

# The Carers Summit: Supported Living Options — Five Years On

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The lives of family and friend carers<sup>1</sup> are intrinsically linked with the people they care for. The inability to access appropriate, affordable sustainable housing and homelessness issues faced by people with disability or mental illness are likely to be shared by their carers.

Emerging evidence indicates that increased carer stress (because of the lack of carer support, lack of capacity or decision to discontinue their caring role) may contribute to homelessness or a housing crisis for people for whom they care.<sup>2</sup>

On 14 March 2012, Carers ACT convened the Carers Summit: Supported Living Options to urgently address the unmet need for disability and mental health housing in the Australian Capital Territory (ACT). The Summit provided a forum for over 100 participants — carers, advocates, economists and experts from the disability and mental health sectors to change the conversation — from focusing on disability housing problems to focusing on solutions, new models of funding, service delivery and innovation.

The National Disability Insurance Scheme (NDIS) implementation in 2013 and disability reform that provided individualised funding, choice and control for people living with disability meant the Summit was an opportunity to consider disability and mental illness housing solutions with wrap-around services funded through NDIS participant plans to assist independent living.

The Summit's call to action asked 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 NDIS.<sup>3</sup>*

The Summit's final report indicated the requirement for better-targeted housing investment by governments, and a greater willingness to adopt a mix of funding models and service arrangements.

## Forward to 2017

### The NDIS, Housing and Specialist Disability Accommodation

The ACT is the first jurisdiction to transition all age and condition cohorts into the NDIS, which began in June 2014. A projected 460,000 people with disability or mental illness across Australia will be participants by July 2019 when the NDIS is fully implemented. As of 31 March 2017 there were 78,006 approved plans including the Early Childhood Early Intervention (ECEI) approach. The ACT had 5,988 approved NDIS participant plans and one ECEI.

In relation to accommodation there were 825 approved registered accommodation or tenancy providers (with 38 registered in the ACT) and 29 approved registered specialised disability accommodation (SDA) providers (with one registered in the ACT).<sup>4</sup> The SDA allocations commenced on 1 July 2016.

A tenet of the NDIS is for people with disability to have choice and control over their lives. The Joint Standing Committee on the NDIS said the lack of adequate housing can significantly limit people's ability to fully exercise choice and control. Ultimately, it restricts their ability to participate in society and live an ordinary life.<sup>5</sup>

The Joint Committee said this about carers:

*... increasing the independence of people with disability is likely to decrease the pressure on carers, because with increased independence comes reduced reliance on family and friends to meet everyday support needs. This is particularly the case when NDIS funding enables adults with disability to move out of their parents' homes and into appropriately supported independent accommodation.<sup>6</sup>*

Most NDIS participants (94 per cent) will need affordable, mainstream housing rather than SDA provided through the NDIS.<sup>7</sup> However, in submissions to the Joint Standing Committee's Inquiry on Disability Accommodation the National Disability Insurance Agency (NDIA) estimated an unmet need of affordable housing for 127,000 participants, and the Disability Housing Futures Working Group estimated between 35,000 to 55,000 participants will not have their housing needs met in the first decade of the NDIS.<sup>8</sup>

Many people with disability or mental illness of working age will be Disability Support Pension (DSP) recipients. Anglicare Australia's survey, the 2017 Rental Affordability Snapshot, highlighted the rental affordability crisis for people living on the DSP. Only 0.9 per cent of over 67,000 properties surveyed Australia-wide were affordable, with two affordable properties in the ACT. Accessibility and suitability of properties to meet specific disabilities were not considered in the survey.<sup>9</sup>

Carers and caring families had welcomed the NDIS as a wrap-around service to support independent living

for people with disability and mental illness. But what does this 'elephant in the room' of unmet housing need mean for carers and the people they care for?

Known barriers people with disability or mental illness face in our competitive housing system mean, to prevent homelessness, carers and caring families will have little choice but to continue as a key housing provider for the people they care for regardless of their NDIS eligibility, and the impact on them and family members.

### The ACT and Affordable Housing, Disability Housing and Homelessness

The ACT Government has responded to the unmet need for housing in the ACT, including disability housing in various ways, including:

- It transitioned residents in its supported disability housing to alternate housing of their choice, supported by wrap-around services through their NDIS participant plans if they chose to do so.
- It began a five-year (\$608 million) public housing renewal program, the largest renewal of public housing in ACT's history to replace 1,288 public housing units with new, modern homes.<sup>10</sup> In the interim, people with disabilities and their caring families will need to consider private rental as a housing option.
- It mapped disability housing innovations across Australia on behalf of national housing agencies and policy advisors. The mapping's key finding was a set of principles evident across all housing innovations. This included stakeholders working together towards a common vision to provide housing that changes the lives of the people who will live in it as critical.<sup>11</sup>
- It encouraged the development of specialist disability housing options and accommodation options for people at risk of homelessness in the ACT, supported by funding or land allocation, including:
  - *Common Ground Canberra Stage 1* to provide a long-term supported and inclusive community for homeless people and families, as well as low-income earners. Stage 1 includes 40 self-contained one-

bedroom units, and space for on-site support providers and administration, group programs and community activities. The tenancy agreement is governed by the Residential Tenancies Act 1997 (ACT). The ACT Government has committed to Stage 2.

- Project Independence to provide social housing for people with an intellectual disability. This model means residents can acquire equity in a property and the ability to live as independently as possible. The model is based on up to ten residents living in three separate homes, with accommodation for a live-in resident coordinator to support residents.
- The ACT Labor and the ACT Green 2016 Parliamentary Agreement made a commitment to work with community and business partners to construct purpose built housing for people experiencing mental health concerns and housing difficulties, utilising the *MyHome for Canberra* project plan.<sup>12</sup> (Caring families, organisations and community members have advocated tirelessly since the 2012 Carers Summit for ACT and Federal Government support to develop *MyHome for Canberra* as a solution to long-term housing needs of people with enduring mental illness.)
- Its 2017–18 Budget committed \$500,000 funding for minor upgrades to the Brian Hennessy Rehabilitation Centre (BHRC) to continue to provide housing for residents with a mental illness who had not transitioned to alternate housing; and \$1.35 million to expand and improve homelessness services. (The BHRC commitment responds to mental health carers' concerns of no appropriate alternatives available in the ACT to provide residents and their families with the sense of having their own home, community and safety that Brian Hennessey provides.)

While some initiatives will provide affordable disability housing options over the longer term, carers and caring families of people with disability or mental illness continue to

experience housing distress and to seek housing solutions.

Several ACT carers and caring families have been able to re-arrange their own assets and income to purchase a separate property for their adult child with disability or mental illness as a solution to the housing situation.

Other ageing parent carers, with or without considering the benefits the NDIS provides to participants, hesitate to transition the adult child they care for to alternate disability housing. Families are interconnected which can lead to carers and care recipients wishing to live in the same household. It may be the choice of the person with disability or mental illness to continue living within the family household, given that the carer could become lonely or have care needs of their own that can be fulfilled by the care recipient. A reduction in household income in households that are already financially disadvantaged can also be a significant factor in deciding on living arrangements.

#### Endnotes

1. Parliament of Australia 2010, *Carer Recognition Act 2010*, Canberra.
2. Petersen M, Parsell C, Phillips R and White G 2014, *Preventing first time homelessness amongst older Australians, Final Report*, Australian Housing and Urban Research Institute, Melbourne.
3. Carers ACT 2012, *Carers Summit: Supported Living Options Final Report*, Canberra.
4. National Disability Insurance Scheme 2017 *COAG Disability Reform Council Report March 2017*, Canberra.
5. Parliament of Australia (PoA) 2016, *Joint Standing Committee on the National Disability Insurance Scheme Accommodation for people with disability and the National Disability Insurance Scheme inquiry report*, 5 May 2016, Canberra, p.6.
6. *ibid*, p.38.
7. *ibid*, Chapter 3, p.25.
8. *ibid*, Chapter, 2 p.7.
9. Anglicare Australia 2017, *Anglicare Australia Rental Affordability Snapshot*, Canberra, p.5.
10. ACT Government 2017 *ACT 2017–18 Budget Papers*, Publication No 17/0494, Canberra.
11. Kelly S and Sheehan M 2014, 'What is a Reasonable and Necessary Support to Live in Safe, Appropriate Affordable Housing?' *Parity*, vol. 27, no. 5 pp 33–34.
12. ACT Labor and ACT Greens 2016, *Parliamentary Agreement for the 9th Legislative Assembly for the Australian Capital Territory*, October 2016, Canberra.