

RECEIVED
27 AUG 2010
LEGISLATIVE
COUNCIL



26 August 2010

The Director
Standing Committee on Social Issues
Parliament House
Macquarie St
Sydney NSW 2000

Dear Sir/Madam,

Carers NSW response to additional written questions on notice

Carers NSW is pleased to provide a response to the additional written questions on notice received from the Committee. We hope that the Committee finds this response to be satisfactory.

- 1. In your submission you state that there is significant unmet need for accommodation choices for people with disability and that this problem will be severely exacerbated in the future.***

Can you please explain your position and offer suggestions to how ADHC can address the problem?

Carers NSW agrees with the Disability Investment Group's assessment that "of all disability services, the most significant unmet demand and the greatest anxiety for families relates to housing and accommodation".¹ The extensive, urgent need for supported accommodation for people with a disability is a challenge that must be addressed. Carers NSW has commented on this issue in several recent submissions, including in our submission to ADHC consultations on the second phase of *Stronger Together*, and the Productivity Commission Inquiry into Long term Disability Care and Support. This response is based on our submission to that Inquiry.

The lack of supported accommodation options for people with a disability is of huge significance to a large number of people, many of whom are at breaking point. Under the current system it seems that unless carers do 'break' (or die), accommodation will not be provided. Sadly, in these cases 'breaking' means leaving the person with a disability at respite or in hospital, effectively relinquishing the caring role and with it the opportunity to have any say in the future of the person with a disability. That such desperate and traumatic measures have become the effective access point for entry into supported accommodation is an indictment of the current system.

It is families, carers and people with a disability who have been leading the way in the development of supported accommodation models for people with disabilities.

Carers NSW Inc. ABN 45 461 578 851

Roden Cutler House, Level 18, 24 Campbell Street, Sydney NSW 2000 • PO Box 20156, World Square NSW 2002

P 02 9280 4744 F 02 9280 4755 E contact@carersnsw.asn.au www.carersnsw.asn.au

Carers line: 1800 242 636 (free call)

Carers NSW is funded by State and Australian Governments

Donations over \$2 are tax deductible

Carers NSW believes that the NSW Government must provide funding and support to realise the models being developed by families and carers who have been forced to take matters into their own hands.

Co-operative owned housing

Co-operative owned housing would make possible the creation of the supported accommodation that people choose, and that will meet their needs. Housing co-operatives have the capacity to meet the unique economic, social and cultural needs of the people who require accommodation and their carers. Co-operative housing would be characterised by:

- joint ownership of infrastructure, acquired with funds provided by Government and private contributions when possible
- tenancy management, selection and property maintenance managed through a brokered management company
- care and support services contracted independently of the accommodation model, on an individual/family basis.

Obviously, co-operative housing would not be an option for everybody, but it does offer a good solution to some of the unmet need for supported accommodation, especially for the existing groups of families, carers and people with disabilities that have already developed accommodation models and are advocating for funding to realise them. Funding would need to be provided by ADHC (or in partnership with NSW Department of Housing through social housing allocations in model below) to these individuals in order for them to develop these models. Carers NSW believes this would be an appropriate and effective allocation of funding, particularly in light of the difficulty of the NSW Government to be able to roll-out the necessary infrastructure to meet the current need.

RASAID – A case study

An example of a potential housing co-operative that could be developed through funding from ADHC is Ryde Area Supported Accommodation for the Intellectually Disabled (RASAID). RASAID is a group of 19 families who have been working together for over five years with the goal of achieving supported accommodation for their family members with disabilities. RASAID has developed plans for a clustered residential model for 20 residents, consisting of a congregation of four or five houses. They believe their model has the following advantages:

- the person with a disability would remain in their local area
- the person with a disability would live with a group of disabled peers with whom he/she has grown up, allowing for the maintenance of social networks, whilst maintaining their privacy
- the person with a disability remains close to their work or day programs
- the transition to accommodation would be planned and the person would be supported by their carer throughout the support arrangements will be enhanced by assistance from the carers who live close by and would maintain their relationships with the people with disabilities.²

Perhaps the greatest strength of this and other models developed by families and carers is that they have been designed by the very people who need it, with much time, consideration and thought invested in the final product. These are the models of their choice, and they are informed by an intimate knowledge of the person who needs accommodation, and a genuine commitment to their wellbeing.

Partnership-delivered supported accommodation

There can be no one size fits all approach to supported accommodation. Options other than co-operative housing must also be available. The model employed by the *Housing and Accommodation Support Initiative (HASI) for people with mental illness* program in NSW is illustrative of another approach which would be the choice of some people.

HASI is a partnership program between NSW Health, the Department of Housing and the non-government (NGO) sector that provides housing linked to clinical and psychosocial rehabilitation services for people with psychiatric disability.³ Each HASI client receives services from three local service providers:

- a housing provider, generally public or social housing (funded by the NSW Department of Housing) who provides long-term, secure and affordable housing, as well as property and tenancy management services
- an NGO who provides accommodation support and rehabilitation associated with disability (funded by NSW Health)
- specialist mental health services, which provide clinical care and rehabilitation.⁴

The structure of the HASI program is designed to separate support functions so that each client receives the services and housing that suits their particular needs. Although services are delivered in partnership, and providers do sign a Service Level Agreement, the separation of these functions enables each service provider involved to focus on their area of expertise. The Service Level Agreement defines the major roles of each partner, and establishes processes for communication, information exchange, dispute resolution, reporting, review and evaluation.⁵

Similar models have been applied to other population groups in NSW, including the *Disability Housing and Support Initiative (DHASI)* funded by ADHC under *Stronger Together* for people with an intellectual disability or an acquired brain injury. Fifty places in the program were created in the first two years of *Stronger Together*.⁶

Carers NSW supports the roll-out of programs such as DHASI and acknowledges the progress ADHC has made to date in this regard. DHASI is a good option to meet the unmet need for accommodation of some people, and the capacity of this program needs to be expanded considerably. Consideration should also be given to the application of this or similar partnership-models to other population groups in NSW.

2. *Your submission notes that Census data has revealed a strong relationship between providing assistance and age in NSW, that is, as people age, they are more likely to provide unpaid assistance until they reach 65.*

Can you please tell us what steps you are taking to support older carers?

Carers NSW has first hand experience of the needs of older carers, particularly older parent carers (older people caring for adult children). An older carer is an older person (aged over 60) who provides unpaid care and support to a family member or relative. Some older carers are much older than 60. Carers NSW provides support to carers who are in their seventies, eighties and nineties. There are several ways in which we are providing support to older carers.

Older parent carers

Older parent carers in particular have often been caring for a very long time. Caring for such long periods of time, often with little or no formal support, can have significant impacts upon the social, emotional, physical and financial wellbeing of the carer. Older parent carers are still caring at a time when their own health may be deteriorating and they are at risk of a range of age-related issues, in addition to the long-term impacts of their caring responsibilities. When age-related issues present, their caring responsibilities do not necessarily diminish nor does the level of support they receive increase.⁷

In many cases older parent carers are living the consequences of long-term exclusion from the workforce and the accumulated costs of caring over time. Often they have given up on a service system which has failed them in the past, and are receiving no formal support in their caring role. They often lack the resources, such as savings, which would enable them to arrange alternative support for the time when they can no longer care, or to achieve a different balance of formal and informal care.

Older parent carers report their anxiety about who will care for their child with a disability when they can no longer continue caring. Often they also state that they want a choice about when their caring role ceases.

Support Coordination Program for Older Parent Carers

Carers NSW is a provider of the *Support Coordination Program for Older Parent Carers*. This is an ADHC-funded program which aims to identify and engage 'hidden' older parent carers, and assist families to build and strengthen their social supports and focus on ways to assist older parent carers to plan for the future.

The key components of the Support Coordination services include identifying and engaging hidden older parent carers, succession planning, case management, facilitated carer support, and access to flexible and meaningful respite opportunities for adults with a disability. A number of Carer Assistance Packages (CAP) are available through this program, for the payment of services and supports that are brokered on behalf of carers and people with a disability by their Support Coordinator.

Carers NSW delivers the *Support Coordination Program for Older Parent Carers* in three of the 16 service areas: South East Sydney, Orana/far West and Mid North Coast. Carers NSW has a total caseload of 360 clients for mainstream services and 150 clients for Aboriginal-specific services. Of these, 150 and 60 (respectively) have access to CAP Packages.

My plan, my choice

Carers NSW also provides support to older parent carers through the *my plan, my choice*: Individualised (Packaged) Support Participatory Action Research Strategy currently being undertaken by ADHC. *My plan, my choice* aims to have families intimately involved in the decision making around how best to meet their unique needs. Carers in the program have been awarded support packages of \$20,000 - \$45,000, and are supported to participate in the decision making of how these funds are utilised. Carers receive assistance from a support planner (an ADHC Case Manager). Once approved, a Support Intermediary (from Carers NSW) assists with

the implementation and accounts side of the program. This pilot of self directed care is being conducted by Carers NSW in the Mid-North Coast.

Carers NSW experience as a provider of these programs has demonstrated to us the importance of providing carers with assistance and support to choose the services and supports they need. The Committee will no doubt be aware of the current move towards person-centred services and individualised funding, where the person needing services is at the centre of decision-making about the services and supports they receive. While Carers NSW supports this shift, and believes that giving carers more control over the services they use is important for increasing their choices and quality of life, it is essential that we avoid creating more work for carers and that they are not left to navigate the complex service system on their own. This will be a key issue for older carers and other 'hidden' carers, including young carers, Aboriginal carers and carers from culturally and linguistically diverse backgrounds.

Older Aboriginal carers

Carers NSW also provides support to older carers who are Aboriginal, through the provision of the Aboriginal stream of the *Support Coordination Program for Older Parent Carers* and through the development of other projects. Recently, Carers NSW has developed the *Aboriginal Carers Health and Wellbeing Training Project*. Older Aboriginal carers were involved in this project and in the production of the DVD component. The resulting resources are based on a train-the-trainer model, and aim to improve the capacity of Aboriginal carers, health professionals and service providers working with Aboriginal carers. Carers NSW expects that older Aboriginal carers, as well as other Aboriginal carers, will benefit from this resource.

Carers NSW has also revised the Koori Yarning Resource Manual, which is a resource for service providers to work with Aboriginal carers in a culturally-appropriate way.

The delivery of the *Support Coordination Program for Older Parent Carers* and the development of the *Aboriginal Health and Wellbeing Training Project* has confirmed to us the importance of employing and working with local people who know and understand the local community, and who are able to build and maintain relationships with the community. Our future service provision to Aboriginal carers will be informed by these experiences.

Research partnerships

Carers NSW is also active in carrying out and assisting research projects, some of which have addressed older carers. For example, Carers NSW is currently in a partnership with the University of Sydney Faculty of Health Sciences, the Council on the Ageing and the Association of Senior Computer Clubs of Australia. The topic of the research is *Connecting Older Adults: Can the use of information communication technologies enrich an older adult's social relationships and assist in combating social isolation?* This research will focus on older adults, including older carers, and is funded by Ageing, Disability and Home Care under the Ageing Grants Program: Applied Research Grants.

Carers NSW is also involved in other potential research partnerships. For example, Carers NSW, the University of Western Sydney and Alzheimer's Australia NSW have applied for funding to conduct research on *Meeting the needs of male primary carers, aged over 65 years caring for their partner with dementia*. A research proposal was submitted to the Australian Research Council: Linkage Projects in March 2010.

Carers NSW has also applied for funding from the Australian Research Council in partnership with the University of Western Sydney, South East Sydney Illawarra Health Service: Multicultural Health Service, and St George Migrant Resource Centre to carry out research on *CALD Carers: determining how CALD carers make decisions around the care options they select, including use of nursing home care, accepting care in the home and/or utilising hospital and other health services*. This research will include older carers.

Policy direction

Carers NSW provides policy direction to the NSW Government and Australian Government through its participation in advisory groups, roundtables and written responses to government-initiated inquiries. Older carers and carers who care for frail older people are included in this policy work. Recent examples of Carers NSW submissions relating to older carers and older Australians are:

- Productivity Commission Caring for older Australians Inquiry
- Senate Inquiry into planning options and services for people ageing with a disability
- Productivity Commission Inquiry into Long Term Disability Support and Care
- NSW Health Dementia Services Framework 2010-2015 Framework
- Ageing, Disability and Home Care *Stronger Together* discussion paper
- NSW Government Remaking of the Guardianship Regulation 2005

It is also a member of the National Network of Carers Associations and contributes to policy discussions and direction at a national level through this vehicle.

General carer services

Carers NSW also provides general carer services, which are also a source of support for older carers. The *National Carer Counselling Program*, the *Carer Line*, our network of Carer Support Groups and the resources we have developed to support these are open to and used by older carers.

As the peak body for carers in NSW, Carers NSW is also committed to raising awareness in the community of carers needs, including the needs of older carers. The Education, Training and Development team go out into the community to provide awareness sessions and training. Carers NSW has also developed the *Working with Carers Training Package*, which is designed for management or staff of ADHC services, or ADHC funded-services, as well as other service providers and health professionals. The package is a train-the-trainer model, which aims to improve the capacity of health professionals and service providers to work with carers. This education package includes a specific section on older parent carers.

Older parent carers – unmet need

Carers NSW is proud of our work to date to support older carers, and acknowledges the contribution of ADHC through their support and funding of some of these programs, particularly the *Support Coordination Program for Older Parent Carers* and the *Working with Carers Training Package*. However, Carers NSW would like to do more for older parent carers. More services are required, with the capacity to assist more people.

3. Can you please provide the Committee with an organisational chart for Carers NSW?

Please find the Carers NSW organisational chart attached. The organisational structure of Carers NSW has changed significantly in recent weeks, as the Committee was made aware through our evidence at the Public Hearing. A current Carers NSW organisational chart to 30 September 2010 is attached, together with a revised organisational chart from 1 October 2010.

I have also attached a corrected version of the transcript of my evidence at the public hearing.

Conclusion

Carers NSW appreciates the opportunity to have participated in the public hearing of the Inquiry into services provided or funded by Ageing, Disability and Home Care, NSW Department of Human Services. We hope that this response to the additional written questions on notice is satisfactory. If you require any further information about our submission to this Inquiry or the evidence given at the Public Hearing please contact Alison Parkinson on 02 9280 4744 or email alisonp@carersnsw.asn.au.

Yours sincerely,



Elena Katrakis
CEO
Carers NSW

Endnotes

¹ Disability Investment Group (2009) The Way Forward – A New Disability Policy Framework For Australia, Canberra.

² RASAIID (2010) Ryde Area Supported Accommodation for the Intellectually Disabled [online] Available at: www.rasaid.org.au/

³ NSW Department of Health (2006) Housing and Accommodation Support Initiative (HASI) for people with mental illness, Sydney.

⁴ Ibid

⁵ NSW Department of Health (2006) Housing and Accommodation Support Initiative (HASI) for people with mental illness, Attachment 1 Service Level Agreement Sample, Sydney.

⁶ Ageing, Disability and Home Care (2008) Stronger Together: A report card for the first two years June 2008, Sydney.

⁷ Ibid