



## **NATIONAL DISABILITY INSURANCE SCHEME**

### **An Ordinary Life at Home**

**Submission from:**

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## Introduction

### About Scope

Scope (Aust) Ltd ("Scope") is a leading provider of services to people with disability in Victoria, and one of the largest not-for-profit organisations in Australia. Our origins stretch back to 1948, when a group of parents who wanted better lives and opportunities for their children with disability established the Spastic Children's Society of Victoria.

Scope's mission is to enable each person we support to live as an empowered and equal citizen.

Scope provides services including Supported Independent Living (SIL), therapy and individual support options to more than 7,000 people and their families across metropolitan and regional Victoria. Scope also works with corporate and community organisations to improve inclusiveness for people with disability.

Scope enacts its mission through SIL by supporting customers to live in a home they choose, and a community they value, with a true sense of belonging. We do this by providing services in place, raising awareness, and building community capacity to enable the citizenship of people with disability.

In late 2018, Scope was one of five not-for-profit providers selected, through a formal tendering process, for the transfer of Victorian Government disability accommodation services. Home@Scope is a wholly owned subsidiary of Scope formed to operate the transferring houses. The participants have now all completed their transition to the National Disability Insurance Scheme.

Scope provides SIL services to 1,250 people at 284 locations statewide.

### Our response

We have approached the consultation paper as a starting point for a discussion about the need for developing a shared vision and strategy for Home and Living across a likely ten-year timeframe. It will be necessary to unpack the existing arrangements between the Commonwealth and State and Territory Governments to implement change through bilateral public policy.

Our response also includes a review of the research evidence as it applies to group homes along with direct quotes from Scope customers living in supported accommodation. We then follow with our provider perspective on several of the salient issues before briefly addressing some of the barriers to more innovative options.

## Vision and strategy

The vision for Home and Living under the NDIS should be based around meeting individual needs according to what is 'reasonable and necessary' and adhering to the underlying principles of choice and control. Ideally, this will in future mean there are more participants living in community with people they choose. One serious complicating factor, however, is that there are currently thousands of NDIS participants living in houses owned by State and Territory Governments with people they did not choose.

Achieving the vision will therefore require development and implementation of an integrated Commonwealth, State and Territory Government strategy. This strategy will have to consider such elements as: revenue return on existing housing assets; plans for legacy stock; plans for construction of potential future housing assets; endorsement of NDIS policy settings related to home and living by key stakeholders; and alignment of State and Territory Government plans with these still undetermined policy settings.

Over time, Commonwealth, State and Territory Governments will need to revisit and unpack the various bilateral agreements, with a view to ensuring home and living policy is consistent across all jurisdictions.

Scope suggests that bringing the vision to life probably involves formulating a ten-year strategy prior to refining public policy. It is worthwhile looking to the history of disability housing in Australia to provide further context.

## Background

The movement from large residential institutions to group homes as the preferred housing option for people with disabilities that commenced in the 1970s neglected for a long time to involve people with disabilities in any meaningful way. This was essentially a government led initiative that sought to align housing options with what was then considered best practice. Yet the 'dimensions of culture'<sup>1</sup> identified by Bigby *et al* that affect quality of life, which may have provided a more solid foundation for success, were not considered at a systemic level until much later; and the issues emerging from failure to attend to the 'dimensions of culture' has entrenched poor practice at many group homes.

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<sup>1</sup> Bigby, C., Knox, M., Beadle-Brown, J. and Bould, E., (2014), Identifying good group homes for people with severe and profound intellectual disability: Qualitative indicators using a quality of life framework, *Intellectual and Developmental Disabilities*, 52(5), pp. 348-366

Numerous people currently living in group homes made the journey from large institutions – and unfortunately many group homes have perpetuated dynamics that replicate the culture of residential institutions, emphasising routine over individualisation, and have little concept of what life might look like in a world where residents exercise choice and control. Young found in her 2006 Australian-based study of 30 people moving from a residential institution to either community living options or cluster housing<sup>2</sup>, that there were better outcomes in terms of adaptive behaviour, choice-making and quality of life among the former group.

High performing group homes are those attuned to the way the 'dimensions of culture' interact and shape the experience of people living there. The people responsible for running the best performing group homes anticipate or respond to change in the dimensions as needed – and the more competent staff are aware of the interplay between individual characteristics and the group home environment<sup>3</sup>.

From an evidence-based perspective, there has been limited research pertaining to the efficacy of group homes undertaken in Australia or overseas. The 2012 study by Bigby, *et al*<sup>4</sup> involved a cohort of people with intellectual disability comprising 34 focus group participants and 31 survey respondents (30 of whom overlapped with the focus group participants). While the findings from this research are sound, it should not be extrapolated from this relatively small sample size that the findings are applicable to all people currently living in group homes.

The study completed by McConkey, *et al*<sup>5</sup> contrasted the experience of individuals in Ireland living in personalised arrangements, group homes and congregate care respectively. While those people with personalised arrangements achieved the most positive outcomes, the outcomes for people living in group homes were also often positive, and the study concluded that further longitudinal research was required.

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<sup>2</sup> Young, L., (2006), Community and cluster centre residential services for adults with intellectual disability: long-term results from an Australian-matched sample, *Journal of Intellectual Disability Research*, v50 (6), pp. 419-431

<sup>3</sup> Qian, X., Tichá, R., Larson, S.A., Stancliffe, R.J. and Wuorio, A. (2015), The impact of individual and organisational factors on engagement of individuals with intellectual disability living in community group homes: a multilevel model, *Journal of Intellectual Disability Research* v59 (6), pp. 493-505

<sup>4</sup> Bigby, C., Bould, E., & Beadle-Brown, J., (2015), Not as connected with people as they want to be: optimizing outcomes for people with intellectual disability in supported living arrangements, Living with Disability Research Centre, La Trobe University

<sup>5</sup> McConkey, R., Keogh, F., Bunting, B., Garcia Iriarte, E. and Flatman Watson, S. (2016), Relocating people with intellectual disability to new accommodation and support settings: contrasts between personalised arrangements and group home placements, *Journal of Intellectual Disabilities* v20 (2), pp. 109-120

## Participant experience

The SIL services that Scope delivers reflect both the remnants of a legacy approach as detailed above and the desire for people to create a home. This is evident in the feedback we have from participants about what it is like to live in a house owned and run by others alongside people they probably did not choose as housemates.

Scope has multiple systems for listening to participants in order to improve our services. This includes Customer Reference Groups, regular large-scale satisfaction surveys and an ongoing Voice of Customer program.

We have compiled a representative selection of direct quotes from SIL participants focused on what they like, dislike and would want to change about their service. This is presented in the table below.

### Feedback from Scope customers

<b>Support</b>	<p>"Always being asked questions, where are you going, what are you doing. I am in control of my own destiny".</p> <p>"I like the people. We have a laugh. It's my home".</p> <p>"I like it here – they help me with things".</p> <p>"I would to be able to do more for myself".</p> <p>"I have a responsibility to look out for some of the other people who live here – I speak up for them".</p>
<b>Staff</b>	<p>"I worry about who will be on and do I like them and are they any good".</p> <p>"Make some staff take ownership. Some staff say, no my shift is finished and then they leave stuff".</p> <p>"One staff member is bossy. She has no idea. She has everything in place for her and it should be about us not her".</p> <p>"Staff bitch and moan, and don't think the residents pick up on it".</p> <p>"The staff are great".</p>
<b>Participants</b>	<p>"I like some of the people I live with. Get rid of Mark*".</p> <p>"If I had the chance, I would kick one person out".</p> <p>"John* rams my walker and he is rude".</p> <p>"One person I live with drives me a bit crazy. She complains about everything".</p> <p>"Rosie* has a very loud voice, but she can't help it".</p>

\* Names have been changed

The comments break down into three main areas: Support (overall impressions of the service); Staff (people providing direct support in the house); and Participants (the other people living in the house).

Across the opinions expressed in these comments, the unifying factors are the importance of people and relationships. There are obvious themes of independence, power (including 'power over' others) and achieving a balance between individual needs and routine – similarly, the desire for harmonious relationships, particularly with other participants, is clear. In short, the experiences recounted in these comments is redolent of factors that contribute to making a house a home, as outlined in the research evidence above.

The desired approach is for participants actively to choose to live in a house that operates with a shared support model. This includes choice regarding the location and the people with whom they live.

## **Provider perspective**

### **Current situation**

The Home and Living market remains dynamic; the shifts and changes in policy settings have unsettled investors and made it difficult to embed appropriate, innovative service models.

Scope supports the broad proposition that five bed group homes are outdated, and that group living is not a preferred living option for many people. Indeed, Scope has been working for several years to transform its Supported Independent Living (SIL) services to transition away from this service model. This involves implementing a transitional model for five bed group homes that will allow us to decant government housing stock to three bed non-group homes.

The Specialist Disability Accommodation (SDA) market may eventually evolve to supplant five bed group homes with more innovative housing models, but there is no indication as to the timeframe over which this may occur. As demonstrated at Scope, however, improving practice in traditional settings, and supporting participants out of group homes into more contemporary settings e.g., three bed homes with advanced technology, is not dependent on the evolution of the SDA market. This is not to suggest, however, that SIL is inexorably linked to SDA.

There are many aspects of forward-looking SIL models that should work as well in group homes as they do in those more contemporary settings. The adoption of new service models must occur in the context of understanding and responding to the emotional experience of people currently living in group homes. The inference that

group homes are always an inferior option may end up influencing the staff working in these settings and impede the changes that need to occur while group homes are in transition.

People may choose more innovative options over time, but further evolution of group homes from the current state into more innovative service models may also prove to be a desirable change. This should be predicated on following a set of principles designed to embed better practice.

The principles underpinning better group home models include the following:

- The house should be a home. This means activities that relate to living an 'ordinary life' are the priority. The experience would ideally reflect what it is like to live in any shared living arrangement.
- There must be a genuine and effective shared decision-making framework in place with provision for the involvement of supportive decision-makers, as required.
- The recruitment of staff must be values-based, and the team of people focused on delivering service to the participant.
- The home ideally becomes an organic part of the community. This is also one of the more effective ways of improving safeguards for participants.
- The model is sustainable, which is contingent on:
  - The capability of support workers to facilitate group decisions.
  - The appropriate delegation of decision-making authority to staff.
  - A shift to coaching and practice leadership away from operational management.
  - Performance measures are developed around the team and the individual.

The proposed changes to the practice model need to acknowledge the deep emotional impact on residents who have lived for decades in institutional settings, including group homes. The introduction of any new service model for these customers in particular, whether that involves improvements to practice in an existing five bed group home, or relocation to a more contemporary option, must be attentive to their emotional experiences. Indeed, the changes for many individuals living in group homes are likely to be incremental rather than transformational as they start to become aware of what might be possible.

**Recommendation:**

Incorporate principles for high-performing group homes into the NDIS Practice Standards.

## Looking ahead

As the National Disability Insurance Scheme (NDIS) market has matured, the range of housing options available to Scheme participants has increased, but there remains uncertainty about what the future holds. Potential investors in disability housing stock have previously been hesitant to invest owing to a lack of data related to supply and demand; a problem compounded by continual changes to NDIS rules and policies. However, the overriding considerations in planning for and delivering better housing options for people with disability, in particular people with high and complex support needs, are clear.

The Tune review report into the *NDIS Act 2013*<sup>6</sup> notes that the separation of in-home support from the provision of housing represents a contemporary approach to accommodation for people with disability,<sup>7</sup> and this is consistent with the projection from the Productivity Commission that the NDIA should encourage “an accommodation model that gives people the capacity to unbundle the provision of the ‘bricks and mortar’ and the provision of services”.<sup>8</sup> Nevertheless, the delineation of responsibilities between the NDIS and social and mainstream housing is still to be clarified in sufficient detail to give people with disability confidence about their choices.

Scope contends, however, that with the disaggregation of Home and Living, there is an opportunity to understand the range of existing and emerging options available to participants. These options will suit some people better than others in line with their life stages, support needs and individual circumstances. There should be opportunities for participants to move between these options as their needs change.

### **Recommendations:**

Recognise that Home and Living options exist along a continuum of supports that should be responsive to the needs and preferences of participants.

Enable participants to combine or move between different Home and Living options as required.

## Social housing

While SDA provides an ongoing ‘bricks and mortar’ housing solution for people with disability, it is available to a relatively small number of participants. As the NDIS is

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<sup>6</sup> All references to the *NDIS Act 2013* are to the version consolidated as of 27 November 2020

<sup>7</sup> Tune AO PSM, D. (2019), Review of the National Disability Insurance Scheme Act 2013: Removing Red Tape and Implementing the NDIS Participant Service Guarantee, Canberra, December 2019, p.108

<sup>8</sup> Productivity Commission (2011), Disability Care and Support, Productivity Commission Inquiry Report Volume 1, No. 54, 31 July 2011, pp.231-232



eventually expected to fund just six per cent of participants (28,000) for SDA this means the other 94% will have different housing arrangements; and they will most likely be living in private or social housing as do nearly all the 4.4 million people in Australia estimated to have a disability.

This is borne out by figures from the most recent census. The percentage of all people with disability Australia-wide living in private dwellings, as opposed to institutions or group homes that provide 24/7 services, is high (96%) and higher still for people aged under 65 (99% compared with 91% for those aged 65 or over). These percentages have been gradually increasing, with large numbers of people with intellectual disability moving from congregate care facilities to community-based options throughout the 1990s.

Yet the number of people with 'severe or profound disability'<sup>9</sup> living in private dwellings is still somewhat lower (87.1% for all ages and 75.3% for those aged 65 and over)<sup>10</sup>. Summer Housing observed in their evidence to the Disability Royal Commission hearing into group homes that a range of housing options is required to "enable people with disability to live in the community like anyone else".<sup>11</sup> The objective should be to facilitate choice for people with high and complex support needs who are ineligible for SDA to live in the community; and social housing should inevitably be part of the mix in making this happen.

People receiving the disability support pension (DSP) are already members of 27.9 per cent of state public housing households, which is three per cent more than households with people on the aged care pension, and over 10 per cent more than households with people receiving other government payments.<sup>12</sup> While many people on the DSP would be ineligible for the NDIS, the fact remains that people with disability comprise the most significant cohort of tenants and are "much more likely to live in public housing than the wider community".<sup>13</sup>

In 2013, the then Council of Australian Governments (COAG) agreed on a set of principles to determine the responsibilities of the NDIS and other service systems, including housing. This document was subsequently updated in 2015.<sup>14</sup> The principles anticipate that social housing will continue to be available for people with disability in need of housing assistance subject to existing allocation and

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<sup>9</sup> We have substituted the term 'high and complex support needs' in place of the ABS term 'severe or profound disability' from this point in the document.

<sup>10</sup> Australian Bureau of Statistics, *op cit*

<sup>11</sup> Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, Report on Public hearing 3: the experience of living in a group home for people with disability, p.29

<sup>12</sup> National Housing Finance and Investment Company (2020), State of the Nation's Housing 2020, p.50

<sup>13</sup> Productivity Commission, *op cit*, p117

<sup>14</sup> Council of Australian Governments (2013), Principles to determine the responsibilities of the NDIS and other service systems, 27 November 2015

prioritisation processes. However, it is often those allocation and prioritisation processes that act as a barrier to more people with disability accessing social housing.<sup>15</sup>

The underlying issue is that people already living with family or in group homes are not eligible for priority access to social housing. This may be despite their living situation being inappropriate, based on their individual needs. We suggest that the issue could be addressed in part by implementing a more focused approach to the NDIS interface with social housing providers. The Productivity Commission recommended that the NDIS develop memoranda of understanding with mainstream housing providers including the “process for making referrals between the two”.<sup>16</sup>

Having tightly written memoranda of understanding in place would define the pathways for people with disability seeking an alternative housing solution. The memoranda would also develop greater understanding about the range of available housing options and give people greater confidence along these pathways, including NDIS participants who are ineligible for SDA.

**Recommendation:**

Refine the Principles to determine the responsibilities of the NDIS and other service systems to ensure that the responsibilities of the various social housing agencies, and the areas where they intersect, are sufficiently defined in memoranda of understanding.

## Individualised Living Options

### *Stage 1 – Exploration and Design*

Scope notes the criticality of planning and working with participants and their families/carers during the exploration and design stage to develop the service proposal. Many participants, specifically those living in the family home with aging parents, will require plan reviews to ensure they have sufficient time and funding to complete the process – and the complexity of family dynamics in these situations will need to be taken into consideration in determining the period over which this should extend.

**Recommendations:**

Ensure that participants and families are engaged during the exploration and design stage of Individualised Living Options.

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<sup>15</sup> Australian Housing and Research Institute (2016), Addressing the housing needs of participants critical to NDIS success, AHURI Risk & Policy Bulletin, January 2016

<sup>16</sup> Productivity Commission, *op cit*, Recommendation 5.7, p.68

Provide sufficient time and funding in participant plans for the exploration and design stage of Individualised Living Options.

### *Stage 2 – ILO Supports*

The NDIS unit price for delivering 1:1 ILO Supports is insufficient. This will need to be addressed if the service is to be viable. The current pricing probably accounts for the low numbers of service providers delivering Stage 2.

#### **Recommendation:**

Revise the NDIS unit price for delivering 1:1 ILO Supports to ensure the item is viable for service providers.

## **Conclusion**

The forthcoming reforms to Home and Living require demonstrable generational change. This will involve development of a shared vision and integrated strategy for which Commonwealth, State and Territory Governments will be responsible.

While more innovative pathways may prove attractive to participants in the longer term, the starting point for many people will be what they currently know – and the choice about any change should be at their own pace. Otherwise, there is a risk that the housing options that emerge in future are not truly individualised, but as with the move from residential institutions into group homes, again reflect the thinking about what is currently considered to be best practice without a substantial evidence base.

## Appendix

### Scope recommendations

Incorporate principles for high-performing group homes into the NDIS Practice Standards.

Home and Living options should be considered to exist along a continuum of supports that are responsive to the needs and preferences of participants.

Enable participants to combine or move between different Home and Living options as required.

Refine the Principles to determine the responsibilities of the NDIS and other service systems to ensure that the responsibilities of the various social housing agencies, and the areas where they intersect, are sufficiently defined in memoranda of understanding.

Ensure that participants and families are engaged during the exploration and design stage of Individualised Living Options.

Provide sufficient time and funding in participant plans for the exploration and design stage of Individualised Living Options.

Revise the NDIS unit price for delivering 1:1 ILO Supports to ensure the item is viable for service providers.