

16 December 2015

Ms Tessa Thompson
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Dear Tessa

NDIS Specialist Disability Accommodation Policy Framework

Carers ACT welcomes this opportunity to provide comments to inform the NDS's submission to the Joint Standing Committee on the National Disability Insurance Scheme (NDIS), and addresses three specialist accommodation models: innovative multi-resident accommodation, individual accommodation and shared equity accommodation.

Introduction

Sustainable, suitable accommodation for family members with a disability, including psychosocial disability, has been a key concern for many informal carers in the ACT, particularly older carers with adult children. The lack of specialist accommodation is considered to be a crisis and in need of urgent and lasting reform by key stakeholders.

Our comments are informed by consultation with carer members and clients for our 2015-16 Carers ACT Budget Submission – Providing housing pathways for people with disability and caring families

(<http://www.carersact.org.au/Assets/Files/Carers%20ACT%20Response%20to%20ACT%20Government%202015-16%20Budget%20Consultation.pdf>) and the 2012 Supported Living Options Summit convened by Carers ACT

(<http://www.carersact.org.au/Assets/Files/Final%20Carers%20Summit%20Report%20April%202012.pdf>).

Some 100 people attended the Supported Living Options Summit from a diverse range of perspectives – individual, carer, government and community sector. This engagement allowed the Summit process to gather information that represented a variety of views and, as such, allowed for the identification of and responses to issues raised by different stakeholders. The potential role of the National Disability Insurance Scheme in specialist accommodation was addressed by several speakers and Summit participants. The Summit was facilitated by Dr John Mendoza and Dr Ken Baker NDS CEO was a speaker.

Supporting Family Carers

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A key component of the Summit was a “global café” where ten organisations delivering different accommodation models hosted a table to discuss how their model operated, how it was funded, its governance and to answer participant questions. Participants were asked to complete a feedback form so the outcomes of the discussions could be analysed and reported.

A summary of the models – a model’s strength, its weakness, its suitability for the ACT, if families or government thought they could contribute financially to this model – is provided in the Summit’s final report. See the Summit link above.

Three recommendations from the Summit were delivered to the ACT Chief Minister. One of these called on the ACT Government to “Lobby federal government to include the ACT as one of the launch sites with a view to complementing supported living services under the National Disability Insurance Scheme.” The ACT NDIS trial site commenced in July 2014, with full rollout by end June 2016 anticipated.

Innovative multi-resident accommodation

Echoing the NDS concern that “existing innovation should not be ignored” Carers ACT includes a case study where elements of an existing innovation have been adapted as a model for specialist accommodation for people with psychosocial disability in the ACT.

Case Study 1: MyHome in Canberra

Following on from the 2012 Summit a group of ACT carers and friends of people with a psychosocial disability became interested in developing one of the innovative models presented at the Summit – Home Queanbeyan – in the ACT. A description of Home Queanbeyan is included in the Summit report.

After community consultation, including mental health consumers and their families, strategic and business development plans for MyHome in Canberra have been developed and MyHome in Canberra has been incorporated. The Board has received significant community support to develop MyHome in Canberra, including the potential leasing of suitable land from the Uniting Church, pro bono legal advice and the voluntary contribution of Board members either with lived experience of mental illness or caring or with relevant skills and knowledge. Currently its Board is seeking funding support from both the ACT and Australian Governments. This is the link to its website: <http://myhomeincanberra.org.au/>

While many of MyHome in Canberra’s potential residents would be eligible for NDIS individual support packages questions have been raised: whether MyHome in Canberra would be considered “innovative” as it has been modelled on an existing model; does the model allow residents sufficient choice and control; and the appropriateness of its model of care. The strategic and business development plans have addressed these concerns. A mental health clinician, who is a Board member, is assisting develop the model of care. A copy of the strategic plan is attached.

Individual specialist accommodation

While the NDIS SDA Policy Framework’s key focus appears to be a pricing and payments framework for specialist accommodation providers (cost of land, geographical location, cost benchmarking etc.) Carers ACT is concerned that accommodation options for individuals with enduring disability whose choice is not to live in multi-resident specialist accommodation are not discounted, and believes that sufficient funding needs to be allocated for the NDIS cohort that is likely to be included in the *Framework’s Part 3 – For whom in what circumstances*, and *77. Informal support*.

Pertinent to the above is a literature review by the Home Modification Information Clearinghouse, City Futures Research Centre, University of New South Wales, which provides

an insight into the housing situation, and housing needs and preferences of caring families. Often the housing choice for the person with a disability is to be well supported in the family home, or in separate accommodation adjoining the home. It also identifies that for many families with members with a disability choose to modify the family home, in effect to become a workplace where the primary carer and family support the person with a disability. This is the link to the report: <http://www.homemods.info/publications-by-hminfo/occasional/caring-for-the-carer-home-design-and-modification-for-carers-of-young-people-with-disability#main-content>

The below case study relates to a Carers ACT colleague who is the primary carer for a daughter with an enduring and chronic psychosocial disability. Permission to include this personal story was provided.

Case Study 2: Independent living outside specialist multi-resident accommodation

The parents of a young woman with severe and chronic psychological disability, with a young child, chose to build a separate residence on the block of their family home. Their daughter was involved in this decision because previous attempts to live independently in rented accommodation were unsuccessful and without the intervention and support of her parents she and her young son would have become homeless. Her parents had also contributed financially to the rental costs of private accommodation.

The family solution, in agreement with their daughter, was to establish a purpose built dwelling next to the family home. This was made possible because of amendments to the ACT residential zoning regulations allowing for a second residence up to 90 square metres on an existing housing block, and the parents choosing to take out a loan to fund its development. Their daughter was involved in the design of her purpose-built two-bedroom home so that she was able to maintain it and live as independently as possible. For example, cupboards were designed for easy visibility and access because of the daughter's condition. She is a Disability Support Recipient and will assist with loan repayments. Energy saving elements were incorporated into the house's design, which were considered essential to reduce her utility costs.

The benefits are that the daughter is able to live independently and her recovery is aided by a 'circle of support' provided by her family to her and her young son. Her home environment is 'normalised', particularly for her son who is more comfortable having friends over to visit. This will help reduce the stigma and marginalisation often experienced by people living with severe mental illness.

Her home will also be her place of work. She is a published author and an artist, and her ability to continue with these activities helps promote her recovery and sense of self-identity.

In the above case study the parents had the capacity, land and financial, to develop a purpose-built dwelling for their daughter and young grandson. It's unlikely that the majority of families with a family member eligible for NDIS Tier 2 participation would have similar capacity. For these families and people with disability access to the NDIS capital costs for specialist accommodation would assist them obtain suitable accommodation when more specialist accommodation is not their choice or their best option.

Changes to state and territory legislation and agreements with the National Disability Insurance Agency may be required to assist people with disability and families to navigate local planning regulations and legal requirements to allow for the residence built on an existing block to have its own title, for example. This will also assist the person with disability maintain independence while gaining an asset.

Joint equity specialist accommodation

During consultations with carers and discussions at the Summit it was apparent that families of people with disability, and people with disability, supported the opportunity to invest in joint equity accommodation.

Case study 3: Joint equity specialist accommodation

Project Independence is a new social housing model in the ACT for people with mild intellectual disability. It represents a new model of home ownership in the ACT, as tenants will have an opportunity to acquire equity in a property to help build their economic independence, and the ability to live as independently as possible.

The housing development is based on up to ten tenants living in separate homes with separate apartments in a residential area, and who still will be eligible to receive formal and informal support. Separate accommodation for a resident coordinator to support residents is included.

Project Independence has its own skills-based governance group and several professional supporters. It is also guided by a strong philosophy and principles, as well as defined expectations of residents.

It is supported by the ACT Government through its donation of land and funding. Its genesis was a Canberra businessman and the father of a son with a disability who wanted to live independently.

Construction of the first development began in early 2015 and tenants are expected to move in by the end of 2015. See <http://www.projectindependence.com.au/> for more information about Project Independence.

If you would like to discuss the NDIS and specialist accommodation further please contact Colleen Sheen, Senior Policy Advisor, on 02 6296 9900 or 0411 027 531, or email colleen.sheen@carersact.org.au

Yours sincerely



Louise Gray
Acting CEO

Att: 1