



Supporting Family Carers

SUBMISSION TO THE BUDGET 2012-2013

ACT GOVERNMENT

DECEMBER 2011

Carers ACT acknowledges that modern day Canberra has been built on the traditional lands of the Ngunnawal people. We offer our respects to their Elders past and present, 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 its policy and representation activities.

Enquiries on this submission may be directed to:

Dee McGrath
Chief Executive Officer
T: (02) 6296 9901
E: deem@carersact.asn.au

Carers ACT
2/80 Beaurepaire Cres
Holt ACT 2611

This document was prepared by:

Dee McGrath, CEO
Louise Gray, Policy Adviser
Natasha Flores, Policy and Research Officer

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 Carers living in the Australian Capital Territory.

These Carers 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 7,000 families through our counselling, information, respite support, education, social support and case co-ordination services. Our services were assessed in 2009 to meet HACC and NCCP accreditation standards 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 enable 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.

Executive Summary

2011 has been a year of considerable progress in establishing mental health and disability as areas in need of systemic and material reform. With the federal government's decision to endorse the Productivity Commission's recommendation that a National Disability Insurance Scheme be implemented, disability services have been placed at the forefront of the social reform agenda. Similarly, the federal government has announced significant increases in funding for the Mental Health Sector in the last two budgets. It has been consulting with the community and sector experts and is on the cusp of announcing a 10 year roadmap for Mental Health reform. In many cases the actual improvements are yet to be experienced on the ground, nonetheless, the past year has proven that disability and mental health are priorities for government attention with community response sending a clear message – inaction is not an option. Government must respond to the need identified through its own processes and inquiries.

Reflecting the role which carers have played in ensuring that people with disability and people with mental health issues receive the support they need, in 2011 the ACT government introduced a Charter for Canberra's Carers. Linked to the National Carer Strategy, this charter reflects an increased recognition of the important contribution which Carers make to our community. Carers ACT welcomes this acknowledgement of Carers as key stakeholders in progressing reform in the disability, aged care and mental health sectors.

The 2012-13 ACT Budget process represents an important opportunity to ready the nation's capital for the next stage of reform in these areas. Rather than proposing costly investment in capital to establish a supported accommodation footprint or a band-aid solution of one off funding to support a small percentage of people with disability or mental health needs, Carers ACT has developed a suite of budget options which offer an opportunity for considered action. This suite of options seeks to prepare the ACT for the National Disability Insurance Scheme and other reform underway at the federal level, through in depth analysis of need and establishment of genuine priorities.

The Carers ACT budget proposal focuses on two key priority areas for people with disability and people with mental health needs:

- **Supported accommodation;** and
- **Meaningful options for young people with disability** who are unable to access employment.

Carers ACT proposes two strategies for the identification of supported accommodation need and the development of appropriate policy responses:

- A **summit** in which stakeholders will come together to a) constructively discuss the accommodation and support needs of people with disability, people with mental health needs and their carers and b) develop and prioritise practical responses which meet those needs.
- In depth **economic analysis** and comparison of the costs of enacting these practical responses. To obtain a genuine cost of action, the cost of inaction, such as reduced Carer participation in employment, must also be included in the comparison.

Carers ACT believes that these two strategies will allow the ACT government to prepare itself for future demand and plan effectively for accommodation service responses which genuinely meet identified need in the community.

The Carers ACT budget proposal further recommends urgent action to address the gap in support for young people with disability who are, as a result of the severity of their disability, unable to access employment opportunities through supported or open employment.

Carers ACT would also like to endorse the Budget submission from the Mental Health Community Coalition, with whom Carers ACT has worked closely to ensure a coordinated community response to issues of common interest.

Identifying Budget Priorities

Consultation

To ensure that Carers ACT is representing the needs of Canberra's Carers and related key stakeholders, a series of forums with Carers were hosted in order to discuss the issues of main concern which should be brought to the attention of the ACT government in setting the Budget for 2012-13 and beyond. Consultations focused on the needs and lived experience of people with disability and people with mental ill health and the people who care for them.

Consultations with Carers have clearly highlighted the following as being areas of urgent need:

- Supported accommodation; and
- Quality of life activities and programmes for young people with disability.

These issues are both pivotal to enabling people with support needs due to disability or mental illness to live independent, meaningful lives in which choice of lifestyle can be a genuine factor.

Carers expressed serious concern that the provision of accommodation and accommodation support is crisis driven. With long lead times necessary to properly plan for and transition into supported accommodation, many older Carers are concerned that time will simply run out, forcing a reactive response resulting in distress for the person with care needs. A planned transition to supported accommodation means that the Carer is better placed to support the person through the process, which results in better outcomes for the Carer and the person for whom they care.

Consultation with Carers of young people with disability aged between 18 and 26 highlighted a concern that delays in addressing support needs are causing poor outcomes for their sons and daughters. They noted that, while post-school options funding is provided to support young people with moderate disability to achieve a supported or open employment outcome, there is little available to assist young people with more severe disability to learn living and social skills and improve their capacity for independence. Carers are finding themselves unable to return to or maintain employment as their sons and daughters are unable to find meaningful ways to fill their time once school and post-school programs are finished.

There is a pressing need for action but, in the context of broader reform and the need for lasting, systemic solutions, this action must be informed by evidence and lived experience. As such, Carers ACT recommends a measured response of practical investigation and analysis of options to be included in the 2012-13 ACT Budget with a commitment to further reform in

the out years in tandem with federal reforms, particularly arising from the National Disability Insurance Scheme.

Understanding the Context

There are 38 900 people with disability, of which 6000 have severe and profound disability, living in the ACT under the age of 65¹. The number of people with mental health needs in the ACT is estimated at 38 500².

On the supply side, in the ACT in 2009-10, there were 433 accommodation support service users funded under the National Disability Agreement. Two hundred and thirty one of these accommodation support service users lived in group homes. Accommodation support funding is given to 67 group homes, five personal attendant carer provider agencies, and 30 in home accommodation support outlets.³

The pressure on Carers to support people with disability or mental health issues in their homes and to ensure that they are able to access meaningful activities once they have finished school, has flow on effects for the labour market.

Carers are an important, but often under-utilised workforce resource. In the Carers ACT Territory Pre-2008 Election Survey, 160 of 259 Carers who responded indicated that they were not currently in the workforce due to retirement or caring commitments. Twenty five per cent of these Carers said they would like to return to the workforce fulltime or part time if they could be supported to overcome barriers preventing participation.⁴ Funding for disability specific after school care programs, holiday programs and post school options will give Carers, particularly Carers of children and young people the opportunity to participate more fully in employment. The benefits of increased participation will be experienced not only by caring families but by the ACT economy (in terms of taxation and superannuation contributions). Importantly, Carers will also benefit from increased self esteem, improved relationships and better long-term physical and mental health outcomes.

With the current ACT skills shortage, historically low unemployment levels and the impact of the territory's ageing population set to reduce workforce participation rates, the ACT Government must find ways to better utilise its working-age population so that it can remain economically productive.

¹ SDAC 2009 State Tables for ACT Table 1.

² From National Survey of Mental Illness 2004-2005 (number for ACT calculated from the National percentage and the ACT population).

³ Australian Institute of Health and Welfare, Disability Services Report 2009 – 2010

⁴ Carers ACT, Better Support for Carers: A Submission to the House of Representatives Standing Committee on Family, Housing and Youth Inquiry into Better support for Carers. July 2008, p.15

Supported Accommodation

In addition to the experience we are hearing directly from Carers, there is other evidence to support the existence of significant unmet need in the area of accommodation and accommodation support for people with disability or mental illness. In the ACT the percentage of the estimated potential population⁵ of people who received accommodation support has increased slightly from last year putting us just above the national average. Whilst improvement in this area is certainly a step in the right direction, the percentage of people who receive support is still incredibly low. In the ACT, 58 people per 1000 potential population receive accommodation support). The actual number of these potential people and others with moderate disability or episodic mental illness who require accommodation support and the type of support they require is not known. This lack of data is well recognised and is not just an ACT issue. In the Disability sector a project has commenced as part of the National Disability Agreement (NDA) termed "Better Measurement of Need" to develop a national model to better estimate demand through improvements in data reported under the National Minimum Data Set and jurisdictional level unmet demand data.

Disability ACT estimates that "based on current service usage in the ACT, the combination of the ageing carer population and client base within disability (it is predicted) that an additional 15 -20 people will require formal disability supported accommodation services each year."⁶ There is suspicion among Carers of people with disability expressed at our consultations that these 15 – 20 people which Disability ACT plans for are only those whose natural supports have broken down. They suspect that there is little budgeting for accommodation for people to move out of home because they want independence, quality of life or to plan for the future. For many years older Carers have expressed concern about what will happen to the person they care for when they become frail or die. They are at breaking point and have commented on the fact that a supported accommodation option is not available unless someone 'falls over.' The current system for providing support to obtain an appropriate home and the support required to live, regardless of the reason they need extra support, is crisis driven which puts unacceptable extra pressure on families who already be experiencing high levels of stress.

"... we had his name in a list with Housing ACT but it was only after a suicide attempt that they realised that he couldn't stay at home and something was done..."

Shortage of supported accommodation options means that many young people with disability or in some cases mental illness are forced to remain living at home and do not have the same opportunities as other young people to move out of home, live in the community, and demonstrate their potential to be independent and create a home of their own. The pressure on Carers

⁵ Potential population is defined as the number of people with severe and profound disability

⁶ From House to Home, Housing, Tenancy and Support for People with Complex Needs Related to their Disability. November 2010 dhcs ACT

increases and so does the demand for respite care services. A further effect of insufficient supported accommodation solutions is that, when a family relationship breaks down or moves into crisis, respite places may be used over the medium to long term as a reactive measure to address this. This means that families in genuine need of respite are unable to access it, putting them at increased risk of family breakdown.

For people with mental illness, the lack of supported accommodation options means that the accommodation and support provided by the Carer may be the only thing stopping the consumer from being homeless. Carers and consumers are seeking more appropriate accommodation options that operate in an environment which provides support when the person is unwell, but that encourages independent living when the person is well. The National Mental Health Strategy has been a step towards national collaboration on mental health initiatives. However, government data demonstrates that improvement has not been consistent across all service lines, with government spending on mental health in the ACT increasing by \$17.5 million between 2002-03 and 2007-08 but residential services actually decreasing as a proportion of mental health funding⁷.

There is an urgent, identified need to develop a system of delivering of supported accommodation which is individually tailored, offering real quality of life, with meaningful activities and appropriate care levels to better meet the needs of people with disabilities and mental illness.⁸

“.....he is not living in suitable accommodation and I feel like he is rotting away smoking.....”

The Carers we consulted with specifically about supported accommodation for this submission were diverse in the type of needs which the person they cared for possessed, including mental illness, physical and intellectual disability and in the model of accommodation that was preferred. There were, however, strong commonalities in what was considered vital for supported accommodation including:

- That the accommodation is not just a place to live but is a home. A home where they can continue their relationship with their family and create new relationships with other people
- There needs to be the flexibility for individual choice within reason, including who to live with and how many people to live with, the facilities in the home, location to amenities.
- That accommodation provides a life to them and the person they care for.

⁷ Department of Health and Ageing, National Mental Health Report 2010, May 2011

⁸ Carers ACT' Have your say' ACT Election Survey Report: A Report on the Carers ACT Survey of Membership Regarding Critical Issues of Concern to Carers Prior to the ACT Legislative Assembly Election 2008' July 2008, p.38

It is clear from our discussions with Carers and from the ACT Government's own "House to Home" report that there is no one size fits all solution for supported accommodation. Key to the success of any government response to this area of need is the ability to choose what is best for the individual. Accommodation options could therefore include:

- Group homes;
- Community villages where individuals require some supervised care;
- Cooperative owned housing models;
- Hostels for the more able;
- Sharing family homes with a number of individuals; and
- Intentional communities in which support is shared between several closely located residences.

The National Disability Insurance Scheme presents an opportunity to ensure that individual choice can be respected by preparing to offer a range of supported accommodation solutions. Knowing that individuals will have their own funding and the right to determine what services they purchase to meet their own support needs, it is timely to consider how government and the community can ensure that a range of service options exist.

A Proposal for Informed Change

Carers ACT recognises that the issue of unmet need for supported accommodation has been raised many times. Despite this, comprehensive and lasting solutions have not been identified or implemented. As such, Carers ACT is recommending a fundamental review of needs, recognising that these are likely to be diverse and changing over time, to establish an approach to this complex issue which will achieve genuine results for Canberra's most vulnerable populations.

Inclusive Discussion of Options - Summit

Carers ACT met with Minister Joy Burch in November 2011 to discuss our proposal for a summit to explore options and opportunities that build on housing, tenancy and support options available to people with a disability in the ACT, including the needs of people who have a mental illness and dual disability. Immediately after this meeting, Minister Burch issued a media release committing to government participation in such a summit.

Carers ACT welcomes governmental involvement in this important initiative and appreciates Minister Burch's public commitment to ensuring that a summit, which engages Carers, community groups and other stakeholders,

will take place in March 2012. Carers ACT, as the peak body representing Canberra's Carers, looks forward to progressing the summit which will focus its agenda on:

- Identifying the key barriers to supported accommodation for people with disability and mental health issues;
- Establishing accurate information on current supply and demand, including drilling down into anticipated need based on analysis of school leavers with disability and mental health issues over the coming five, ten and twenty years;
- Developing service models which allow for a reasonable degree of choice; and
- Examining funding requirements and how the National Disability Insurance Scheme may link to these.

Lasting Reform – Economic & Social Analysis of Options

With the introduction of a new approach to disability services funding through the National Disability Insurance Service pending, Carers ACT is not proposing that funding be committed to implement new accommodation models without due analysis of all considerations. Informed by the outcomes of the summit proposed in this document, Carers ACT recommends:

Recommendation: 1

A focused body of work is commissioned to analyse the economic and social aspect of supported accommodation issues including:

1. Analysis of the current and potential costs of providing a range of supported accommodation options to the population of people likely to require them in the coming five, ten and twenty year period.
2. Analysis of the opportunity cost linked to the failure to meet supported accommodation needs, including the impact on carers of:
 - a. not being able to participate in the workforce,
 - b. financing the lifelong care of their relative with disability,
 - c. additional health needs as a result of the impact of the caring role on ageing carers
3. Costing a suite of different approaches to supported accommodation.
4. Analysis of current supported accommodation funding and the potential financial impact arising from the introduction of the National Disability Insurance Scheme.

Carers ACT believes that this sort of analysis will be essential to meeting supported accommodation needs in the ACT in a long term and sustainable way, and with appropriate consideration of how it will interact with the National Disability Insurance Scheme. An indicative cost for conducting this sort of analysis is \$250 000. Carers ACT recommends this project be overseen by a steering committee comprising three CEO's of key peak and service providers in disability and mental health, Housing ACT and Disability ACT. The estimated costs include a part time secretariat to drive the project in a timely manner and achieve the outcomes needed for measurable change.

Recommendation 2:

That the ACT Government allocates \$250k in the 2012/13 budget to conduct the economic analysis identified in Recommendation 1.

Quality of Life Activities and Programmes

People with disability and people with mental health needs have the same rights as all citizens to choice, independence and quality of life. The ACT government's Future Directions for Disability ACT harness these concepts as fundamental to policy and program development. In an ideal world, people with disability or mental health challenges will be supported to access programs and activities which will assist them to achieve the best possible quality of life. In some cases, this will be open employment. In others, supported employment is more suitable. Some people may not be able to seek and maintain employment at all and it is this group which risks falling through the cracks, threatening their capacity to achieve the quality of life and independence which others are able to enjoy.

In consulting with Carers and other stakeholders, it is clear that the period of greatest risk for people with disability or mental health needs is immediately after they have completed their secondary schooling. It is then that people find themselves facing the prospect of an unstructured day which may not have many or any, supports or access to the networks and social situations which many of us take for granted. If open or supported employment is not an option, how does this sector of the community fill their time, grow their skills and enhance their lives? It is also at this stage where the pressure resurfaces for Carers as they may be forced to relinquish their workforce activities in order to provide the daily support which was previously accessed through attendance at school.

At present, young people with profound or severe disability often find themselves being kept at school for longer than their peers simply because there are no other options for them. ACT schools authorise this if it can be proven that there is an educational benefit to staying but, in reality, many profoundly disabled young people are not going to be able to achieve this as retention of learning is a serious concern. Current practice is that, in March of a person's final school year, they are assessed to determine future options, whether this pathway is a transition to employment or the allocation of community access hours. Most young people with severe disability fall into

this second cohort and it is this group which Carers ACT recommends targeting through the 2012-12 Budget.

Carers ACT, in consultation with carers and other stakeholders, has developed a suite of proposals designed to address the existing gap in opportunities.

Case Management

The current level of planning needed to ensure that young people with disability or mental health needs receive sufficient support to place them on the path towards the greatest possible level of independence and quality of life warrants greater investment in case management. It is not sufficient to provide information to carers and then require them to approach service providers. Young people in these vulnerable population groups deserve genuine person-centred support which responds to their own situation, circumstances and wishes.

With approximately 15 young people graduating from Black Mountain School each year, representing a reasonable measure of those young people who will need the most support to transition from school and are least likely to be placed in employment, Carers ACT recommends:

Recommendation 3:

- a. A ratio of one case manager to every ten families is established.
- b. Case Managers be located in schools to facilitate case management as a core focus for families in advance of graduation, thus avoiding the potential for gaps in service and support.

At a cost of some \$100k per case manager including salaries and on costs, this is estimated to require funding of \$150k.

Recommendation 4:

That funding of \$150k is allocated in the 2012-13 budget and subsequent budgets to enable the establishment and operation of 1.5 Case Managers based at Black Mountain School.

Community College Programs

Young people with disability and with mental health needs require ongoing assistance and training in work skills, continued functional literacy, life and social skills. These skills must be continually reinforced with a focus on life-long learning.

On leaving school, this cohort of the Canberra population need structured support to ensure that they develop practical skills which are relevant to their daily lives. Carers ACT recommends:

Recommendation 5:

A Budget response which allows the sector and government to look at the school program and determine programs which ensure a smooth transition and a focus on ongoing learning.

By bringing together small groups of people to work together and focus on areas of common interest and/or developmental need, economies of scale will be possible while also allowing the development of social relationships in a non-threatening context which can then be supported to broader social inclusion opportunities. Carers ACT recommends:

Recommendation 6:

That a series of community college programs be developed to allow groups of between five and ten young people to access tailored support.

Program content would be developed with a completely person-centred focus, ensuring that training and opportunities would be aligned with individual need and choice. Content may include:

- learning about transport and how to get to places of relevance to the participants;
- developing skills to assist independent living such as basic food preparation, personal hygiene; managing money etc;
- social inclusion skills including opportunities to learn about socially accepted behaviour prior to taking such skills into practice;
- volunteer work as a stepping stone to supported employment; and
- functional literacy

Carers ACT recommends:

Recommendation 7:

That this initiative is funded at an equivalent level to other post-school options and that this funding is held open to tender for community service provision.

Beyond Supported Employment

Many carers consulted in the development of this submission expressed some frustration that “there is little point building skills if there is nothing to take them to”. Currently, supported employment is federally funded and subject to a cap on places available. This means that the demand for supported employment places is greater than the places actually available. It also means that people requiring more intensive support to achieve and maintain employment may simply miss out all together.

Social enterprises have shown the benefit of providing additional support to assist people who would otherwise not be able to access the workforce to take charge of their own futures. Carers ACT encourages further investment by the ACT government in these models. It would also like to see greater commitment by the ACT government to recruiting people with disability and people with mental health needs to identified positions within the public sector and support to enable them to maintain this employment.

Again looking the number of expected graduates of Black Mountain School, the Canberra Community can expect some 15 people per year to be seeking support to be part of the Labour market. It is necessary for the ACT government to plan for a percentage of this number to be considered for “beyond supported employment” and to contribute additional funding for local supported and open employment service providers to expand their suite of services.

Conclusion

With an ageing population and little progress towards lasting reform in these critical areas, Carers ACT urges the ACT government to commence a carefully managed process of analysis and development of realistic options over the next 12 months to ensure that the ACT is well placed to meet demand arising from the National Disability Insurance Scheme.

The proposed investment in ensuring that options can be identified and developed proactively and with a view to matching solutions to need will ensure that supported accommodation solutions and quality of life options for young people are sustainable over the long term and not a band aid solution.

Carers ACT, on behalf of the population it represents, requests that the ACT government provide the funding as outlined in this submission to ensure that genuine, informed action can be taken to improve the lives of vulnerable Canberrans and the people who care for them. Representing a relatively modest Budget impact, Carers ACT sees this as a relatively minor investment with potential to achieve genuine reform and one which will quickly demonstrate social and economic return through improved community and employment contributions.