



**ACT GOVERNMENT
2011-2012 BUDGET SUBMISSION**

DECEMBER 2010

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.

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

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 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 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.

Current Economic Environment

The ACT economy is outperforming all states and territories except for Western Australia, according to CommSec's State of the States report. Unemployment is the lowest in the nation and the territory also benefits from above average population growth.¹

However, the ACT Treasurer has noted that notwithstanding the economy's improved position, there are still some inherent risks and the Government is committed to returning the Budget to surplus by 2013-2014. As a result it foreshadows additional savings of \$25m in 2011-12 and a further \$25m in 2012-13.

To a large extent the focus of the 2011-2012 Budget Consultation is therefore on seeking feedback on how a return to surplus can be achieved, how resources might be better used; where priorities should be targeted; and where possible savings and efficiencies can be achieved.

Budget Priorities

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

- Supported accommodation
- After school care and school holiday care; and
- Post school options

Additional funding for supported accommodation options will assist a greater number of older Carers to put in place transitional arrangements for the person they care for before the situation reaches crisis point. 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 they care for.

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 CommSec, State of the States, 24 October 2010

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.² 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.

Two other issues are also important in relation to the ACT community sector:

- Funding levels and suggestions for improved efficiencies
- A sustainable workforce

SUPPORTED ACCOMMODATION OPTIONS

The National Disability Agreement (NDA) of which the ACT is a signatory, has as one of its three specific outcomes; that people with disability enjoy choice, well being and the opportunity to live as independently as possible. Currently there are many people with disabilities in the ACT who don't have the opportunity to move out of their family home and to demonstrate their potential to be independent.

This point is illustrated by the fact that in the ACT only just over 2% of the estimated potential population live in government funded supported accommodation. This is approximately half of the national average.³

The lack of supported accommodation options available in the ACT for people living with a disability or a mental illness is well documented. Older Carers have expressed concern and are worried 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' or dies.

² 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

³ Productivity Commission Review of Government Services 2010, (14.26)

Shortage of supported accommodation options means that young people with disability are forced to remain living at home and do not have the same opportunities as other young people to move out of home and live in the community with some degree of independence. There is therefore a flow-on effect to demand for respite care services, which continue to experience high demand.

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.

There is therefore an urgent, identified need to develop a broad range of supported accommodation options which offer a real quality of life, with meaningful activities and appropriate care levels to better meet the needs of people with disabilities and mental illness.⁴

Proposed Solutions: Given that the need for supported accommodation is perhaps the single most pressing issue of concern for caring families, we recommend the ACT Government prioritise this in their planning for social housing development and in conjunction with families develop more innovative supported accommodation options for people with needs associated with disability or mental illness. This can only be achieved through a whole of Government approach and we recommend this strategy be developed within the Chief Minister's Department to ensure a holistic strategy can be developed.

Options developed must include a person-centred, holistic approach that is responsive to changing needs and which encompass community-based solutions linked to other service sectors. Importantly a multidimensional approach to support is required that is inclusive of people with complex needs, for example people with mental illness who also have problems related to drug and alcohol use.⁵

While Carers ACT does not support any one particular model, there is a need to develop alternative optional models, as the current models do not meet everyone's needs or meet demand.

⁴ 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

⁵ Edwards, Robin et al, Housing and associated support for people with mental illness or psychiatric disability. SPRC Report 4/09, report prepared for the Queensland Department of Housing, submitted June 2008 published May 2009

Accommodation options could 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 who have Individual Support Packages

There are a few innovative models in operation. These include the 'Home' in Queanbeyan, which was opened on 1 July this year. The 'Home' is a community initiative which consists of 20 self-contained units catering for both full-time and respite residents in a residential setting. The 'Home' offers supported accommodation for the mentally ill who are living on the streets. Construction of the facility was made possible with the assistance of the Queanbeyan Anglican Church which provided the land; PBS Building which donated its services and constructed the units for the only the cost of the materials, and OzTel Architects, who provided their services free of charge. The community of Queanbeyan contributed more than \$1million to the project, along with donations from local charities and businesses.⁶

Another example is the ACT Community Living Project, which is an initiative of 250 parents/Carers and community members who are seeking to establish a 'village' living environment providing accommodation, including hostel-type unit for people with high-level needs, and which will have the capacity to provide respite care as well; a number of dwellings where people who are more independent will live with appropriate levels of care and supervision, and smaller units for more independent residents including couples. In addition, there will be a number of freestanding units/houses for purchase or rental by community members without a disability. The design of these would be the same as in any other residential suburb.⁷

While these examples demonstrate the strength of the community working together, there should not be an expectation that all funding be provided from within the community. Government should be a significant funder in this area and commit to providing a fixed number of public housing dwellings each year, for people with disability or mental illness.

⁶ <http://www.parliament.nsw.gov.au/prod/parlment/hansart.nsf/V3Key/LC20100902044>

⁷ <http://communitylivingproject.org.au/the-village>

The ACT Housing and Accommodation Support Initiative (HASI) pilot project is a good example of a partnership approach comprising the ACT Government and the community sector. Although we will need to wait for the evaluation of the ACT project, the evaluation of the NSW project has been positive finding that the partnership approach provided through the HASI project enabled people to maintain their tenancies, increase their participation in the community and develop and strengthens social and family networks, among other outcomes.

In addition to supported accommodation options, resources also need to be provided to assist in the planning and provision of accommodation and other supports to be engaged in the event that a primary carer becomes unable to continue in that role. This would provide a necessary back-up support system for consumers, as well as peace of mind for Carers.

OUTSIDE SCHOOL HOURS AND HOLIDAY CARE FOR CHILDREN AND YOUNG PEOPLE

Consultations with parents⁸, particularly those who are employed or are looking for work, have highlighted the need for additional after-school care programs for both primary and high school students with a disability. While it is widely acknowledged that all children can benefit from high quality after school care programs, the programs provide children with special needs with additional, important opportunities. In addition to the benefits of supplementary learning and enrichment activities, afterschool care offers children the chance to engage socially with others in a safe environment in a way often not possible during the regular school day.

Unlike children without special needs, the need for after-school care does not disappear when a special needs student transitions to high school. As one parent commented:

“The disability does not magically disappear when a child turns 12 years of age”,⁹

Children with special needs do not increase their skills of independence at the same pace as other children, who are well equipped to leave behind the world of after school and school holiday programs and are able to move towards a greater sense of independence. For many young people with a disability this new independence is non-existent and there can therefore be limited options for social participation. While they are looking for challenging and age and developmentally appropriate experiences with their peers that are stimulating and fun, they are not able to do this without all day supervision.

⁸ Consultations with parents conducted at Cranleigh School on 5 November 2010

⁹ Quote from a parent attending a consultation at Cranleigh School on Friday 5 November 2010

Currently the only after school care program operating from a special needs school is the Wheelies program which is run at Black Mountain School. This program as its name suggests is for students aged 12 and over who are in wheelchairs. The only other disability specific after school care programs are those run for high school and college students by the ACT's Community Centres; e.g. the Fun 4 Youth program at Tuggeranong and The G club at Gungahlin. Currently there are no disability specific after-school programs for students under 12 years old.

Those children with special needs, under 12 years of age who are attending a special or mainstream school may be able to access mainstream after – school care programs, although decisions about suitability are made on a case by case basis. Therefore children with Autism or Aspergers who require additional staff supervision and a very structured program of activities may be excluded from after school care because the care environment and staff ratios are unsuitable and can actually serve to trigger challenging behaviours.

Additionally, parents report that even if they are able to secure some after school care, it often does not fully cover the days or times they need to continue to work on a full-time or part-time basis.

The result of parents not being able to access the after-school care programs they need is a loss of income for their family, which means that families are less able to manage financial challenges independently and are therefore forced to become increasingly reliant on available public services and income support payments. Additionally, employers lose out on skilled employees and the ACT Government on additional revenue.

The shortage of programs for all ages is exacerbated during the school holidays. While in some instances young people may be able to attend respite or specialised recreation activities, day programs or camps, these opportunities are few and far between. Some families forego recreational respite opportunities because they need to use their allocated respite hours so that they can attend work. The need for quality respite, in which the Carer can have a chance to recharge their batteries, has been well documented, and it is not sustainable for families to continually miss their respite opportunities.

School holiday care providers report demand always out-stripping supply, although the true level of unmet demand is unknown as the Community Centres and other after school care providers do not keep accurate waiting lists.

The lack of appropriate programs means that parents may be forced to negotiate paid leave, leave without pay, or share the care arrangements to cover the 10-12 weeks annual school holidays.

Proposed Solutions: Additional new and innovative programs that provide developmentally and age appropriate opportunities for young people with a disability are urgently required. Parents tell us that after school and holiday programs should be delivered in special needs schools; for example, Black Mountain and those with special units, e.g. Woden.

Programs run in special needs schools will not only provide a safe and familiar environment for children with special needs, but moreover will optimise the use of existing infrastructure and eliminate the need to provide transport for the special school students to travel to other after school care programs. This offers a cost effective solution for government and better outcomes for the children and families.

For children in mainstream schools who will need to access these proposed after school care programs in special needs schools, consideration should be given to the inclusion of transportation from the mainstream to the special school as it would be impractical for a parent to leave work at 2.15pm to collect their child from the school, drive them to the after school care program and then return to the workplace. This would cut into already shortened hours, and would no doubt be unacceptable to employers.

Carers ACT is pleased to see that Recommendation 4 of the The Standing Committee on Health Community and Social Service's report *Love Has Its Limits - Inquiry into respite care services in the ACT*, which was tabled on 7 December, also supports this approach:

*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.*¹⁰

POST SCHOOL OPTIONS

The transition from school to adult life is an important point for all young people. For students with disabilities this process can be even more difficult. About 30 young people with moderate to severe disabilities leave the ACT school system each year. While the ACT Disability People Information Pack for School leavers with a disability states that 'people with a disability leaving school should have the same access to activities and lifestyle opportunities that are available to any young person'¹¹, this is not the case for many young people when they move out of the school system.

¹⁰ Legislative Assembly Standing Committee on Health Community and Social Service, *Love Has Its Limits - Inquiry into respite care services in the ACT*, 7 December 2010, p.45

¹¹ http://www.dhcs.act.gov.au/__data/assets/pdf_file/0003/67629/2009_School_Leaver_Information_Pack.pdf

“...my daughter graduated into nothingness. Since she has left school after much campaigning she now attends a local day program for two afternoons a week. We as a family are paying half the current costs for this program which will be over \$5000 a year. This is currently manageable for us as we are both working but once my husband retires, I fully intend that the entire burden will be assumed by the local authority as on one income it will not be possible.”¹²

School leavers with a profound disability, who are assessed as unsuitable for employment or further vocational training face a reduction from 35 hours of schooling per week (including transport) to a maximum of 17 hours in total of ongoing community access support per week provided for by Disability ACT. Those who are capable of participating in employment or pre-vocational training may also face a considerable increase in ‘down time’, depending on the hours of employment or training which they are able to access. Not only does this reduction in hours significantly limit a parent’s capacity to engage in the workforce and increase the volume of their caring role; the bigger risk is that the young person will regress socially and developmentally and will lose the skills developed at school. Disability ACT is phasing in a transition program which will assist students and their families to plan their future path beginning in year 11. This program aims to be individualised, making use of the school’s understanding of the individual student’s strengths. This system has been trialed with 27 year 12s this year.

Despite this approach some parents have commented that they were left to a large extent to develop their own Futures plan with very little guidance or assistance from either the Education Department or Disability ACT. This means that often they do not know that programs, such as after school care hours may be transferable, even though the young person is no longer in the school system. The incorporation of these hours is invaluable in building up a meaningful, structured program, which could incorporate a mix of social, health and wellbeing and skills development activities.

Proposed Solution: Increase the number of post school options for all young people with special needs.

An example of an innovative employment program is that provided through Café Ink at the Woden library. This social enterprise, which was opened in July this year, is helping people with a disability to increase their social and economic participation through paid employment, work-skill development and an opportunity to access training.

For those young people who may not be undertaking a supported employment program, there is an urgent need for inclusive programs that offer them the opportunity to learn and maintain social skills, and build ongoing relationships with peer groups. The importance of social engagement cannot be over estimated. Programs should also be developed that take advantage of the willingness of service providers to be collaborative in order to achieve better outcomes for

¹² O’Dea Karna, Submission 189, Disability Care and Support

their clients.

In addition to programs it is also important that families are provided with additional assistance to help them develop a Futures Plan. Although some families may be able to navigate the disability system, there are many others who do not have the emotional or physical stamina or time to navigate the system. Better co-ordination between people with disabilities and their families and the departments, service providers and the general community will also assist young people gain access to services and programs that will enable them to develop to their potential.

FUNDING LEVELS AND SUGGESTIONS FOR IMPROVED EFFICIENCIES

Noting that the 2011-2012 ACT Budget will be lean, Carers ACT urges the Government not to bow to pressure to fund a plethora of initiatives or spread investment across a number of service providers. We believe organisations would prefer the Government to adequately fund a smaller number of initiatives, and ensure that funding provided reflects the true costs associated with running services. Organisations have consistently argued that underfunding impacts on the reach of services, their quality, on client access and the scope of services to innovate and adapt to changing need. It also compounds an organisation's ability to recruit and retain staff with the required skills.¹³

Carers have spoken about the need for better integration and more active collaboration across the disability, community care, and mental health agencies. Improved collaboration will reduce costs, reduce duplication of effort and provide a more holistic and strategic approach to meeting need more effectively. Finding and accessing a service that is provided by a number of providers make it difficult for Carers to navigate the service system and receive the services they require.

Carers ACT encourages the ACT Government to better understand the investment in community care services by the Australian Government in the Territory. This will enable more evidence based planning for unmet need and demand so that resources are allocated more effectively. We also recommend ACT Government Agencies research existing Australian Government funded services before tendering for what may be believed to be 'new' services to meet unmet need or demand. This approach would reduce or mitigate the impact of difference accountability requirements for service agencies.

¹³ Productivity Commission Government Services Ch.11.

In the lead up to the last ACT Election, Labor promised to reduce red tape for caring families through the *'Making Life Easier Initiative'*. The Government undertook to review administrative requirements and consider new technologies to cut red tape and improve access for Carers. We seek information about progress on this initiative and how the key milestones are being achieved.

SUSTAINABLE WORKFORCE

Without a sustainable workforce made up of skilled staff, effective services cannot be delivered to Carers or to care recipients. Low salaries within the social and community and disability sector continue to be a significant barrier to the sector's ability to attract and retain skilled and qualified staff.

Carers ACT acknowledges and applauds the fact that the ACT Government has declared its support for the principles and central arguments for the case currently before Fair Work Australia to increase the pay of workers covered by the Social, Community, Home Care and Disability Industry Award (formerly SACS award). The annual Australian Community Sector Survey undertaken by ACOSS has repeatedly revealed these as the single most pressing issues facing services in recent years (ACOSS 2010, 2009). The consequence of not funding higher wages will be that the community sector will continue to lose its skilled staffing base; meaning that service provision could ultimately be jeopardised. Carers ACT therefore call on the ACT Government to commit to funding any pay increase resulting from the pay equity case.

CONCLUSION

Carers ACT would like to thank the ACT Government for the opportunity to input into the Budget process and especially thank the many Carers who contributed their views. The recent passage of the National Carers Legislation and development of the draft National Carer Strategy demonstrate the beginning of the journey to where the community shares the care of people with a disability, equitably. The ACT Government has recently released a draft ACT Carers Charter for consultation and Carers ACT will be providing a written response to the document in the New Year.

While these are important first steps, Carers are saying that they want to see governments take some practical actions to support them, and that they want to be consulted in a meaningful way on the development and design of services.

We have not included respite care as one of the priority areas, not because it is not important – it is. However, Carers ACT provided a Submission to the *ACT Legislative Assembly's Inquiry into Respite Services in the ACT* in March this year and note the tabling of the Committee's report *Love Has Its Limits - Inquiry into respite care services in the ACT* on 7 December. The Committee made 28 recommendations, including: establishment of after school hours care at the 4 special schools in the ACT; greater support for older carers; minimum mandatory standards for disability support workers; greater promotion of information access points; better understanding of the benefits of respite care for both carers and care recipients; bilingual community education programs aimed at de-stigmatising disability and mental health; and increasing flexible respite options.

Mr Doszpot (MLA Chair) noted the angst and frustration expressed through submissions and directly by Carers who appeared before the Committee and said that '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 they need'. There is no doubt that ACT Carers fully support this sentiment.