King's fund in the UK, which is a charity that seeks to understand how the health system in England can be improved.⁴ The Carer compass, which was developed from extensive research with Carers, categorises eight key needs of Carers.

Although the needs of each Carer maybe categorised into these eight key groups, the methods of fulfilling that need for each Carer can be diverse. For example, some Carers might need emotional support in the form of affordable professional counseling whereas others might find the emotional support of family members to be appropriate.

⁴ Kings Fund Website

A Diagram of The Carers Compass⁵



How Carer's Needs Change – Life Course Framework

In addition to considering the categories of needs resulting from Caring, when developing and planning services aimed at supporting caring relationships it is important, to understand how needs change and the transition points that occur throughout the caring journey. Carers NSW and NSW Health have developed a Carer Life Course Framework which outlines the common phases which Carers go through and suggests specific needs they might experience at each phase. Whilst not a prescriptive guide it has been tested with a number of focus groups of Carers and found to correlate with the experiences of the majority of participants.

Carer's Need for 'Time Off'

The Carer Compass and the Life Course Framework give a good overview of the likely types and timing of Carer need. When asking Carers' in the ACT directly about their top three needs they reported:

- Improved financial supports
- Affordable, accessible, safe, flexible good quality respite options

⁵ Ibid

- Better funding for agencies and services to enable them to offer more services of higher quality, in flexible ways appropriate to needs, and to have sufficient numbers of well paid, trained staff

Carers need for 'time off', that is affordable, safe, flexible good quality respite options is reiterated nationally in Who Cares...? Report on the Inquiry into Better Support for Carers. Recommendation 33 of this report states that the Minister should recognise the ageing demographic of the Carer population and the increased longevity of many care receivers by increasing capital and recurrent funding for respite care as a matter of urgency.⁶ Similarly Recommendation 34 states that more in – home assistance, including personal care support for the care recipient is needed which is affordable and flexible.⁷

Respite effect

When quality respite is provided in a timely manner it can have positive health and well-being effects on the Carer and on their ability to continue in their caring role. The benefit Carer's obtain from respite is sometimes called Respite effect.

3 Needs of Respite Care Services Staff

The quality of service hinges greatly on the staff members directly providing the support. The 26% of respondents to Carers ACT's *"Have your say"* survey who considered services to be unsatisfactory or very unsatisfactory often indicated that the problems related to:

- agency support workers not arriving
- high turnover of agency staff
- lack of training for support workers⁸

There is a range of well documented evidence of skills shortage that all point to the same conclusion – the low pay and conditions offered to respite workers makes it difficult for community organisations to attract and retain quality workers.

⁶ Ibid 1

⁷ Ibid 1

⁸ Have your say p3

Carers ACT would support measures to increase the pay and conditions of support workers as we believe that this would assist in retaining quality staff and therefore improve support to Carers. Any such increases in pay and conditions and the ongoing investment in professional development training needs to be built into government program funding allocated to non government agencies.

4 Range, availability and suitability of respite care services

While there are some good respite options in the ACT, feedback from families indicate that these are not only inadequate to cater for existing demand but certainly fail to address current needs of a number of Caring families – particularly those caring for dependents with disability and/or mental illness.

Of the Carers we surveyed in the *'Have Your Say'* report, 52% considered the services provided to them, including respite services were satisfactory or higher. This is great result for the people within those caring relationships, but it still leaves a high percentage of people who are not getting appropriate services. This percentage can only be used as an indication of unmet need. Other unmet needs could also include people living in the community who don't realise or think that it is appropriate to ask for help to perform their caring role.

Range of Services available

There are a number of respite brokerage service models in the ACT delivered by a large number of agencies which are funded by both the Commonwealth and ACT Governments. Each funding contract targets very specific groups: age specific for Carers, age specific for Care recipients, specified health conditions of the Care recipient, etc. This leads to people reporting difficulty in navigating the complex service system to find an appropriate respite service that meets their needs. System complexity and narrow definitions of target groups and guidelines are likely to be one of the main barriers for Carers accessing respite. Furthermore such restrictions do not enable service providers to respond to 'need' as it presents. An example of this is younger people with dementia. Dementia has traditionally been funded by departmental portfolios responsible for ageing and therefore younger people with the condition often lack support as they do not meet age requirements. The Commonwealth Department of Health and Ageing are also redesigning their guidelines for the Respite and Carelink Centres to build in greater flexibility.

Carers ACT would support measures to map respite services being delivered in the ACT. The benefit of such a review would enable the ACT Government to see systemic service gaps and to make informed decisions as to where ACT funding should be directed that would be complementary to Commonwealth investment. An example of such mapping is underway within Mental Health ACT and this work is to be commended.

Centralised Needs Assessment

In order to plan and deliver effective, equitable respite services there must be knowledge of the extent and nature of need in the community. Carers ACT believes that a reliable evidence based approach is necessary to measure not only respite demand but community care support needs in general.

A centralised assessment using a matrix tool which examines the impact and intensity of care on a 'whole of family' basis could provide a clearer understanding of the support needs in the community. Centralised assessment and improved data sharing across the sector could also assist reducing the need for duplication and inconsistency of assessment while also reducing the demands on Carers and care-recipients to continually repeat their story and/or medical history. Continually having to repeat your story with emphasis on the areas which are not going well is an invidious situation. In effect Carers need to try to prove in assessments that their story is worse than others. The reduction of the number of these assessments would in many cases be welcome.

Centralised and a more transparent assessment process may also mean a more equitable, consistent system of allocating support. Sometimes it seems that Carers need to have the resources and negotiation skills to secure the respite they need and that some Carers maybe better able to do this than others.

Hidden Un-met Need

In attempting to quantify need in the community it is important to consider not only current demand for services but those people with caring needs or responsibilities who have not identified and so not attempted to access the supports available. These people maybe experiencing some of the negative effects of caring which are also negative effects to the broader community. Such effects may have required giving up paid employment or becoming unable to continue caring due to health problems. Carers ACT believes that we, as a community, have a responsibility to actively seek to inform these hidden Carers of the supports available so that they know where to go when and should they need to access support.

5 *Government and Non-government Respite Care Provider Interactions*

Carers ACT welcomes the concept of a National Disability Insurance Scheme and will be fully endorsing the campaign. We will also continue to work with the Commonwealth Government through our national peak, Carers Australia, as well as with the ACT Government to achieve sustainable funding systems, which build community capacity through strategic investment in preventative care, building a skilled workforce, and needs-based funding.

Planning and Collaboration

Given a choice, most people with care needs would opt to stay in their own home, hence the increase in demand for CAPS, EACH and EACH-D packages. The ageing population coupled with fewer tax payers, will force the government and the community to work collaboratively and smarter to better meet growing and changing needs.

Through our daily interface with Carers, they continue to report their difficulty in navigating the community care system including accessing respite services with the capacity and flexibility to meet their need. However, much of the need for respite support is due to insufficient packages of supports. As a result, short term/emergency respite funding is often used to support full care costs currently not met with Individual Support Packages (ISPs), CAPS, EACH and EACH-D packages.

There is a clear need for enhanced mechanisms to more accurately determine and measure unmet need and future demand in the ACT. We would also support greater government/sector collaboration to provide a better safety net for families. Privacy legislation is often used as a barrier for enhanced collaboration and a more seamless referral system between government and amongst non-government providers.

CACT would support whole of government planning around community care needs and input into development of strategic and annual plans but also reviewing, evaluating and revising strategies so that they continue to effectively meet changing need. Any planning must also ensure any developed or increases in respite services meet the National Disability Services Standards, National Common Standards and other relevant national and international standards and have compliance monitoring fundamentals that clearly show funded services are addressing the need.

6 Experience of Respite Care Service Users

Many of the Carers connected with Carers ACT, particularly those caring for children with high level disability or dependents with severe mental illness, report frustration about inadequate support to meet their needs – from both government and non government service providers.

Carers who access respite often report there is insufficient respite hours to meet their need. Some services can only offer limited access at times such as weekends – primarily because available funding does not enable them to pay penalty rates to staff. Limited access means limited capacity for families to look forward to or enjoy a quality respite effect.

The following extract is from a young mother with a child with a disability:

“We currently receive some services from xxxxxx. We are fortunate to have a great girl that Susan (name changed to protect identity) gets on with well. We had some difficulty in getting services from them initially – “Susan had to get worse” we were told – not great when you’re dealing with a terminal diagnosis of a child.

We constantly juggle with getting appropriate back up if our regular worker is unable to make it for any reason – which makes holding down a demanding job more difficult. Our previous coordinator was great, but has left after only 18 months and we now have someone who treats us like a number, not a family.

We also have another worker from another agency for an occasional few hours on a weekend to spend with our other son. They’ve been wonderful and flexible. We rely heavily on grandparents – but they are getting older and finding it increasingly difficult to cope with Susan’s physical size. We occasionally use paid babysitters, but the cost is prohibitive and as Susan’s needs increase, we will need people who understand not just kids, but kids with disability ... and be able to assist with her brother.

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. So please don’t erode services ... we need affordable, flexible, compassionate and reliable services.”

When Carers need to attend to their own medical needs, it is also difficult to find sustained 24/7 replacement care for the care recipient. The Carer of

John (name changed to protect identity) needs a hip replacement and will need four weeks reprieve from caring for her husband who needs round the clock care. The replacement care costs for four weeks round the clock care, will cost thousands of dollars and it is difficult for any one agency to provide that level of support. This case just highlights the cost of caring borne by families and where program designs and funding capacities are ineffective:

As a care recipient, my needs are high and I require care provided on a 7/24 basis as quadriplegic..... It is not as though my care can be reduced. There are procedures performed for me by my Carer, that if not undertaken on a timely manner over each 24-hour period, they can have life-threatening consequences. This need in my care also identifies in me that my care needs are not only high, but are also very demanding on my primary Carer and as such impacts on her health and well being.

7 Practical and Financial Support Needs

Just as governments have recognized the importance and good economic sense of promoting healthy lifestyle programs to communities, so they must recognize that investment in a comprehensive system of support for Carers is the only option to help them continue in their role and maintain their irreplaceable contribution to the wider community. Current and future ACT Governments need to work with the Commonwealth to commit to more inclusive strategies which recognize and address the costs of providing care, by:

- increasing the level of subsidy available for essential equipment and home modifications
- offering a low or no-interest loan scheme to help Carers on low incomes to get out of debt and/or to pay for unfunded portions of equipment or home modification costs
- extending the existing pensioner discount on utilities to all Carers where the care-recipient is co-resident (subject to reasonable income thresholds)
- establishing a medical supplies service administered through ACT Health, where consumable medical supplies (including continence aids and tube-feeding formula) are available for registered purchasers to obtain on behalf of people with disabilities and chronic health conditions at minimum possible cost
- developing more suitable post-school options for young people and adults with special needs. There is an urgent, identified need to develop a range of options which offer a real quality of life, with

meaningful activities and appropriate care levels to better meet the needs of people with disabilities in the ACT

Short term respite programs fill a gap but do not provide sustainable support for families. Carers ACT would fully support the development of life-long support for families supporting dependents with care needs.

8 Respite Needs for Young Carers and Their Families

It is critical that this Inquiry consider the different needs of Young Carers as a separate group of adult Carers.

Young Carers and their families have consistently identified responsive and adequate respite as their most important and pressing need but have also reported that a host of significant challenges have prevented them from receiving this support. In particular, they have observed that without a family-responsive focus (where the needs of all family members and those of individual members are assessed and responded to and where the dynamics of the family are understood and taken into account) respite can be both inaccessible and unresponsive to their needs. This becomes particularly apparent when Young Carers are caring for single parents who are not able to access residential care if their child is not supervised or supported while they are away. Other challenges exist when providers do not respond to parent's apparent unwillingness to accept support and therefore are not available to assist Young Carers directly⁹

Responding to the key barriers associated to service delivery (such as the family's lack of awareness of programs, issues with cost and transport, in dealing with family member's fears of judgment or child removal, and limiting eligibility criteria) is essential if Young Carers and their families are to receive support¹⁰.

In essence, we would argue that the following principles are necessary to enable Young Carers' access to quality and responsive respite:

1. No wrong doors
Access points to Carer support (including, but not limited to respite) need to be varied and open. Young Carers and their families need for

⁹ Carers Australia, 2002; Cass, Smyth, Hill, & Blaxland, 2009; Moore, 2005; T. Moore, Morrow, McArthur, Noble-Carr, & Gray, 2006; Nankervis, 2005

¹⁰ Moore & McArthur, 2007

all professionals around them to support them in accessing appropriate assistance even when that particular worker or service does not directly provide Carer support. When Young Carers or their families are ineligible for support from a particular agency to whom they have sought assistance, warm and active referrals are necessary.

2. Whole-of-family need is assessed
All members of the family are engaged in needs assessments to ensure that real need is identified. This will include the needs of the cared-for relative, the needs of each family member (including the Young Carer), and the needs of the family as a unit (including family support, mediation and relationship-building opportunities).
3. Services are integrated and co-ordinated
The needs of the whole family are taken into consideration when designing, developing and providing services. In particular, respite will be provided to both the cared-for relative and the Young Carer at the same time to ensure that each member is enabled to enjoy full benefits.
4. Respite is meaningful and life-enhancing for all family members
Services are provided to ensure that the respite experience is a positive one for all family members. For Young Carers, respite should allow them to relax and rejuvenate but also to re-engage with life-enhancing and affirming activities and to reduce the negative impacts of care (in essence, to achieve the 'respite effect'). This might include social activities, skills development, support groups, social and recreational activities. Resources are allocated to ensure these positive outcomes.
5. Services are well promoted with information provided on availability and accessibility
Families are provided with information about what respite is available, when it is available, how much it costs, how flexible it is, how to access it and how it will meet their needs. Information will also be provided on how Carers might be engaged and supported through the process and what complaints and quality assurance mechanisms are in place.
6. Services are flexible to meet individualised need and circumstances
Packages are developed to meet the specific needs of families and are flexible enough to respond to emergencies, to changing need and circumstance with little or no consequence to the family. For Young

Carers, respite will be available during times their relative are particularly sick; when they feel particularly overwhelmed and stressed; when they have extra work to do for school (i.e. assignments, exams); when other supports (both formal and informal) aren't available; and when they, themselves are sick or run-down.

7. Services are of high quality
Quality service is ensured to ensure client satisfaction and safety and Carer confidence. Staff are well-trained, programs are well-designed and management allows client and Carer feedback. Carers, including Young Carers, are able to inspect facilities and policy and procedure manuals, with queries for information responded to promptly and responsively.
8. Services enable Continuity of Care
Families are aware that services are available at 'crisis' points but also during 'down times' to prevent Carer burnout. Young Carers, in particular, are given opportunities to 'test out' services before peak periods.
9. Services value the 'care team'
That the part that Carers, including Young Carers, assume in supporting their cared-for relative is acknowledged and valued in the development and provision of respite services. This includes their input into service design and delivery on an ongoing basis.

Services are promoted in a way that affirms families rather than problematises them to ensure that family members, including Young Carers, do not experience feelings of guilt or shame, or fear of inappropriate external intervention or scrutiny.
10. Services allow Carer involvement and communication
Carers are encouraged to visit, inspect facilities and keep in contact with their cared-for relative throughout their stay. When providing supports to Young Carers, providers should ensure that they too are able to keep in contact with their families and visit when necessary.
11. Services are affordable to individual families
Families are not restricted from accessing appropriate and responsive services due to financial constraints. Service providers will work with brokers and funding providers to ensure that families needing services are not excluded.
12. Services are accessible to families

Transport is co-ordinated to ensure access to families.

13. Services are efficient and effective
Packages are developed to ensure that they meet the real needs of families. When unable to meet such needs, service providers will work collaboratively with other agencies and providers to ensure that service gaps are filled.

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