



Agenda Item 8.1 Attachment C

## **Independent Advisory Council to the NDIS**

# **Pathway to contemporary options of housing and support**

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**March 2018**

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## Introduction

This report draws together a suite of papers that explore the way in which the NDIS can promote innovative approaches to housing and support to enable better outcomes for participants.

This paper is written in the context of the requirements of the United Nations Convention of the Rights of Persons with Disabilities (UNCRPD) as outlined in the Objects of the NDIS Act. Article 19 of the UNCRPD, living independently and being included in the community, outlines the most pertinent requirement in relation to housing and support and requires the NDIS to ensure that people with disability have the opportunity to choose where they live, with whom they live and have access to a range of in-home, residential and other services to support living and inclusion in the community.

Most of the housing and support transitioned into the NDIS from states and territories is of a traditional nature with housing and support linked and residents being required to move house if they were unhappy with the support. The SDA payments however have drawn a line in the sand as to acceptable options and legacy stock grouping more than 5 people with disability will be phased out over the next decade.

For the first time, the NDIS provides reasonable and necessary support that will enable adults with disability to mature into adulthood with the right of passage of moving out of the family home. The demand for housing and support will be greater than ever before but the national crisis in affordable housing will inhibit or delay many people making that transition. Noting that any stock built today will enhance or inhibit the rights of people with disability in the future, it is incumbent on the NDIS to ensure that the new housing and support developed is evidence based and contemporary.

The paper will

- critique existing models of housing and support in terms of their delivery of positive outcomes for participants and Scheme sustainability
- identify requirements to facilitate contemporary approaches and describe a number of options
- identify strategies to improve traditional approaches including pathways to transition and processes to improve practice
- identify barriers to the adoption of contemporary approaches
- identify what needs to change to ensure the delivery of more contemporary approaches.

## **Section 1: The need for change**

At full Scheme roll out, NDIA costs for Supported Independent Living (SIL) and Specialist Disability Accommodation (SDA) will be approximately \$5 billion and will employ approximately 60,000 FTE staff<sup>1</sup>. Representing almost 25% of the cost of the Scheme, it is an area of high risk requiring focused consideration, expectations and perhaps even its own outcomes framework.

Best practice contemporary options of housing and support are required to facilitate positive outcomes for participants and sustainability of the Scheme and yet options transitioned from state and territory systems do not provide a strong base on which to build.

The IAC is pleased to note that SDA policy has eliminated the growth of the poorest performing options with its requirements in relation to number of residents and density restrictions. The policy setting requiring the separation of housing from support strengthens the underpinnings of evidence-based approaches but this is contested with many providers (and now National Disability Services<sup>2</sup>) exerting pressure to remove the requirement. Separation of housing and support is critical to the fundamental NDIS premise of choice and control to ensure participant residents dissatisfied with support do not have to move homes.

Currently group homes are the dominant model of housing and support in Australia with 17,000 people with disability live in group homes. Although there is significant variation in the quality of homes, research presented in this paper will provide evidence that the best group homes are 'not that good' and that more contemporary approaches are simply not available in most parts of Australia.

This section builds the case for change on the basis that group homes are expensive options that do not derive the benefits of more contemporary approaches, that many residents of group homes have profiles similar to participants living in less restricted and less costly options and that group homes are associated with abuse. The section also outlines factors in group homes that put residents at risk, thereby identifying practices that must be avoided in any option of housing and support.

### **What do we know about group homes?**

#### **Group homes lack the benefits of other housing and support options<sup>3</sup>**

The use of group homes as a housing and support option emerged in Australia and other western nations in the 1970s and has become the dominant mode of accommodation for people with disability. Approximately half of all Australian disability

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<sup>1</sup> Summer Foundation

<sup>2</sup> National Disability Services (2017) *How to get the NDIS back on track*, Accessed at <https://www.nds.org.au/news/how-to-get-the-ndis-on-track-nds-paper-released> 10 July 2017

<sup>3</sup> Bigby, C., Bould, E., & Beadle Brown, J., (2015), *Optimising outcomes for people with intellectual disability in supported living arrangements*, p12

expenditure is on accommodation and most of this is on group homes<sup>4</sup>. Though the group home was at one time the leading edge option for improving lives of people with disability, leaders in the field now no longer consider it the best option. In fact, just as large residential institutions were eventually viewed as harmful, today group homes have met the same fate and are themselves seen as out-dated, harmful and inconsistent with the true-life potentials, rights of person and social inclusion of persons with disability. The disability world has pressed onward with further innovation, leadership and updated concepts and standards of quality.<sup>5</sup>

A 2015 study of people with intellectual disability relocating from a large residential centre confirmed the findings of many previous studies that those in group homes had better outcomes than those who stayed in the large residential centre but those who moved to more personalised arrangements generally seemed to fare better than those who moved to group homes.<sup>6</sup> Moreover, the study found that there were significant reductions in staff costs across personalised arrangements and to a lesser extent group homes compared to congregate settings. The study also confirmed that those with high support needs could be adequately supported in personalised models, including persons with medical conditions and challenging behaviours. The study findings question the future of group homes in a post-de-institutional era, suggesting that people currently living with family carers would be better advised to seek personalised support arrangements rather than group home placements although the reservations for parents around safety, supervision and support for their relatives will have to be addressed.<sup>7</sup>

### **Many residents have similar profiles to people in less restricted alternatives**

A number of studies both in Australia and overseas recognise that many people in group homes have very similar support needs to those in more flexible personalised arrangements where the unit cost is much less. Comparison of data about service users in supported living and group homes, drawn from a longitudinal study, showed that approximately a third of residents of group homes had an Adaptive Behaviour Scale score that fell in a similar range to that of people in supported living arrangements<sup>8</sup>.

### **Group homes are associated with abuse and neglect**

“Epidemiological research suggests that compared to the general population, people with disabilities experience significantly higher rates of abuse and that people with intellectual disabilities and those who reside in residential services are at particularly high risk.”<sup>9</sup>

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<sup>4</sup> OPA Guide to visiting group homes p3

<sup>5</sup> Kendrick, 2017, *Why group homes are no longer optimal: A commentary*

<sup>6</sup> McConkey, et al (2015) 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) 116

<sup>7</sup> Curreyer, B., Stancliffe, R, and Dew, A., 2015, Self determination: adults with intellectual disability and their family, *Journal of intellectual and developmental disability* 40:394-399

<sup>8</sup> Bigby, C., Bould, E., & Beadle Brown, J., 2015, Op cit p11

<sup>9</sup> Ibid p3

Abuse and neglect of people with disability has been the subject of numerous inquiries in Australia in the past few years. Reports of the Victorian Parliamentary Inquiry<sup>10</sup> and the Australian Senate<sup>11</sup> document evidence of the widespread nature of abuse and neglect of people with disability over a long period of time. The Inquiries document criminal physical and sexual assault, verbal and emotional abuse, financial abuse and neglect endangering life and express regret that for too long, the lived experience of people with disability, their families and carers had been ignored.

Many of the stakeholders who gave evidence to the Victorian Parliamentary Inquiry viewed the socially and physically isolated nature of some government funded supported residential accommodation or group homes as a factor that increased the risk of abuse for residents. Commenting on research that found that residents in group homes were more likely to experience abuse than other people with disability, the Australian Cross Disability Alliance stated that *institutional settings are widely acknowledged to be breeding grounds for the perpetration of violence and abuse, and cultures that condone violence and abuse. Perpetrators often deliberately target people with disability in institutional and residential settings, particularly those who are least able to resist or make a formal complaint.*<sup>12</sup>

The isolation of group homes is consistently identified as a factor in abuse with recommendations that *Substantial contact with people outside the residence lessens opportunities for abuse to occur and increases the possibility of early detection if it occurs*<sup>13</sup>. People who gave evidence to the Inquiry commented on the increased risk of sexual assault for people who live in residential settings, of the prevalence of 'unexplained' injuries and bruising of clients living in supported residential accommodation and of the failure to respond to concerns raised by staff and families.

In May 2017, 100 prominent academics called for the phasing out the practice of placing people with disability together in group homes amid growing reports of neglect and abuse and mistreatment particularly in group homes<sup>14</sup>.

## Factors in group homes that put people at risk

Limitations of residents and a culture of silence make it incredibly difficult to find out what was really going on in a group home<sup>15</sup>.

Research identifies features of living in supported accommodation that increase the risk of violence, abuse and neglect, including institutional or isolating service design, having a large number of staff provide support to you, relying on others for intimate personal support, and receiving intensive support for challenging behaviour<sup>16</sup>.

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<sup>10</sup> Parliament of Victoria, Family & Community Development Committee *Abuse in disability services* 2016

<sup>11</sup> Parliament of Australia's Senate Standing Committee on Community Affairs (2015) [Report on the Inquiry into abuse and neglect against people with disability in institutional and residential settings](#)

<sup>12</sup> Parliament of Victoria, op cit p36.

<sup>13</sup> ibid p36

<sup>14</sup> ABC News *Group homes for people with disability must be phased out to prevent abuse academics say*, 18 May 2017

<sup>15</sup> ABC NEWS *Group homes for people with a disability must be phased out to prevent abuse, academics say*, by the National Reporting Team's Alison Branley *Posted Thu 18 May 2017, 6:23am*

<sup>16</sup> Robinson, S, 2013, *Safe at home? Factors influencing the safety strategies used by people with intellectual disability*, Southern Cross University



The Public Advocate of Victoria reported to the Senate Inquiry that data from notifications to the Office of the Public Advocate show that *there are three main factors contributing to violence: firstly, the group home environment, where we see inappropriate placements and, particularly, a lack of alternative accommodation; secondly, workforce issues such as lack of training, insufficient staff, high numbers of casualised staff and a lack of leadership; and, thirdly, cultural issues, particularly tacit acceptance and normalisation of violence and bullying.*<sup>17</sup>

Exploring further, factors that put people at risk:

## Inappropriate placements


Most current group home residents did not have a choice as to where they lived and with whom and many are *required to live in group accommodation with other residents who make their lives unsafe, miserable and intolerable*<sup>18</sup>. Judgements about compatibility of residents had to compete with a range of other factors including the lack of alternatives. Even within the paradigm of choice and control of the NDIS, many believe that participant choice is constrained by the time frames provided in SDA payments for SDA providers to fill a vacancy and the absence of decision making frameworks that give authority to the voice of residents in shared living.

## Workforce issues

The casualisation of the workforce in services for people with disability is well documented with the implication that many staff do not know residents well and so are less likely to have the knowledge, skills and experience to provide effective support. The research is unequivocal however that good staff support is linked to good outcomes: that the quality of life of residents lies in staff practices such as how staff communicate, interact and provide assistance.

Research by Bigby et al<sup>19</sup> documents the impact of staff practices on resident quality of life outcomes. Her team developed and tested a set of qualitative indicators that translate abstract concepts and expectations<sup>20</sup> into QOL outcomes and associated staff practices for people with severe and profound intellectual disability. The research demonstrated the impact of staff practices on QOL outcomes, differentiating between group homes in relation to observations of residents and staff in relation to the indicators. The research concluded that the better performing group homes were 'not that good' with none of the better houses performing strongly on domains of personal development or interpersonal relations. The research recommended that a framework of qualitative indicators that measured outcomes and staff practices would provide valuable guidance for observations by auditors, community visitors, funders, advocates and families. Its value in staff training was also stressed. The Guide to Group Homes and Guide to Visiting for the Victorian OPA and CV program were developed as a result of this research.

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<sup>17</sup> Senate Inquiry Colleen Pearce, Public Advocate, Office of the Public Advocate, Victoria  Page 215

<sup>18</sup> Australian Parliament op cit Page 217

<sup>19</sup> Bigby, C., Knox, M., Beadle-Brown, J., & 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), 348-366

<sup>20</sup> Indicators were developed for Quality of Life domains of emotional wellbeing, interpersonal relations, material wellbeing, personal development, physical wellbeing, self-determination, social inclusion and rights



The Inquiries into abuse document practices that are staff rather than resident centric and practices that put residents at risk. Women in group homes being showered by male support workers in male bathrooms because it is convenient for the support worker to ‘do’ the person at that particular time<sup>21</sup> is one example that exposes the significant vulnerability of many residents. Other practices such as prioritising looking after the house rather than supporting residents to be known and participate in community activities is an example of a staff practice that leads to low levels of resident engagement, personal development and poor outcomes.

## Cultural issues

In a review of literature exploring possible causes of abuse, Hutchinson et al<sup>22</sup> identify culture as one of the factors consistently contributing to abuse. Schein defines culture as *a pattern of shared basic assumptions ... that have worked well enough to be considered valid and, therefore, to be taught to new members as the correct way to perceive, think and feel in relation to those problems.*<sup>23</sup>

Bigby and Beadle-Brown<sup>24</sup> identify five dimensions of culture that are common in group homes and by which resident quality of life outcomes could be differentiated. Table 1 outlines the dimensions for under-performing and high performing group homes.

Table 1: Dimensions of culture in group homes

Dimension	Under performing group homes		High performing group homes	
	Polar end	Descriptor	Polar end	Descriptor
Alignment of power holder with organisational values	Misalignment	“We’re not going to do it that way”	Alignment and strong respected leaders – shared responsibility, collaborative problem solving and teamwork	“Vision and mission is exactly what we live”
Regard for residents	As ‘other’	“Not like us”	Positive regard as part of the same diversity of humanity	“Like us”
Perceived purpose	Doing things for	“We look after them”	“Making the life each person wants it to be” – respecting choice	“It’s her choice”

<sup>21</sup> Australian Parliament op cit Page 236,

<sup>22</sup> Hutchinson, A., & Stenfert Kroese, B., (2015) *A review of literature exploring the possible causes of abuse and neglect in adult residential care*, The Journal of Adult Protection 17 (4) 216-233

<sup>23</sup> reported in Bigby & Beadle Brown *Culture in higher performing group homes*

<sup>24</sup> Bigby, C., Knox, M., Beadle-Brown, J., & 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), 348-366

Dimension	Under performing group homes		High performing group homes	
			including social milieu, quality personal care and comfort	
Working practices	Staff centred	“Get it done so we can sit down”	Person centred – attentive, relational, committed, flexible	“The guys come first, no matter what”
Orientation to change and new ideas	Resistance	“Yes but”	Openness to ideas and outsiders – continual scrutiny internally and externally	“Let’s face it, everyone can improve

Numerous people currently living in group homes made the journey from large institutions; yet many group homes have nevertheless perpetuated dynamics that replicate the culture of residential institutions, emphasizing routine over individualisation, and have little concept of what life might look like in a world where residents exercise choice and control.

The corollary is that 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.

## Isolation

One factor, additional to those identified by Public Advocate of Victoria as placing residents at risk is their isolation and lack of relationships with people who are not paid to provide support. A significant proportion of residents of group homes live and spend their days in services that are closed systems where they have very little contact with people who are not paid to be there. They have little or no access to information that might let them know that their lives are very different to the lives of other Australians including other Australians with similar disabilities. They have little or no insight to other possibilities that they might rightfully claim. They have very little experience to know whether the way in which staff treat them is appropriate.

In her 2012 study, Bigby<sup>25</sup> found that most group home residents had no more than a passing acquaintance with people other than staff or family. The challenge of facilitating genuine relationships is borne out in a study of 110 people with intellectual disability before and after they moved from congregate settings to either personalised accommodation or group homes<sup>26</sup>. Whilst people living in personalised settings

<sup>25</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>26</sup> McConkey, R., Bunting, B., Keogh, F., & Garcia Iriarte, E., The impact on social relationships of moving from congregate settings to personalized accommodation, *Journal of Intellectual Disabilities* Accepted 29 May 2017

scored higher on the five chosen indicators of social relationships than did persons living in grouped accommodation, only one in five persons increased their social relations as a result of changing their accommodation, stressing the vital importance of IAC recommendations in relation to authentically building and sustaining informal support.

Relationships with people independent of a service provide a critical safeguard for vulnerable people. Robinson<sup>27</sup> reminds us that many people with intellectual disability cannot 'do it on their own' and need others to create safe spaces, cultures, environments, enabling relationships and service structures in which people's voice is heard and respected.

In conclusion, acknowledging the variability in quality, the group home model of housing and support does not produce good outcomes and the strategies required to improve practice (Section 3) will not be without cost.

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<sup>27</sup> Robinson, S., 2013, Safe at home? factors influencing the safety strategies used by people with intellectual disability, Southern Cross University

## **Section 2: Contemporary options of housing and support**

Contemporary options of housing and support can be identified by:

- enhanced participant choice and control including enabling the participant to choose where they live, who they live with and who provides support
- the separation of housing and support
- targeted strategies that build and utilise informal support to reduce the need for 24/7 paid support, increase relationships and enhance safeguards.

People with disability who have a perceived need for 24/7 paid support often have few options other than shared supported accommodation. The vast majority only need one to one support at specific times of the day but the lack of informal or drop in support options for assistance at irregular and unpredictable times forces them into shared supported accommodation. The challenge in moving from 24/7 paid support to less restrictive and less costly options is to find alternate ways to provide the irregular or 'just in case' assistance.

Home Share, Shared Lives, KeyRing, options for irregular support and technology are showcased in this section to describe the characteristics of contemporary options, identify the elements that reduce the need for paid support and identify what is required for their widespread development in the context of the NDIS.

### **Requirements to facilitate contemporary options**

#### **Effective participant capacity building**

Building the capacity of person with disability to live in their own home requires sustained capacity building over a significant period of time. Effort is usually directed at enhancing self help skills such as in the areas of personal care, household tasks and travel. Planned effort must also be directed to building capacity to stay alone for increasing periods of time coupled with either or both increased informal support or the use of on call services providing irregular support. Peer support is an important part of capacity building: connecting people who are seeking to live in their own home with a combination of paid and informal support with people who have been living in their situations for some time enhances motivation and positive belief in the possibilities.

Current effort at capacity building has not produced the outcomes desired. There are few services providing capacity building in the ILC space; capacity building in participant plans is often unspent and few providers work with participants in ways that increase independence. The IAC proposes to work with Scheme Actuary to report on participant outcomes and then scope options to enhance effectiveness of capacity building. Disabled Persons and Family Organisations may be well placed to provide capacity building of this nature, including support for building informal support and safeguards as outlined below. Their lived experience, coupled with the availability of peer networks will assist participants to build and implement a vision of an ordinary life in their own home.

## Effective development of informal support

The development of informal support is perhaps the most important ingredient in positive outcomes for participants<sup>28</sup> and the sustainability of the Scheme. Increased informal support is associated with lower package costs as well as increased relationships reducing social isolation and increased safeguards arising from connection to people who care about, not just care for the person.

The current reliance on LACs and Support Coordinators to strengthen informal support is not fit for purpose and will never achieve the nature of informal support required to impact on Scheme sustainability.

Research by Bigby<sup>29</sup> that even people in supported living did not do well in the areas of interpersonal relationships and personal development strengthens the argument that developing informal support requires specific expertise.

The IAC often references work by Stancliffe<sup>30</sup> as to what is required to build and sustain real informal support through intensive, cost effective work. This would fit well in capacity building in the NDIS Price Guide in the domain of relationships which currently only funds behaviour support and social skills development.

Housing and support options that use significant informal support need to ensure effective support for the informal supporters including support for planned or unplanned breaks.

## Effective development of personal safeguards

Personalised safeguards are a critical element of enabling vulnerable people to experience positive risk safely. The IAC is concerned that the NDIS responsibility to assist participants develop their personal safeguards is seldom understood and acknowledged. The IAC has written extensively on this topic<sup>31</sup> and sees a role for the NDIS to assist participants to plan and implement strategies that address their specific vulnerabilities in their specific circumstances. Such a strategy is pivotal to enabling participants to experience increased independence safely and has been suggested<sup>32</sup> as a threshold for enabling families to feel confidence in more individualised, less restrictive and less costly arrangements.

The Quality and Safeguards Framework refers to this as developmental safeguards, supporting and empowering individuals and includes providing information for decision making, building capacity and strengthening natural supports. These are the responsibility of the NDIS.

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<sup>28</sup> especially in the domains of health and wellbeing and safety

<sup>29</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, p9

<sup>30</sup> [Stancliffe, Sydney University: Transition to Retirement Policy Bulletin](#)

<sup>31</sup> IAC, (2015) *How can the NDIS help participants enhance their personal safeguards in order to experience greater independence, economic participation and community inclusion.*

<sup>32</sup> Curreyer, B., Stancliffe, R, and Dew, A., 2015, Self determination: adults with intellectual disability and their family, *Journal of intellectual and developmental disability* 40:394-399

## Effective leadership - Someone holding it together

Supported living arrangements inherently have multiple intertwined aspects of paid and informal support and especially when developed around a participant with cognitive impairment, require an identified person, trusted by the participant, to 'hold it all together'. Such a leader who will orient, support and monitor paid and informal supporters also responds to concerns that informal supporters will not inherently improve practice. A leader provides a key strategy to facilitate the lifestyle of choice and mitigate against risk.

Cocks<sup>33</sup> recognises the importance of leadership in his writing on supported living; that at least one key person acts upon a clear vision and provides the leadership necessary for the arrangement to be created and endure. Providers have also identified the importance of this role in their sense of responsibility to fill gaps left by poorly constructed schedules of funded support and going beyond what they were funded to do. In particular, providers argue that "intangible and nebulous types of support such as case management, coordination with other services, monitoring and support with a wide range of other life areas were undervalued by funders and in the construction of individualised packages of support"<sup>34</sup>.

## Home Share

Home share is a simple, normative and effective way of supporting people with disability to live independently. Home sharing brings people together: a person with disability who is the householder and requires some companionship and some assistance and the homesharer, a person or persons who needs somewhere affordable to live.

There are a number of different ways in which homeshare is facilitated.

- Many people with disability organise a home share with the help of family and/or a support agency
- There are a small number of formal Homeshare Programs
- The My Place WA homeshare program (described as a Co-resident model)

In all but the program organised by My Place, the householder provides free/reduced rent in exchange for companionship and negotiated assistance by the homesharer. In the My Place program, the homesharer is an employee, either of the participant or of My Place on behalf of the participant.

Formal Homeshare services, including My Place connect householders and homesharers and safeguard, support and monitor the relationships.

The Homeshare model has been extensively evaluated and found to be a positive and effective way of supporting people to live independently. The Homeshare model

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<sup>33</sup> Cocks, E., & Boaden, R., (2009) *A guide to developing personalised residential supports*, Centre for Research into Disability and Society, Curtin University of Technology p17

<sup>34</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 p37

“deliver(s) large net economic benefits to householders who receive at home care, to homesharers who would otherwise have to pay rent, to governments for the delay in entering more expensive forms of care”.<sup>35</sup>

## Target group

Formal Homeshare programs tend to make links for people with mild to moderate support needs. My Place WA, where the homesharer is paid, supports participant with significant disability. Most housing and support options for people traditionally seen as requiring 24/7 paid support use a homesharer as an important element of informal and unpaid support.

	Homeshare programs	Organised by family and/or support provider	My Place WA
Target group: People with	Mild to moderate support needs	Complex disability	Complex disability
Payment of rent by house sharer	No	No	No
Payment of house sharer	No	No	Yes

## Availability in Australia

Formal Homeshare programs are available

- in the ACT by Community Connections
- in Victoria by Uniting Care Community Options, Independent Disability Services, Wesley Homeshare and Geelong DO Care
- in WA by Avivo (formerly Perth Home Care Services)
- in Tasmania by Community Based Support

Many homeshare links may also happen outside formal programs either through family and friends who support the link or through a support provider.

## Obviating the need for 24/7 paid support

Homeshare programs overcome the perceived need for 24/7 paid support by the use of a volunteer housemate recruited and supported specifically as an informal supporter, who in addition to companionship, provides the irregular and ‘just in case’ support. One of the elements of support for the informal supporter is reduced rent. Whilst the My Place model pays the homesharer, the payment does not represent an hourly rate of support and is significantly less than 24/7 paid support. It is important to note that via payment of the homesharer, My Place is able to extend the model to participants with more complex support needs.

<sup>35</sup> [The Australia Institute, \(2015\) 'On for young and old, the economics of Homeshare' Discussion paper, Accessed 7 July 2017](#)



Another avenue of support for the homesharer is the problem solving and mediation of the relationship provided by the Homeshare provider, an important element in maintaining the health of the home sharing relationship.

Participants using home share arrangements also tend to use capacity building and technology to reduce the need for paid support.

## Challenges in the NDIS

### Understanding the Homeshare model

Providers of Homeshare argue that the NDIA does not understand this approach and some providers reported NDIA and outsourced planners actively discouraged participants from moving into or maintaining such relationships. This lack of clarity as to the model is exacerbated by the removal of home share type situations from the 2017/18 NDIS Price Guide with the removal of item 01\_036\_0115\_1\_1 (Assistance in living arrangements (Host family/alternate family situation)).

My Place reported that NDIA and outsourced planners believe that a homesharer who is a paid employee would necessarily be responsible for all areas of support. Participants in their home share program are reported to have challenges in securing reasonable and necessary support for personal care and community access and My Place is required to put in a quote for SIL rather than the participant's needs examined using Assistance with Daily living. My Place argues that the health, wellbeing and safety of the participant is maximised by being assisted to participate in the community by persons other than the homesharer and that multiple relationships are important to sustain the health of the homeshare relationship.

### NDIS approach to volunteer programs

The Homeshare model is perceived to be at risk 'because the NDIS does not have a 'clear path' to secure homeshare support'<sup>36</sup>. Based on a volunteer approach, Homeshare programs require resources to set up and support a homeshare match but the Price Catalogue does not provide an identified way for providers to claim for the establishment, support and monitoring of the match – functions that are fundamental to support for the volunteer connection.

Some participants have used Support Coordination to establish a homeshare match. Experience of Community Connections, a homeshare provider in the ACT indicates as that participants lose the Support Coordination in their plan, they do not have support to mediate the everyday issues that arise in homeshare relationships and many have broken down as a result. The number of homeshare links supported by Community Connection has dropped from 14 to 4 in the two years of the NDIS and the organisation sees it as unethical to establish new links without the possibility of supporting their continuation.

It appears that the NDIS approach to volunteer programs places participants in a no win situation. If participants self-manage, they could bypass the Price Catalogue and purchase home share. They would not however receive Support Coordination to

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<sup>36</sup> <http://www.canberratimes.com.au/act-news/-gx0z0y.html>

support the link because self-managing participants do not have Support Coordination in their plans. If however the homeshare arrangement is viewed as a SIL item, participants are not permitted to self-manage. These NDIS policies inhibit the use of volunteer based programs such as homeshare.

### Meeting household rent

The home sharer provides negotiated informal support in lieu of rent. It thus falls to the participant householder to subsidise the rent of the homesharer. For most participants, the only source of that subsidy is their reasonable and necessary support where the rent subsidy represents significant value for money because the quantum of informal support far exceeds the hours of paid support that could be purchased. It is critical to emphasise that the participant always meets his/her rent obligation. The benefits of the arrangement to the participant are seen in the extent of unpaid support, the widening of the networks and friendships and the improvement in quality of life.

At present, there is no transparent option under the NDIS for people to use their reasonable and necessary support to offset the rent required for an additional bedroom for a home sharer. Some participants from state and territory schemes for supported living (ACT, NSW, WA and Q'ld) have been able to offset the rent for a home sharer from their resources for support.

Some NDIS participants have subsidised the rent of their home sharer through their reasonable and necessary support but fear that it will be considered an improper use of resources and seek formal clarification that that this represents a legitimate, value for money proposition. A system that allowed participants to report their use of reasonable and necessary support against agreed outcomes rather than line items in the Pricing Catalogue would resolve this issue.

## Shared Lives

Shared Lives<sup>37</sup> is model of support in which the person with disability moves in to live in the home of a compatible Shared Lives carer and their family. In England, Shared Lives is also used for short breaks and day support for people who live with their family.

A Shared Lives carer shares their home and family life with an adult who needs care or support to help them live well. Local Shared Lives schemes, which are regulated by the Care Quality Commission, individually match trained and approved Shared Lives carers with people who need their support. The goal of Shared Lives is an ordinary family life, where everyone gets to contribute, have meaningful relationships and is be active, valued citizens.

Shared Lives participants are supported by their Shared Lives carer to develop or maintain independent living skills, friendships and live as part of their local community, all of which enhances their sense of wellbeing in a safe and supported environment. Shared Lives participants also enjoy other activities during the day. Many people

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<sup>37</sup>[Shared Lives UK 'What is Shared Lives?'](#)  
[Shared Lives UK 'The State of Shared Lives in England' Report 2016](#)

moving into Shared Lives arrangements from more institutional services are able to do things for the first time in their lives – learn to cook, volunteer, work, make new friends.

In England 2014/15, over 11,570 people with disability were being supported in Shared Lives arrangements with 6,120 (53%) living in long term arrangements, over 3,260 (28%) enjoying short breaks and respite and nearly 2,190 (19%) receiving day support. 76% of the participants have a learning (intellectual) disability and 5% have a physical impairment.

The UK Care Quality Commission consistently rate Shared Lives as one of the safest and most effective forms of care and support with 96% of participants rating the service outstanding or very good compared to 66.8% of participants in community services and 63.5% in residential care<sup>38</sup>.

### **Obviating the need for 24/7 paid support**

Shared Lives programs overcome the perceived need for 24/7 paid support by payment of the carer on a retainer basis rather than an hourly rate with the expectation that the carer provides the irregular and 'just in case' support as well as other negotiated supports. Additional gains in participant independence can come from strategies to increase participant capacity, informal support and technology.

### **Availability in Australia**

My Place WA offers a Shared Lives type program supporting people with disability to live in the homes of people without disability. My Place has found that it is significantly easier to recruit appropriate Shared Lives carers who open their homes to a person with disability than to find suitable homesharers who go to live in the home of person with disability.

Shared Lives carers are not employees of My Place but are engaged in a similar way to foster carers. Using a number of the private rulings from the ATO, My Place pays a tax-free reimbursement to homesharers making it financially viable for the Shared Lives householder cease other employment to dedicate time and effort for the best possible family situation.

My Place recruits, matches, trains, supports and monitors the Shared Lives carers and sustains many long-term links.

### **Challenges in the NDIS**

The NDIS Price Guide will require adjustment to facilitate Shared Lives Programs into the Australian market. My Place outlines challenges as a lack of understanding of the model by planners, the use of SIL rather than Assistance with Daily Living to determine support, the challenge for the participant in securing reasonable and necessary support for community access and the need for flexibility in the participant budget to meet the variable contingencies in a participant's life.

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<sup>38</sup> <https://sharedlivesplus.org.uk>

The Shared Lives option does not appear to be available other than through My Place WA and Cranes in Grafton, NSW. Very few participants and their families are aware of the possibility to seek a provider to develop it.

## Key Ring

KeyRing is an approach to housing and support through a 'supportive housing system' in which nine (9) members with disability live in their own home close to one another and receive assistance from a community living volunteer and other KeyRing members. The volunteer either lives in the same community or has strong links to the community and supports members to make connections with one another and the local community.

Typically, the relationship members develop with the volunteer is pivotal as the volunteer assists them manage their relationship with one another and within the broader community. In addition, the volunteer assists members with housing and tenancy, community access and inclusion and social support including the development of locally based peer friendship networks. The volunteer lives in his/her home rent free in recognition of this negotiated assistance. Paid staff from the agency hosting the KeyRing model provides support to the members and the volunteer.

People living in a KeyRing model have a variety of housing and tenancy arrangements – living alone, sharing with a friend or partner in public/social housing, private rental or own home.

KeyRing is unique in its focus on establishing a peer support friendship network between members and its ability to assist people make connections within their local community. Loneliness, isolation and vulnerability have been factors in tenancy breakdown for people with intellectual disability living independently. People have tended to have structured day time activities such as employment, volunteering etc. but were lonely and isolated outside these times. KeyRing provides opportunities such as having a friend drop in and someone to have coffee with. Whilst KeyRing does not force people to socialise or mix with other people in the KeyRing, many participants embrace the opportunities to extend their network and make friends. Supporting people develop and maintain networks is a major role of the volunteer.

With the high cost and intense pressure on housing, KeyRing in the UK is using support hubs in some areas to take the place of the volunteer living in the network. These hubs have proven to be excellent and a cost effective alternative and are popular with KeyRing network members because the 24 hour support line means that members are never left without help at the end of the phone.

## Obviating the need for 24/7 paid support

Persons who use KeyRing tend to be people with disability with low to moderate support needs for whom a 24/7 approach would seldom be considered. There are however many current residents of group homes for whom a KeyRing approach would be a feasible option. The use of the 24-hour support line in the support hub however provides a very useful approach for a broader target group and may open KeyRing to

people with more complex needs who have Assistance with Daily Living in addition to the KeyRing support line.

## Availability in Australia

A small number of providers in Australia operate KeyRing models. One is Marillac in Victoria [Marillac neighbourhood connections - Keyring](#)

## Approaches to irregular support

In a study of 34 people with intellectual disability in supported living arrangements, Bigby reported that “most but not all participants felt ... a sense of security that help was available when they needed it. Whether this latter perception was grounded in reality is not knowable, but no examples were given of it not being fulfilled. This suggests that on-call support is a necessary element of support packages in supported living.<sup>39</sup>

In addition, Bigby found that when people move away from 24/7 paid support, they need access to intensive episodic support for those occasions when there is an escalation of need or a break down in informal support. Providers talked about the importance being able to vary the intensity of support as required<sup>40</sup>.

## On Call

The availability of systems for irregular support is a key feature of moving away from the need for 24/7 paid support. There are few stand-alone services in the disability field catering for this need. Sol Connect<sup>41</sup> a small organisation in Scotland that combines a central support hub with the use of technology has filled a niche in reducing the need for 24/7 paid support in Scotland.

Sol Connect, is described as ‘technology enabled care specialists’ that offer advanced remote support through the very latest technology, nation-wide through two programs: Flexilife and Out of Hours Responder.

Sol Connect assists the user to identify their needs via a ‘planning and risk enablement process’ that is used to design a bespoke remote support package that can include phone calls, monitors and responders to provide back-up and a sense of safety. People with disability use Sol Connect for daily reminders for appointments, routines, staff coming in, social Interaction and day to day conversations, support with medication, support with anxiety and mental health, ‘clocking in and out’ ensuring the individual always get the support they require when expected, emergency support with health issues, contacting other professionals or emergency support, monitoring of alerts and alarms and out of hours alarm responders.

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<sup>39</sup> Bigby, C., Bould, E., Beadle-Brown, J., (2016) *Conundrums of supported living: The experience of people with intellectual disability*, Journal of Intellectual and Developmental Disability, p8

<sup>40</sup> Bigby, C., Bould, E., & Beadle Brown, J., (2015), Not as connected with people as they want to be: Optimising outcomes for people with intellectual disability in supported living arrangements, Living with Disability Research Centre, La Trobe University, p44

<sup>41</sup> <http://www.sol-connect.org>

Technology is an important part of the approach with the provision of motion sensors, bed occupancy monitors, door contacts, GPS and enuresis alarms that the service installs and trains the person and others in their use. Sensors can be used to open a camera to get a visual on a specific area of the house or people present, allowing staff to make contact with the person and if appropriate, offer remote support options such as a conversation, reminders or prompts, distraction options such as music, radio or films. Where necessary, the service will dispatch a responder to assess the situation and provide immediate support (e.g. personal care), search for the person and/or contact emergency services or an agreed third party as appropriate.

## Obviating the need for 24/7 support

Assistance such as that provided by Sol Connect is pivotal in providing irregular and 'just in case' support important to obviate the need for 24/7 paid support.

### Availability in Australia

Whilst most SIL providers have on call systems in place, there are few visible services offering irregular and 'just in case' support to people living in their own homes in the way provided by Sol Connect.

Annecto<sup>42</sup> is one example of a service that offers an after hours service with systems that can be used by service providers and people who are self-manage for welfare checks, activating emergency plans, shift replacement and planned and unplanned assistance outside of regular hours. Last financial year Annecto 'After Hours' responded to 34, 864 calls from or related to people with a disability and elderly people, and including young people who would otherwise be living in nursing homes.

Another example is Nightlife, a service in metropolitan Melbourne that uses an on-call system to provide unscheduled visits to people with disability living in their own homes and linked to their service. Nightlife does not however provide the breadth of support available from Sol Connect.

## Technology

Technology has multiple applications in assisting people to move from 24/7 paid support to less restricted alternatives. Technology can:

- automate an environment
- monitor people in relation to specific vulnerabilities thereby enabling people to experience positive risk safely
- activate remote support options such as a phone conversation, reminders, prompts or distractions
- assist people to be connected to friends.

The Home Automation Project<sup>43</sup> run by My Place Foundation set out to demonstrate that consistent and reliable home automation systems that are commercially available

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<sup>42</sup> <https://www.annecto.org.au>

<sup>43</sup> [My Place Foundation "The Home Automation Project" August 2015 \(Accessed 11 Oct 2017\)](#)

in the wider community could be customised and adapted for people with a range of disabilities by competent installers at an economic price.

The project found that the purposes to which home automation is put is limited more by the person's imagination than the technical capabilities of home automation systems or the availability of suitable switching mechanisms. In this project alone, home automation was put to more than 30 different uses in and around the homes of 21 people with disability.

This project established that the design and installation of efficacious home automation systems did not prove to require the involvement of doctors, therapists and clinical engineers. Rather it required the person with a disability, and anybody they chose to be involved in the discussions, to be presented with practical information by people who had expertise in the installation of home automation systems and had the time to sit down and explore all possibilities. On the basis that people don't know what they don't know, these discussions were enhanced by presenting each person with a customised suite of assistive devices that might be useful and practicable to them.

Findings of the project included:

- Two thirds of the installations cost less than \$2,000, the range of costs between \$3,610 and \$20,760 and the average \$12,463, concluding that if the home automation system saved a user 5 hours of support time per week, the average system would pay itself off in one year. This compares to a typical supported disability accommodation package of over \$200k pa or about \$4000 per week, equivalent to about 100 hours of support per person.
- Users experienced:
  - an increased sense of security and safety for the person with disability and everyone who worked or visited the home. In addition people with disability anticipated less physical effort and injury from having to struggle with doors and windows
  - being able to have more 'me time', being able to spend several hours (or even overnight) without any family or carers in the house because of the ease it provided for the person to enter and leave the home and their ability to alert someone if the need arose
  - finding it easier to recruit and retain support staff.
- Unanticipated findings that
  - several people with significant disability withdrew from the project on the grounds that there were people 'more needy than them'
  - four of the original participants chose not to proceed to installation as a result of trepidation about the impact of so much new and unknown technology on their home, themselves and their support staff.
- The importance of having an opportunity to visit the home of a person with a similar disability to have a frank conversation about the pros and cons of home automation: the project now has a network of automated homes around Perth open to interested people.
- The importance of having each participant commit to a six-monthly maintenance visit by installers to reduce likelihood of disengagement as a



result of poor device performance, dissatisfaction with equipment and/or changes in user needs or priorities.

The Summer Foundation showcases similar technological solutions.

Bigby observed the value of technology in enabling people with intellectual disability to connect but “despite being competent in using mobile phones, iPads and computer programs such as Skype, the majority of participants did not have access to the internet or computer at home and made only rudimentary use of devices. They had little or no access to programs or apps designed to compensate for cognitive disability, particularly low literacy, or to the technical support to set up home internet or mobile devices<sup>44</sup>.

### **Availability in Australia**

The NDIS supports the use of technology.

Many participants and their families however have been frustrated that the participant is unable to become more independent through the use of technology because of their inability to afford a smart phone / iPad or internet connection at home. The frustration with the NDIA arises from its prohibition in using reasonable and necessary support to purchase this enabling technology.

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<sup>44</sup> Bigby, C., Bould, E., & Beadle Brown, J., (2015), Not as connected with people as they want to be: Optimising outcomes for people with intellectual disability in supported living arrangements, Living with Disability Research Centre, La Trobe University, p11

## Section 3: Improving traditional options

### Transitioning traditional options

17,000 participants currently live in group homes and whilst NDIA projections indicate that most growth will be in alternate stock<sup>45</sup>, there will be a growth in the number of group homes to 2025.

It is imperative that the NDIA provide a clear pathway that demonstrates to providers how to transition group homes into more contemporary options. Whilst SDA pricing gives clear signals in relation to requirements for transition, there is no guidance as to how, for example, a traditional 5-bed group home (eligible for SDA payments) can offer more contemporary support for residents to become more independent and more included.

One option is to transition a 5-bedroom group home into supported living where people with disability live with people without disability enabling for example, 3 people with disability to share with 2 people without disability. This approach is used in the Netherlands where students live rent free in nursing homes and *in exchange, spend at least 30 hours per month doing some of the things professional staff cannot always do – such as hanging out.*<sup>46</sup>

Modelling by Scope (Aust.) indicates that group homes where one or two people without a disability receive reduced rent in return for providing sleepover duties may be a workable economically viable model. Modelling suggests that costs savings from sleepover are sufficient to fully offset rent for people without disability, and therefore enabling some sharing of these savings between reduced rent and lower package sizes.

Providers indicate that there are two barriers to transitioning traditional group homes into this more contemporary support in a financially viable way:

- there is a gap in household rent because the people without disability are usually rent free in return for negotiated support
- SDA payments are structured around the number of bedrooms in the house, not the number of SDA eligible individuals in the house. This means that if an enrolled SDA house with 5 bedrooms has only 3 SDA eligible residents, the SDA payment per resident is less than if there were 3 SDA eligible residents in a 3 bedroom house.

These constraints represent a significant disincentive to enabling people with disability living with people without disability in SDA and non-SDA housing.

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<sup>45</sup> The first SDA Market Insight (Nov 17) will spotlight “smaller” forms of SDA with 2-3 bedroom dwellings shown as the housing for which most demand/growth is likely to occur.

<sup>46</sup> for example, 3 people with disability living with 2 people without disability in a formerly 5 bed group home [SBS News Story ' My 93 year old flatmate' 3 May 2016](#)

## **Families of group home residents**

Whilst many group home residents do not have engaged families or supporters, many have ageing carers for whom the decision to place their family member in a group home was made in the spirit of making long term plans to keep the person safe and secure. Capacity building that assists residents to see less restricted options will be thwarted without vision building and preparation with their families. People trusted by the family are best placed to undertake this work including (and perhaps especially) providers supporting the group home.

## **Improving practice in tradition models**

Given the large number of people currently living in group homes it is imperative that the NDIA take steps to improve practice and hence lives.

Many current residents have lived in a group home for decades, have high and complex needs, do not have family or allies actively engaged in their lives or have ageing parents who will want to see models of less restrictive options in operation before making any decisions about the future of their adult children. With active strategies, some will move to less restricted options. Many may choose to remain in group homes over the medium term and some will never choose to move.

This section outlines strategies to improve practice and mitigate risk to people living in group homes, grouped in relation to what can be expected from the Quality and Safeguards Framework, investment in residents, avenues for shared decision making and practices of providers.

## **Expectations of the Quality and Safeguards Commission**

There is an expectation that the implementation of the National Quality and Safeguards Framework (The Framework) will improve practice in disability services including group homes. Importantly however, its implementation must balance the best interests of participants with the need to set the bar at a level that will enable most providers to meet expectations. Whilst the IAC recognises the importance of the preventive and corrective standards of the Framework, it is concerned that the registration requirements emanating from the Quality and Safeguards Commission will set minimum standards and will not address the issues of quality canvassed in this paper.

Importantly in relation to improving practice, the Quality and Safeguards Commission will have a developmental and educational role. The Commission will regulate compliance with Practice Standards and it is understood that a Core Module covers rights and responsibilities, governance and operational management, provision of supports and the environment in which supports are provided and that there is a specific set of Practice Standards for SDA. Once the Standards are agreed, supporting material will be developed (evidence questions, good practice examples etc.) all of which should be an opportunity to help shape service delivery. It is understood there will be training to support the Code of Practice that will apply to all workers and providers but a source of funding for training is not apparent at present.

Developmental and most preventative safeguards for participants remain the responsibility of the NDIA. This paper presents the view in scaling up to full Scheme, NDIA practice has been inadequate in these areas and section 2 of this paper outlines what is required of the NDIA to implement developmental and preventive safeguards and support participants to seek and use contemporary options.

Given that the Quality and Safeguards Framework only applies to registered providers and given self-managing participants can use unregistered providers, the IAC proposes that providers of group homes and other closed systems must be registered providers. This is based on the recognition that group homes and larger residential services are more often than not, closed systems heightening the vulnerability of residents and hence increasing the need for external appraisal.

## Capacity building of residents

Strategies that improve life for residents of group homes include:

- genuine and informed person centred planning
- capacity building to identify what is not right and to speak up. This requires residents to have:
  - their communication needs met
  - support for decision making
  - assistance to develop personal safeguards
- assistance to develop relationships with persons independent of the service and who are not paid to be there
- peer support that connects group home residents with people with a similar profile who do not live in group homes
- recognising that behaviours of concern may reflect challenges in shared living and stimulate consideration of more individualised arrangements.

Current NDIA practice in these areas is not adequate to the task with inadequacies arising from first plan processes, the allocation of Support Coordination to the provide of SIL, the absence of support for decision making as identified by the IDRG in its 2016 paper, inadequate or no assistance to develop personal safeguards and inadequate or no assistance to develop relationships with people not paid to provide support.

## Introduction of governance frameworks for shared decision making

Choice for residents in shared support accommodation could be enhanced through the introduction of frameworks to support shared decision-making that would enable residents to make or contribute to the making of decisions about the way in which their home is run.

Such frameworks could identify:

- the nature of governance arrangement including whether there is a choice
- decision making processes including
  - level of participation desired in decisions about services and supports, support staff, daily life and household costs

- requirements for voting
- disagreements and dispute resolution processes
- complaints processes
- processes for selection of co-residents
- process for selection of support provider including
  - service model
  - staffing
  - service agreement
- process for selection of tenancy management provider
- overall management of household including
  - absences
  - changes in tenancy
  - day to day life
  - household costs
  - risk management and safeguards

## Provider practices

Positive organisational culture and effective staff support are fundamentally protective factors associated with positive outcomes including safety for individuals with intellectual disability in residential services. Conversely, negative organisational culture and hotel style staff support ('we do for them') is associated with negative outcomes.

Many authors<sup>47</sup> stress that the implementation of strategies that move away from procedural and managerial response to incidents of abuse to promote protective cultures will provide an important strategy to mitigate risk to residents of group homes.

The elements necessary to bring about sustainable change in the lives of residents of group homes include:

- 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 the person lives. Any obstacles relating to choosing an alternative place to live if the arrangement does not work out should be minimized by the provider and by the NDIA.
- the house is a *home* with priority given to activities that relate to living an 'ordinary life'. The experience should reflect shared living as experienced by people without disability.
- there is a genuine and effective shared decision-making framework in place, with provision for the involvement of supportive decision-makers, as required.
- staff recruitment is values-based and the team of people focused on delivering support to the resident with evidence based staffing and management practices

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<sup>47</sup> Mandeville and Hanson 2000, Marsland et al, 2007; Robinson and Chenoweth 2011, 2012 as reported in Araten-Bergman et al 2017 *Literature review of best practice supports in disability services for the prevention of abuse of people with disability*.

<sup>48</sup> Bigby and Beadle Brown I(2016) Improving quality of life outcomes in supported accommodation for people with intellectual disability: What makes a difference? *Journal of Applied Research in Intellectual Disabilities* p12

- the home is an organic part of the community, thereby opening those houses that may be 'closed systems'.

The sustainability of such a model of shared living 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; and
- performance measures are developed around the team and the individual.

Any transition of traditional models must be attentive to emotional experience of residents and anticipate incremental rather than transformational change.

Strategies to change provider practice are key. Most providers do not read research, so it is important that research is translated into practical accessible advice, backed by training. National Disability Services (NDS) and the Office of the Public Guardian (Victoria) have developed Guides to Good Group Homes that outline what providers should do and what consumers should look for and ask. NDS runs workshops to help promote these approaches.

It is in the interests of the Scheme to assist participants to have yardsticks by which they can measure the quality of services. Given the IAC view that the registration requirements of the Quality and Safeguards Commission will set a low bar, it would be prudent for the NDIA to develop guides that reflect the evidence based practices identified by Bigby to:

- inform quality assessment processes, staff training and organisational structures and processes used by disability services organisations
- develop information and observation tools for consumers, funders and regulators to support judgements and comparisons in residential services such as the guide to visiting adopted by the Victorian Community Visitor Program.
- monitor services, in research and service evaluation.

## **Section 4: Barriers to the adoption of contemporary options of housing and support**

### **1. Barriers within the NDIS**

#### **Lack of mechanisms to foster innovation**

Innovation is featured in the objects of the NDIS Act and yet the NDIA has not yet been successful in fostering innovation. In the transition to full Scheme roll out, the NDIA, its community partners and providers have been overwhelmed by the depth and pace of change required. The anticipated new market of service responses to facilitate real homes, real work and inclusive leisure have not emerged.

The NDIS discourse includes discussion of key elements that participants need to be more independent and more socially and economically engaged, namely support to maximise independence and support to build informal support. Both these elements are critical for the Scheme sustainability because both contribute to the reduction in costs over the lifetime. In this and many other papers, the IAC has argued that the NDIS approach to these critical elements is superficial and unskilled leaving participants with poor outcomes and placing the Scheme at risk.

The IAC Innovations Reference Group and the SDA Pricing category for innovation are two of many NDIS strategies to promote innovation but a preoccupied market has not responded. A targeted strategy is required to develop and showcase contemporary options. A targeted strategy is also required to demonstrate practice in building informal support, developing personal safeguards and enhancing independence.

#### **Lack of policy clarity**

##### **Separation of housing and support**

There is currently policy confusion about the extent to which the separation of housing and support is and will remain a requirement for SDA payments.

Separating the funding for housing from the funding for support is a most significant step forward in the SDA policy because it enables the spread of models of housing and support that are separate. The provider peak, NDS argues strongly for the NDIA not to prescribe the separation beyond separate service agreements. Advocates argue that without separation, participants who are unhappy with their support are forced to move home.

The NDIA indicates that serious investigation of the practical, legal and financial implications in each jurisdiction will be required to decide the viability of mandating separation.

##### **Status of group homes**



Given the evidence that 'high performing group homes are not that good'<sup>49</sup> and 'people with disability currently living with older parent carers would be better advised to seek personalised support arrangements rather than group home placements'<sup>50</sup>, NDIA policy that preferences alternatives to group homes would send a clear signal to future investors and developers and to participants and their families.

### **Lack of information about contemporary options**

Most participants and their families have little information about more contemporary options for housing and support. They confuse concerns for certainty and safety with the bricks and mortar of shared supported accommodation and discount less restrictive options as 'not for their son or daughter'.

The NDIS accepts its critical role in supporting participants and their families to consider a range of options of housing and support and allocates the Housing Options Package to explore options. Participants and their families are not aware of the assistance provided in both exploring options and in taking the steps required to prepare to move. Increased information about the availability of this support would increase participant confidence that help is available for such an important step.

Failure to ensure participants and their families understand the range of contemporary housing and support options will lead to a growth in demand for traditional shared supported accommodation.

### **Lack of availability of contemporary options**

There are few providers of some of the more contemporary options and of significant concern is the fact that many providers of contemporary supports argue they are not viable in the NDIS environment. Home share arrangements, such as that offered by Community Connections ACT are put at risk under the NDIS because the infrastructure costs to establish a match between a person with disability and a house-mate without a disability are difficult to fund in the current pricing regime<sup>51</sup>.

Other contemporary options such as KeyRing and Shared Lives have very little or no exposure in the Australian market. In particular, the concept of Shared Lives provides a significant innovation in support for people with disability, providing the opportunity for long term, short break and day support.

Failure to grow more contemporary approaches will reinforce the most restricted, more contemporary options.

### **Lack of transition pathways for traditional accommodation**

Providers cannot see a pathway that facilitates the transition of group homes into more contemporary options in a sustainable way. More work is required.

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<sup>49</sup> Bigby, C., Knox, M., Beadle-Brown, J., & 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)

<sup>50</sup> McConkey et al (2015) Relocating people with intellectual disability to new accommodation and support settings: contrasts between personalized arrangements and group home placements, *Journal of Intellectual Disabilities* v20 (2) p116

<sup>51</sup> [The Canberra Times 'Canberra homeshare program fear incompatibility problems with NDIS' 2 July 2017](#)

## Lack of operational clarity

### Support to explore, plan and transition into more independent living

In the past, the *Exploring housing options* package provided Support Coordination to assist the participant and their family to explore housing and support options. The work was often undertaken by staff without the requisite knowledge, skills and experience in housing and support to give confidence that contemporary options were fully explored. Elsewhere, the IAC has argued that the generalist nature of the Support Coordinator role inhibits effective support.

The Innovations Reference Group explored the nature of support required to explore, plan and transition participants into more independent living. Attachment C1 articulates the specialised role and expertise of a time limited Housing Support Coordinator, outlining a phased approach and the skills and expertise required at different points of the journey. The approach includes flexibility to draw on technical assistance that lies beyond the traditional disability sector.

### Support for leadership in individual supported living arrangements

Supported living arrangements with multiple elements of informal and paid support need an identified person 'hold it all together'. It is critical that such a role is identified and supported in a participant plan.

### Price Guide

The current Price Guide is a disincentive to some innovative provision that enables people with disability to live with people without disability. The challenges relate to:

- an inability to seek value for money in offsetting the rent of a home sharer for the negotiated assistance they provide
- the lack of provision for the infrastructure costs associated with volunteer programs

Many participants and providers identified challenges to supporting people with disability to live with people without disability in the NDIS environment. The concern was widely shared, by representatives of people with disability wanting to live in their own home, by providers wanting to transition their group homes into more contemporary arrangements<sup>52</sup> and by providers wanting to head lease a property on the private rental market where a person(s) with disability could live with others who don't have a disability.

All these options move toward contemporary approaches by building informal support and maximising inclusion. The barrier they experience however is the ability to subsidise the rent of the people without disability who provide negotiated informal support to the person with disability.

The NDIA Price Guide is also a barrier to effective capacity building, currently providing a limited menu of options. Capacity building in the area of relationships is a case in point, currently outlining items of behaviour and social skills support. Capacity building

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<sup>52</sup> For example, 3 people with disability living with 2 people without disability in a formerly 5 bed group home

in relationship should be a place to source assistance to build informal support and facilitate social connectedness both of which are key to the sustainability of the NDIS.

### Supported Independent Living (SIL) issues

There are currently a number of issues related to SIL that require clarification to support a contemporary approach. These include:

- when SIL should be used and when Assistance with Daily Living (ADL) should be used
- how to calculate reasonable and necessary support when a participant shares their home with a person without disability
- conflicts of interest when the SIL provider provides Support Coordination and Plan Management
- choice of SIL provider in shared living
- on-call requirements and SIL and SDA
- requirements for reducing the SIL budget.

### Plan management

Many participants who seek more contemporary approaches self-manage their funding to maximise flexibility. Many more participants could be supported toward contemporary options if the use of a plan management provider did not limit their flexibility via price controls.

## 2. Barriers outside the control of the NDIS

### Lack of safe, secure and affordable housing

The lack of safe, secure, affordable housing is a barrier to using contemporary options of housing and support for some participants. As a result many will seek to become SDA eligible. Some will remain in their family home longer than planned and this may lead to increased package size as participants lose skills or fail to develop skills, families experience burn out or participants develop behaviours of concern. Some participants will stay in shared supported accommodation when they could do well in less restrictive and less expensive options. Others will live in suboptimal housing in boarding houses or on the private rental market, having to move continually. This will have cost impacts on the Scheme including repeated home modifications and support associated with relocation and building new networks.

Housing affordability is the responsibility of state and territory governments, including in relation to people with disability and it is clear that many participants, especially those in capital cities will struggle to find affordable housing. Other IAC work in the housing and support series<sup>53</sup> identifies strategies that fall to state and territory governments under the National Disability Strategy including minimum mandatory accessibility standards, targeted social housing allocations for people with disability, increasing the availability of shared equity schemes, requirements on developers as a socially responsible way to increase the availability of affordable housing in mixed

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<sup>53</sup> IAC, 2017 *Barriers to housing and support that will have cost implications for the NDIS*

communities and targeted funds for affordable housing through equitable access to aggregated bond models.

### **Ineffective systems and markets**

There are many inefficient systems and markets that impact on participants accessing contemporary options. The lack of a central repository of information about accessible housing means that accessible housing may be vacant or rented to a person who does not value the access features while a person needing access remains in inappropriate housing. Similarly the lack of mechanisms to find housemates (with and without disability) will mean long vacancies in shared housing (SDA and non SDA), threatening the viability of an option for other residents. The paper recommends mechanisms for more effective matching of properties and home sharers.

## **Section 5: What needs to change to promote contemporary options of housing and support**

### **1. Enhance NDIA capacity to foster innovation**

This paper argues that current practice in delivering elements essential for positive participant outcomes and Scheme sustainability are completely inadequate and calls for a targeted strategy to foster innovation.

The IAC recommends that the NDIA develops an innovation strategy including:

- an Innovation Framework to assess all NDIA activity in terms of its impact on the development of contemporary approaches
- a service development capacity to foster innovation including for participants with complex needs. Service development should focus on piloting, evaluating and growing to scale options that develop:
  - participant independence
  - informal support
  - contemporary options for housing and support that reduce the reliance on 24/7 paid support
  - contemporary approaches to respite
  - contemporary approaches to day options
- undertakes further work to develop pathways to transition traditional services to contemporary approaches in a sustainable way
- an exploration of increased flexibility of participant budgets in relation to outcomes.

### **2. Maximise the independence and safety of participants**

The paper outlined four elements that are required to assist participants to seek and enjoy contemporary options for housing and support. These are support to maximise independence, build informal support and develop personal safeguards and a guide/facilitator/ broker to help the participant develop and sustain the arrangement. All these elements are part of the NDIS discourse but their implementation is ineffective.

The IAC recommends that the NDIA:

- pilots approaches to maximise independence, build informal support and develop personal safeguards
- identifies and supports a lead role in supported living arrangements of people with significant disability where the participant is dependent on a combination of informal, on call and paid support
- preferences Disabled Persons and Family Organisations for capacity building for participants planning to move out of home.

### **3. Stimulate the development of more contemporary options on the ground**

The paper has showcased a number of contemporary options that have little or no coverage in Australia.

The IAC recommends that the NDIA:

- retains the separation of housing and support as a policy imperative consistent with the best possible outcome for participants and requirements of the UN Committee on the Rights of Persons with Disabilities
- uses the innovation capacity to develop pilots to understand the requirements of contemporary approaches in the NDIS context
- precludes the practice of SDA providers requiring a participant to use a specified SIL provider

Immediate steps include:

- enable rent subsidy for home sharers
- include Support Coordination in the plans of self-managing participants who use arrangements alternate to 24/7 paid support
- develop mechanisms that assist participants:
  - to identify properties that meet their access requirements by seeding the development of a centralised repository of information about accessible housing
  - locate people (other participants and people without disability) with whom they may want to home share.

### **4. Provide a clear pathway to transition traditional options**

The paper puts the case for the development of a clear pathway to assist providers to transition traditional group homes into more contemporary options of housing and support including:

- deletes the descriptor 'group homes' from housing for 4 and 5 residents in SDA housing types
- undertakes financial modelling that links SDA, SIL, the support model and participant profile to guide the way in which group homes can be transitioned and to ascertain viable options in the longer term
- undertakes further work to develop clear pathways to demonstrate the way in which providers can transition group homes into more contemporary options of housing and support
- requires SIL providers to implement governance frameworks for decision making in shared accommodation
- showcases processes and practices that demonstrate choice of support providers in a property
- develops a strategy to support families and decision makers of group home residents to consider less restrictive options.

## 5. Improve practice in existing options

17,000 people with disability live in group homes. Evidence presented in this paper indicates that better performing group homes are 'not that good' and recommends that the NDIA take steps to improve practice. Areas for improvement include maximising independence of participants, implementing governance frameworks for shared decision-making, by improving practice and ensuring safeguards.

The IAC recommends that the NDIA

- develops practice guides that establish clear expectations as to practice required
- makes representation to the Quality and Safeguards Commission in relation to the development of 'research into practice guides' and training to promote quality practice
- utilises the Framework of Qualitative Indicators developed by Bigby (or similar)
  - to measure quality for compliance with registration requirements
  - underpin staff training, observation tools and quality assessments.
- requires SIL providers to implement governance frameworks for decision making in shared living
- continues to require that SIL and SDA for participants who live in closed systems be Agency managed to assure use of registered providers
- develops a risk assessment framework for participants with SIL and SDA who are seeking to move to contemporary options of housing and support to determine plan management options
- develops a set of minimum quality and safeguarding requirements for self-managing participants with SIL and SDA.

## 6. Calibrate NDIA systems to support contemporary options

The NDIA policy, operation and practice must be organised to enhance the emergence of contemporary approaches.

The IAC recommends that the NDIA:

- develops the role of a Housing Support Coordinator including flexibility to draw on technical assistance that lies beyond the traditional disability sector
- ensures the identification in the participant plan of a role to hold together the multiple elements of informal and paid support involved when a person with complex disability lives in their own home
- reviews the price guide to remove barriers to the development of contemporary options of housing and support including avenues to build informal support.
- reviews plan management policy to maximise participant support for contemporary approaches including the price limit requirement when using a plan management provider
- showcases contemporary options of housing and support including:

- content e.g. approaches designed to enhance accessibility, facilitate informal and community supports
- process e.g. the process and support to enable participants to take up the option

## 7. Promote the implementation of the National Disability Strategy

Many of the barriers to the implementation of contemporary options of housing and support fall outside the responsibility of the NDIS.

The IAC recommends that the NDIA:

Makes representations to Housing Ministers in relation to:

- the National Construction Code (NCC) including the need for
  - minimum mandatory accessibility standards and
  - uniformity of treatment of relation to people with disability across states and territories
- increasing the availability of shared equity schemes to enable participants a share of ownership in their own homes, affordable rent and the ability to choose the specific property they wish to purchase.
- the need for targeted social housing allocations for people with disability.
- the importance of requirements on developers as a socially responsible way to increase the availability of affordable housing in mixed communities
- the need to provide targeted funds for affordable and accessible housing for people with disability through equitable access to aggregated bond models if adopted.

Makes representation to Minister of Social Services in relation to:

- ensuring the Special Disability Trust enables investment for contemporary options of housing and support
- the need for research into policy options that reduce risks of a secure retirement for those who choose to invest financially in housing for their son or daughter with disability.

Makes representations to the Building Ministers to a national commitment to an access standard in the NCC.

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