



Supporting Family Carers

Submission to the Inquiry into Provision of Social Housing

Legislative Assembly for the Australian Capital Territory

Standing Committee on Health, Community and Social Services

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.

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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.

Introduction

Last year there were more people on Housing ACT's priority waiting list than ever before. With around 150 people on the priority list, 920 on the high needs list and 490 on the standard list, it is clear that there are far fewer dwellings available than people who are eligible for housing¹. In this situation, in addition to addressing the lack of availability of social housing, in the short term it is important to have a clear and transparent basis for decision making regarding the provision of housing. Part of this decision making should be a clear understanding of the current needs of prospective tenants on the waiting lists and an awareness of likely future demand for social and community housing.

The social housing register may not be a true indication of the unmet housing need in the ACT community, particularly in relation to the number of people with disabilities or mental illness with unmet housing need. Their needs provide a significant challenge for government as they have both housing and simultaneous support needs to enable them to live independently. It is widely acknowledged that there is a lack of supported accommodation options for people with disability or mental illness living in the ACT. Many people with disabilities or mental illness do not have the opportunity to create a home of their own and reach their potential for independent living. Having a home of your own and having some choice and flexibility about your home is a vital ingredient to a good life and is a foundation for many other endeavours in life. The importance of housing has been recognised by the ACT Government's Social Plan as a priority area and in Disability ACT's Challenge 2014 - A Ten Year Vision for disability in the ACT, it is stated that adults with a disability should be able to "have a place they can call home".

The fundamental nature of housing leads Carers ACT to endorse ACT Disability Advocacy Network (ACTDAN)'s recommendation that the Inquiry of Provision of Social Housing support the inclusion of economic, social and cultural rights, such as housing, as rights under the ACT Human Rights Act.²

In addition to the impacts on the individual of a lack of social housing and accommodation support, many Carers also experience significant effects. Carers ACT has heard from Carers through consultations and other more informal interactions about many situations in which Carers provide accommodation and support at a level beyond that which they can reasonably sustain. There is documented evidence of the negative impacts of unsustainable Caring on Carers. Negative impacts can include reduced wellbeing, social isolation, mental and physical ill health. Recent research highlights that the impact of caring can also have significant financial implications with Carers who have been caring for two years or more having higher poverty rates than non – carers and being more likely to be persistent in poverty.³ One of the reasons for this is that the caring role can reduce the opportunity for engagement in employment. In addition to lost income from reduced employment Carers also have reduced superannuation savings and often don't have the option of retiring or easing back from their Caring role.

As the demand outstrips supply some Carers are forced to live in unsustainable situations waiting until a crisis erupts before action can be taken.

“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.”

Ideally Carers would prefer to act before a predictable crisis and avoid the emotional, financial and other tolls resulting from it. The time when each Carer is no longer able to provide care to the same degree is inevitable. 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. The existence of a care transition plan can also provide the additional benefits of simple piece of mind such as lowering anxiety and improving wellbeing.

¹ On the 4th April 2011

² Submission by ADACAS on behalf of the members of the ACT Disability Advocacy Network (ACTDAN). Inquiry of the Provision of Social Housing. November 2011

³ The costs of caring and the living standards of carers. Social Policy Research Paper No. 43 Trish Hill et al. SPRC University of NSW

In light of the importance to the individual, their Carers and the community of appropriate accommodation and the ongoing crisis in availability of supported accommodation Carers ACT is organising a community Summit in March next year. The agenda of the Summit will focus on;

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

Carers ACT is also recommending an in depth economic and social analysis and comparison of the costs of enacting the practical responses coming out of the Summit. 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.

Whilst we acknowledge that social housing is not the government's response to issues of housing affordability and supported accommodation, it is an important piece of the puzzle to enable many people with disabilities or mental illness to obtain appropriate and reasonable accommodation and support to live in that accommodation.

Recommendation 1: That Housing ACT accepts a forthcoming invitation to participate in the Community Summit to be held in March 2012 and that they commit to working collaboratively with the community to resolve the long standing issue of inadequate levels of supported accommodation.

The demand for social housing

The demand for housing has been increasing. It is probable that demand will continue to rise with factors such as the ageing of the population and the increase in the number of people with disabilities. One of the factors that may also have an impact on the demand for social housing is the probable introduction of the National Disability Insurance Scheme (NDIS). The NDIS has thus far received bipartisan support. The federal Government, in conjunction with the States and Territories have begun work in preparation for the NDIS, including allocating \$10 million to begin constructing the foundations of the NDIS and the establishment a COAG Select Council of Ministers to lead the reform process.

The NDIS may increase pressure on the social housing register because the adequate support it will provide as an entitlement may enable people to consider moving out of their family home. Currently only a fraction of the potential population receives accommodation support. The potential population is defined as the number of people with severe and profound disability under the age of 65. In addition there is a far greater number of people with less severe disabilities who would not be eligible for support under the NDIS but who may still be eligible for the social housing register. Currently there is insufficient data to show how many people with disabilities actually need accommodation and/or support. The National Disability Agreement (NDA) of which the ACT is a participant has funded a project to better measure need of all people with disability.

Recommendation 2: Based on existing evidence of current needs of people on the social housing register, that Housing ACT provide an indication of the likely future social housing needs in their processes of demand management.

Coordination

An NDIS as proposed by the Productivity Commission would fund disability specific services. The Productivity Commission notes that affordable housing is a concern of the general community and should be dealt with in that way. Some of the recommendations about an NDIS which relate to housing include:

- Encouraging accommodation models that separate support from housing, including the possibility of individuals cashing out the cost of public housing to enable them to exert greater control over the details of their living arrangements.
- In some cases NDIS could cover the provision of specialised housing
- In some cases NDIS could cover the cost of housing modifications to both public and privately owned housing.

Recommendation 3: That Housing ACT policy and resource responses are clearly aligned to the timeliness associated with the introduction of the NDIS.

Carers ACT recognises Housing ACT's intentions to become a more of a community service agency and it's recognition that people on the priority and high needs lists will probably have support needs in addition to accommodation needs. Carers ACT has heard from some Carers about the difficulty of securing accommodation through Housing ACT and support to live in that accommodation through Disability ACT. Accordingly, Carers ACT strongly supports the recommendation from Disability ACT's *House to Home* report that the housing and disability support applications are brought together or coordinated in a sensible way.

The NDIS and the Caring for Older Australians report both recommend the separation of the funding of accommodation and support. Whilst this approach may have many benefits, not least an improvement in flexibility and accommodation and support choices, it is necessary for there to be coordination of the provision of these services.

Recommendation 4: That there is evidence of coordination between applying for housing and applying for support to live in that housing.

Communication

Currently Carers ACT is assisting several Carers with negotiations with Housing ACT. The difficulties that these Carers have encountered include lack of communication or unclear communication from Housing ACT as to the process of their application. There has been confusion over the difference between high needs and priority needs categories, with some Carers mistakenly believing that high needs meant their application was being considered as a priority and other Carers who have believed that submitting extra information was enough to trigger a review of their status.

Recommendation 5: That clients on the waiting list receive more and clearer information about the decision making process.

Conclusion

Carers ACT would like to thank the Committee for the opportunity to contribute to this inquiry, particularly as appropriate housing is such an important issue to Carers in the ACT and the people to whom they provide Care. We look forward to continuing to contribute to addressing the issue of the lack of supported accommodation.