

Independent Advisory Council
to the NDIS

Pathway to contemporary options of housing and support

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Introduction

This report explores how the NDIS can promote contemporary approaches to housing and support to enable better outcomes for participants.

This paper is underpinned by 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; enabling NDIS participants 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.

The prevailing models observed in states and territories is of a traditional nature with housing and support linked, and residents having to move house if they are unhappy with the support. The Specialist Disability Accommodation (SDA) model has provided a benchmark for acceptable specialised accommodation options and the phasing out of legacy stock dwellings of more than five people with disability.

For the first time, the NDIS provides participants with the reasonable and necessary support to fulfil a common milestone - moving out of the family home. The demand for housing and support will be greater than ever before. With the current housing affordability issues in Australia, the NDIA, in its unique role as market steward, has the opportunity to enable development of new housing and support models that are 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, the current estimate for the demand of Specialist Disability Accommodation (SDA) is approximately 28,000 participants, to a value of \$700 million per year¹.

The Independent Advisory Council (IAC) is pleased to note that SDA policy has eliminated growth of the poorest performing options through resident number and density restriction requirements. Evidence-based approaches underpin the policy setting requiring separation of housing from support but this is contested with many providers (and now National Disability Services²) 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 living in group homes. Although there is significant variation in the quality of homes, it is unlikely shared supported accommodation transitioned from state and territory systems will provide a strong base on which to build.

The research presented in this paper will provide evidence that more contemporary approaches are needed to facilitate positive outcomes for participants, and encourage sustainability of the Scheme.

This section builds the case for change on the basis that group homes are expensive options that do not derive benefits of more contemporary approaches; and that many group home residents have profiles similar to participants living in less restricted, less costly options. The section also outlines factors in group homes that may 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 options³

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 expenditure is on accommodation and most of this is on group homes⁴. 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. Akin to changing societal views on large residential institutions, group homes are now seen as inconsistent with true life potential, rights of the person and social inclusion of persons with disability. The global disability community has progressed further with innovation, leadership and updated concepts and standards of quality.⁵

A 2015 study of people with intellectual disability relocating from a large residential centre confirmed previous studies of better outcomes for those who moved to more personalised arrangements rather than group homes.⁶

¹ NDIA, (2018) SDA Provider and Investor Briefing

² 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

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

⁴ OPA Guide to visiting group homes p3

⁵ Kendrick, 2017, *Why group homes are no longer optimal: A commentary*

⁶ 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

Moreover, the study found there were significant reductions in staff costs across personalised arrangements. The study also confirmed those with high support needs could be adequately supported in personalised models, including persons with medical conditions and challenging behaviours. These study findings question the future of group homes in a post-de-institutional era, suggesting people with housing goals would be better advised to seek personalised support arrangements rather than group home placements. The reservations for family members/parents around safety, supervision and support for their relatives would need to be addressed.⁷

Many residents have similar profiles to people in less restricted alternatives

A number of studies in Australia and overseas recognise many people in group homes have very similar support needs to those in more flexible personalised arrangements. Longitudinal studies about service users in supported living and group homes, showed approximately one third of group home residents had an Adaptive Behaviour Scale score that fell in a similar range with people in supported living arrangements⁸.

Isolation in group homes can increase risk of 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.”⁹

Abuse and neglect of people with disability has been the subject of numerous inquiries in Australia in the past few years. Reports from the Victorian Parliamentary Inquiry¹⁰ and Australian Senate Inquiry¹¹ provide evidence of the widespread nature of abuse and neglect of people with disability over a long period of time. The reports document criminal physical and sexual assault, verbal and emotional abuse, financial abuse and neglect endangering life. They 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 isolating 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 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.”¹²

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”¹³. People who gave evidence to the Inquiry commented on the increased risk of sexual assault for people who live in residential settings; the prevalence of ‘unexplained’ injuries i.e. bruising; and the failure to respond to concerns raised by staff and families.

⁷ 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

⁸ Bigby, C., Bould, E., & Beadle Brown, J., 2015, Op cit p11

⁹ Ibid p3

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

¹¹ 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](#)

¹² Parliament of Victoria, op cit p36.

¹³ Ibid p36

In May 2017, 100 prominent academics called for the phasing out of placing people with disability together in group homes amid growing reports of neglect and abuse and mistreatment, particularly in group homes¹⁴.

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.”¹⁵

Research identifies institutional or isolating service design, with a large number of support staff, and residents relying on others for intimate personal support or intensive support for challenging behaviour, increases the risk of violence, abuse and neglect¹⁶.

Data from notifications to the Office of the Public Advocate show there are three main factors contributing to violence: “inappropriate placements (particularly, a lack of alternative accommodation); workforce issues (such as lack of training, insufficient staff, high numbers of casualised staff and a lack of leadership); and, cultural issues (particularly tacit acceptance and normalisation of violence and bullying)”.¹⁷

Inappropriate placements

Most current group home residents did not have a choice of 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”¹⁸. Judgements about compatibility of residents compete with a range of other factors including lack of alternatives. Even within the paradigm of choice and control of the NDIS, many believe that until operational processes are well established (e.g. including timeframes for SDA assessment enabling vacancy management) and there are diverse SDA options available, participant choice will be constrained. Strong decision-making frameworks need to give authority to the voice of residents in shared living.

Workforce issues

The casualisation of the workforce in shared supported accommodation services for people with disability is well documented with implications 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 that good staff support is linked to good outcomes. The quality of life of residents is greatly affected by how staff communicate, interact and provide assistance.

Research by Bigby et al.¹⁹ 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 expectations²⁰ into Quality of Life (QOL) outcomes and associated staff practices for people with severe and profound intellectual disability. The research concluded that the better performing group homes were ‘not that good’ with none performing strongly on domains of personal development or interpersonal relations. The research recommended

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

¹⁵ 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*

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

¹⁷ Senate Inquiry Colleen Pearce, Public Advocate, Office of the Public Advocate, Victoria [Page 215](#)

¹⁸ Australian Parliament *op cit* Page 217

¹⁹ 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

²⁰ 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

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. 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.

Inquiries into abuse suggests practices are staff rather than resident centric and put residents at risk. Women in group homes being showered by male support workers in male bathrooms because it is convenient for the support worker²¹ 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 participate in community activities is an example of staff practice that leads to low levels of resident engagement and personal development, and poor outcomes.

Cultural issues

In a review of literature exploring possible causes of abuse, Hutchinson et al.²² 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”.²³

Bigby and Beadle-Brown²⁴ identify five dimensions of culture that are common in group homes and can differentiate resident quality of life outcomes. Table 1 outlines the dimensions for underperforming and high-performing group homes.

Table 1: Dimensions of culture in group homes

| Dimension | Underperforming 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 including social milieu, quality personal care and comfort | “It’s her choice” |

²¹ Australian Parliament op cit Page 236,

²² 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

²³ reported in Bigby & Beadle Brown *Culture in higher performing group homes*

²⁴ 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 | Underperforming group homes | | High-performing group homes | |
|-------------------------------------|-----------------------------|----------------------------------|--|---------------------------------------|
| 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 their group homes have perpetuated dynamics that replicate the culture of residential institutions. That culture emphasises routine over individualisation with 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 attuned to the way the dimensions of culture interact and shape the experience of those living there. The people responsible for running the best performing group homes anticipate or respond to change in the cultural dimensions as needed.

Isolation

A significant proportion of group home residents live and spend their days in 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 show them 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 minimal experience to know whether the way staff treat them is appropriate.

Relationships with people not connected to a service provide a critical safeguard for vulnerable people. Robinson²⁵ 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 peoples’ voices are heard and respected.

In her 2012 study, Bigby²⁶ found 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 homes²⁷. Whilst people living in personalised settings scored higher on the five chosen indicators of social relationships than those living in group accommodation, only one in five increased their social relations as a result of changing their accommodation, stressing the vital importance of authentically building and sustaining informal support.

²⁵ Robinson, S., 2013, Safe at home? factors influencing the safety strategies used by people with intellectual disability, Southern Cross University

²⁶ 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

²⁷ 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

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.

The vast majority of people with a perceived need for 24/7 paid support only need one-to-one support at specific times of the day. The lack of informal or drop in support options for assistance at irregular and unpredictable times means there are few options other than 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, and KeyRing models for irregular support and technology are showcased in this section. They 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 a 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 in areas such as personal care, household tasks and travel. Increasing the person's ability to be alone for longer periods of time can occur through informal support and on-call supports. Peer supports can also enhance the motivation and belief of the person's ability to live in their own home.

Disabled persons and family organisations may be well placed to build capacity 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 create 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 participants²⁸ and the sustainability of the Scheme. Increased informal support is associated with lower package costs as well as heightened relationships reducing social isolation and strengthened safeguards arising from connection to people who care about, not just care for the person.

²⁸ especially in the domains of health and wellbeing and safety

Research findings by Bigby²⁹ 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 references work by Stancliffe³⁰ as to what is required to build and sustain real informal support through intensive, cost effective work. This would fit well in the 'Improved Relationships' support category and there is an opportunity for the NDIA to include this in the support catalogue.

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 has written extensively on this topic³¹ 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 is suggested³² as a threshold for enabling families to feel confident in more individualised, less restrictive and less costly arrangements.

The Quality and Safeguards Framework refers to this as developmental safeguards which support and empower individuals, and includes providing information for decision making, building capacity and strengthening natural supports, where this is their choice.

Effective leadership - Someone holding it together

Supported living arrangements inherently have multiple intertwined aspects of paid and informal support. When developed around a participant, particularly with cognitive impairment, it requires an identified trusted person, a leader, 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 is a key strategy to facilitate the lifestyle of choice and mitigate against risk.

Cocks³³ recognises the importance of leadership in supported living and suggests at least one key person acts upon a clear vision and provides the leadership necessary for the arrangement to be created and sustained. Providers have also identified the importance of this role 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"³⁴.

²⁹ 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

³⁰ Stancliffe, <https://sydney.edu.au/health-sciences/cdrp/pdfs/policy-bulletin-2-retirement-2013.pdf>

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

³² 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

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

³⁴ 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

Home share

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

There are a number of different ways in which home share is facilitated:

- Through the help of family and/or a support agency
- Formal Home Share Programs
- Formal Employee Model (e.g. co-resident model, My Place WA home share program).

Generally, the householder provides free or 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 householder or of My Place on behalf of the householder.

Formal home share services connect householders and homesharers and safeguard, support and monitor the relationships.

The home share model has been extensively evaluated and found to be a positive and effective way of supporting people to live independently. The home share model “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”.³⁵

Target group

Formal home share programs tend to make links for people with mild to moderate support needs. My Place WA, where the homesharer is paid, supports householders 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.

³⁵ The Australia Institute, (2015) *On for young and old, The economics of Homeshare*, Discussion paper, <http://www.tai.org.au/content/homeshare-report>
Accessed 7 July 2017

| | Formal home share programs | Organised by family and/or support provider | Formal Employee (i.e. My Place WA) |
|-------------------------------|--------------------------------|---|------------------------------------|
| Target group People with: | Mild to moderate support needs | Complex disability | Complex disability |
| Payment of rent by homesharer | No | No | No |
| Payment of homesharer | No | No | Yes |

Availability in Australia

Formal home share programs are available in (not an exhaustive list):

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

Many home share 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

Home share programs overcome the perceived need for 24/7 paid support by the use of a volunteer housesharer 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. The homesharer also receives problem solving and mediation support by the 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 home share model

Providers of home share argue the model does not easily translate into the current NDIS. The intention to create more flexibility for these models by removing 'host family' from the NDIA Price Guide, was interpreted as a lack

of support for home share type situations.³⁶ A lack of continuity in support coordination has hindered or discouraged participants from taking this option.

Operationally, confusion exists between the expectation of support provided by the homesharer and the need for additional funded support. Participants in their home share program have reported challenges in securing reasonable and necessary support for personal care and community access.

A provider quote is required rather than the participant's needs examined and funds established using relevant categories i.e. Assistance with Daily living. My Place argues 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 home share relationship. Further, placing home share as a Supported Independent Living (SIL) item means participants cannot self-manage this support.

Establishing a home share market

The Home share model is perceived to be at risk 'because the NDIS does not have a 'clear path' to secure home share support'³⁷. Based on a volunteer approach, Home share business models require resources to set up and support a home share match, akin to SDA providers managing vacancies. The removal of home share from the Price Guide means there is no longer a signal (benchmark) of how providers should consider costs for the establishment, support and monitoring of the match; functions that are fundamental for the volunteer connection.

Some participants have used support coordination to establish a home share match. Experience of a home share provider in the ACT (Community Connections), indicates that participants without support coordination in their plan, may not have sufficient support to mediate the everyday issues that arise in home share relationships. This may result in arrangements breaking down. The number of home share links supported by Community Connection has reduced from 14 to 4 in the two years of the NDIS and the organisation sees it as unethical to establish new participant clients without clarity on how the model fits within the Scheme.

Meeting household rent

The homesharer 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 potential rent subsidy is their reasonable and necessary support. In these situations the subsidy represents significant value for money because the informal support exceeds the amount 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.

Some participants from state and territory schemes for supported living (ACT, NSW, WA and QLD) have offset the rent for a homesharer through reduction in resources for support. A system that allowed participants to report their use of reasonable and necessary support against agreed outcomes, rather than line items, would need to be tested against the legislation.

³⁶ Note: Supports that are price controlled are located in the Price Guide. Supports that are recognised for purchasing remain in the csv file support catalogue. In the 2017/18 Price Guide the following item was removed but it still exists in the support catalogue as a quotable item - 01_036_0115_1_1 Assistance in living arrangements (Host family/alternate family situation)).

³⁷ <http://www.canberratimes.com.au/act-news/-gx0z0y.html>

Shared Lives

Shared Lives³⁸ is a 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 individually match trained and approved carers with people who need their support. The goal of Shared Lives is an ordinary family life, where everyone contributes, has meaningful relationships and are 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. Participants also enjoy other activities during the day. Many participants moving from institutional services are able to do things for the first time in their lives – learn to cook, volunteer, work, make new friends.

The scheme is regulated and reported on by the UK Care Quality Commission. 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 rates Shared Lives as one of the safest and most effective forms of care and support with 96% of participants rating the service as outstanding or very good compared to 66.8% of participants in community services and 63.5% in residential care³⁹.

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 through a retainer rather than hourly rate, with the expectation that the carer provides 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 similar 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 than to find suitable housemates in the home of person with disability.

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

Householder or host 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 home sharers.

³⁸ <http://sharedlivesplus.org.uk/faq/about-shared-lives>
http://sharedlivesplus.org.uk/images/1Launch_copy_Final_The_State_of_Shared_Lives_in_England_-_2016.pdf

³⁹ <https://sharedlivesplus.org.uk>

This makes it financially viable for the householder to dedicate time and effort for the best possible family situation.

Challenges in the NDIS

NDIS funding will require adjustment to facilitate Shared Lives Programs into the Australian market. My Place outlines improvements are required so planners better understand the model, use Assistance with Daily Living rather than SIL to determine support, ensure appropriate reasonable and necessary support for community access, and have flexibility in the participant budget to meet the variable contingencies in a participant's life.

Shared Lives, more commonly known in state systems as Host Family programs, have historically been available in NSW, VIC and SA, largely for children leaving state care. Across these programs there are different arrangements relating to payment coverage, how payments are made to hosts and responsibilities of the service provider in terms of set up, support and monitoring. It has proven difficult to transfer these options into the NDIS and further attention and consideration of how individuals can maintain their living arrangement, which are in most circumstances very positive, is needed. In WA, these options have been developed as a choice for people with an individual funding package, including children leaving care. The extent to which participants and their families across Australia are aware of this option is low.

KeyRing

KeyRing is an approach through a 'supportive housing system' in which 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. The volunteer assists members with their relationship to one another and within their broader community. In addition, the volunteer assists members with housing and tenancy, community access and inclusion, and social support including the development of local peer friendship networks. The volunteer lives in their home rent free in recognition of this negotiated assistance. Paid staff from the agency hosting the KeyRing model provides support to 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 in making connections within their local community. Loneliness, isolation and vulnerability have been factors in tenancy breakdown for people with intellectual disability living independently. People tend 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 or 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 to develop and maintain networks is a major role of the volunteer.

With the high cost and intense pressure on housing, KeyRing in the UK uses support hubs in some areas to replace the volunteer living in the network. These hubs have proven to be an excellent and cost effective alternative and are popular with KeyRing network members because the 24 hour support line means members are never left without help.

Obviating the need for 24/7 paid support

People who use KeyRing tend to be persons with disability with low to moderate support needs for whom a 24/7 carer support would seldom be considered. There are however many current residents of group homes for whom a KeyRing approach would be a feasible option. Access to a 24-hour support hub may also provide a useful approach for a broader range of participants living in the community including with those with complex needs, and participants with Assistance with Daily Living in their plan.

Availability in Australia

A small number of providers in Australia operate KeyRing models. One is Marillac in Victoria <http://marillac.com.au/services/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 unclear, but no examples were given of it not being fulfilled. This suggests, for some people, on-call support may be a necessary element of packages in supported living.⁴⁰

In addition, Bigby found when people move away from 24/7 paid support, they need access to intensive episodic support for occasions when there is escalation of need or a breakdown in informal support. Providers talked about the importance of being able to vary the intensity of support as required⁴¹.

On call

Systems availability 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. Sol Connect,⁴² 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 latest technology, nationwide 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 visits, social interaction and day to day conversations, medication intake, support with anxiety and mental health, ‘clocking in and out’ to ensure the individual always get the support they require when expected, emergency support with health or other issues, monitoring of alerts and alarms including out of hours alarm responders.

⁴⁰ 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

⁴¹ 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

⁴² <http://www.sol-connect.org>

Technology includes provision of motion sensors, bed occupancy monitors, door contacts, GPS and enuresis alarms. Sensor operated cameras provide a visual on specific areas of the house or people present. This allows staff to make contact with the person and, if appropriate, offer remote support options such as a conversation, reminders or prompts, and distraction options such as music, radio or films. Where necessary, the service will dispatch a responder to provide more direct assessment and 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

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

Availability in Australia

Whilst SIL providers may have on-call systems in place for their clients, there are few visible services offering remote irregular and 'just in case' support to people living in their own homes as provided by Sol Connect. There is, however, evidence of growth in the use of technology for monitoring and increased independence.

Annecto⁴³ 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-managed. They offer welfare checks, emergency plan activation, shift replacement, and planned and unplanned assistance outside of regular hours. In the 2016/17 financial year, Annecto 'After Hours' responded to 34,864 calls from, or related to, elderly people and people with a disability or, 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 is 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 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 Project⁴⁴ run by My Place Foundation set out to demonstrate that commercially available, reliable home automation systems available in the wider community could be customised for people with a range of disabilities by competent installers at an economic price.

The project found use of home automation is limited more by the person's imagination than the technical capabilities of home automation systems.⁴⁵ In this project alone, home automation had more than 30 different uses in and around the homes of 21 people with disability.

⁴³ <https://www.annecto.org.au>

⁴⁴ Accessed @ <https://www.myplace.org.au/downloads/HAP.pdf> 11 October 2017

⁴⁵ *ibid*, p2

This project established that 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 experts in home automation systems installation who 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 include:

- Two thirds of installations cost less than \$2,000, with costs ranging from \$3,610 to \$20,760 (the average \$12,463)
- If the home automation system saved a user five hours of support time per week, the average system would pay for itself in one year. This compares to a typical supported disability accommodation package of over \$200k pa or about \$4,000 per week which is 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
 - more 'me time', spending several hours (or even overnight) without any family or carers in the house because of the ease for the person to enter and leave the home, and their ability to alert someone if needed
 - 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 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 each participant committing to six-monthly maintenance visits 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"⁴⁶.

⁴⁶ 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

Availability in Australia

The NDIS supports the use of technology. There are emerging examples of customisable home automation features and integrated technology infrastructure built in new SDA dwellings. There are also sporadic examples of companies facilitating technology packages for people in their home.

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 constraints in using reasonable and necessary support to purchase this enabling technology, particularly where other programs can assist access. Access to advice on setup and training, and support for such technology as a key part of a more complex system to address a participant's goals, is generally considered reasonable and necessary.

SECTION 3: Improving traditional options

Transitioning traditional options

Currently 17,000 participants live in group homes and whilst NDIA projections indicate most growth will be in alternatives⁴⁷, there will be a growth in the number of group homes to 2025.

It is imperative the NDIA 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 would be benefit in providing 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.

The SDA Provider and Investor Brief identifies options of mixed tenancy arrangements. Organisations could use this model to transition a 5-bed group home into supported living where people with disability live with people without disability enabling, for example, three people with disability to share with two 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”.⁴⁸

Modelling by Scope (Aust.) indicates 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 cost savings from sleepover arrangements are sufficient to fully offset rent for people without disability, and therefore enabling sharing of these savings between reduced rent and lower package sizes.

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

- There is a gap in household rent due to reduced or free rent for the person in exchange for support

⁴⁷ The NDIA SDA Provider and Investor Brief notes “smaller” forms of SDA with 2-3 bedroom dwellings are likely to be highest in demand/growth.

⁴⁸ for example, 3 people with disability living with 2 people without disability in a formerly 5 bed group home
<http://www.sbs.com.au/news/dateline/story/my-93-year-old-flatmate>

- SDA Providers can have mixed tenancy arrangements in SDA, however the absence of an SDA payment may reduce motivation for providers to consider this option

These constraints need to be considered in order to incentivise or grow more contemporary housing and support models.

Families of group home residents

Whilst some group home residents do not have engaged families or supporters, many have ageing carers for whom the decision for their family member to reside 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 access flexible 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 the NDIA takes steps to improve practice, and hence, the quality of residents' 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 less restrictive options in operation before making any decisions about the future home of their adult children. With active strategies, some current residents of group homes 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 for people living in group homes. Themes are grouped in relation to what can be expected from the Quality and Safeguards Framework, investment in residents, avenues for shared decision making and provider practices.

Expectations of the NDIS Quality and Safeguards Commission

There is an expectation the implementation of the National Quality and Safeguards Framework (the Framework) will improve practice in disability services including group homes. Importantly, 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 the registration requirements emanating from the NDIS Quality and Safeguards Commission (the Commission) will set minimum standards and will not address the issues of quality canvassed in this paper.

Importantly, the Commission will have a developmental and educational role. The Commission will regulate compliance with Practice Standards. It is understood a Core Module covers rights and responsibilities, governance and operational management, and provision of supports with 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 are 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.

In collaboration with the Commission, the NDIA will have an active role in developmental and preventative safeguards for participants. Section 2 of this paper outlines suggested actions for the NDIA and the Commission to implement developmental and preventive safeguards, and to support participants explore contemporary options.

Given the Framework only applies to registered providers, and given self-managing participants can use unregistered providers, the IAC supports 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 resident vulnerability 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 who have a similar profile and 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 practices should include the above constructs from first plan processes. The Participant Pathway review will improve planning and plan implementation. Targeted strategies are required to ensure effective support for decision-making, the development of informal support and personal safeguards and the management of conflict of interest.

Governance frameworks for shared decision making

Resident choice in group homes could be enhanced through introduction of frameworks to support shared decision-making that would enable residents to make, or contribute to, decisions about the way in which their home is run.

Such frameworks could identify:

- the nature of governance arrangements 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 authors⁴⁹ stress that strategy implementation which moves away from procedural and managerial response to incidents of abuse towards promoting protective cultures, will provide an important approach to mitigate risk to group home residents.

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

- participants actively choose to live in a house that operates with a shared support model. This includes choice of the location and people with whom the person lives, and minimising obstacles relating to choosing an alternative place to live if the arrangement does not work out
- 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
- 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 are focused on delivering support to the resident through evidence based staffing and management practices⁵⁰
- the home is an organic part of the community, thereby opening houses that may be 'closed systems'.

The sustainability of such a shared living model is contingent on:

- the capability of support workers to facilitate group decisions
- the appropriate delegation of decision-making authority to staff
- a shift from operational management to coaching and practice leadership
- performance measures developed around the team and the individual.

⁴⁹ 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*.

⁵⁰ 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

Any transition of traditional models must be attentive to the 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 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 so they can measure the quality of services. It would be prudent for the Commission and 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

Barriers within the NDIS

Lack of mechanisms to foster innovation

Innovation is featured in the objects of the NDIS Act and the NDIA Corporate Plan articulates a role in fostering innovation. The anticipated new market of service responses to facilitate real homes, real work and inclusive leisure will take time to emerge. This is against the current backdrop of the pace of transition and depth of change required.

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 to build informal support. Both elements are critical for Scheme sustainability because both contribute to the reduction in costs over the lifetime.

The IAC Innovations Reference Group and the SDA Support Catalogue are two of many NDIS enablers to promote innovation. 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 infrastructure and support is beyond the current SDA model.

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

Status of group homes

Given the contention that ‘high performing group homes are not that good⁵¹’ and ‘people with disability currently living with older parent carers would be better advised to seek personalised support arrangements rather than group home placements⁵²’, NDIA policy that preferences alternatives to group homes would send a clear signal to future investors and developers, and to participants and their families. In addition, action to drive quality of support in group homes would provide a clear message as to the requirements of shared living under the NDIS.

Lack of information about contemporary options

Most participants and their families have little information about contemporary options for housing and support. They preference familiarity of the group home model and discount less restrictive options as ‘not for their son or daughter’.

The NDIS plays a critical role in supporting participants and their families who have a housing goal to consider a wider range of more independent living options. Participants and their families are not aware of the assistance the NDIS can provide, through NDIA partners or support coordinators, in exploring options and taking the steps required to prepare to move to more independent arrangements. Increased information about the process and availability of support would increase participant confidence to think more broadly about housing options.

In turn, improving participants and their families understanding of the range of contemporary housing and support options will lead to a growth in demand for these models.

Lack of availability of contemporary options

There are few providers of the more contemporary options, and of significant many providers of contemporary supports argue they are not viable in the NDIS environment. Home share arrangements, such as 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 regime⁵³.

⁵¹ 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)

⁵² 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*

⁵³ <http://www.canberratimes.com.au/act-news/canberra-homeshare-program-fear-incompatibility-problems-with-ndis-20170629-gx0z0y>

Other contemporary options such as KeyRing and Shared Lives have very little or no exposure in the Australian disability market. Failure to grow more contemporary approaches will reinforce the most restricted, prevailing housing options.

Lack of transition pathways for traditional accommodation

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

Lack of operational clarity

Support to explore, plan and transition into more independent living

The previous *Exploring housing options* package provided assistance to 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. The Reference Group articulated 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 included 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 to 'hold it all together'. It is critical that such a role is identified and supported in a participant plan.

Price controls and support catalogue

The current NDIA price controls and support catalogue pose challenges 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 in supporting NDIS funded participants to live with people without disability in the community. The concern was widely shared by representatives of people with disability wanting to live in their own home, providers wanting to transition their group homes into more contemporary arrangement⁵⁴, and providers wanting to head lease a property on the private rental market where NDIA participants 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 NDIS participant.

⁵⁴ For example, 3 people with disability living with 2 people without disability in a formerly 5 bed group home

The NDIA Price Guide is also a perceived barrier to effective capacity building through providing a limited menu of options, rather than funded supports with price caps.

Capacity building in the area of relationships highlights the current literal interpretation, outlining items of behaviour and social skills support. Capacity building in relationships should also be promoted in the support catalogue, as a place to source assistance to build informal support and facilitate social connectedness, both of which are key to Scheme sustainability.

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 or 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 delivers 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. There is also a role for third party plan management providers to support the development and demand for contemporary support options that offer value for money services.

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. With limited housing options participants may seek access to SDA or remain in group homes, postpone living away from their family or move to less desirable, less stable alternatives such as boarding housing. Participants are often required to move between these less optimal arrangements with cost implications for the Scheme including repeated home modifications, greater need for living supports, and assistance 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 series⁵⁵ 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 availability of shared equity schemes, requirements for developers as a socially responsible way to increase the availability of affordable housing in

⁵⁵ IAC, 2017 *Barriers to housing and support that will have cost implications for the NDIS*

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

Effectiveness of 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 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, limited mechanisms to find housemates (with and without disability) will mean long vacancies in shared housing (SDA and non SDA), threatening the viability of this option for other residents. The paper recommends the growth of mechanisms for more effective matching of properties and home sharers.

SECTION 5: What needs to change to promote contemporary options of housing and support?

Enhance NDIA capacity to foster innovation

This paper calls for a targeted strategy to foster contemporary approaches and innovation.

The IAC recommends the NDIA develops a strategy including:

- a framework to assess the role and impact of NDIA on the enablement of contemporary approaches and innovation
- articulating a service development capacity to foster innovation, including for participants with complex needs. Service development should focus on research, pilots, evaluation and growth or support of scalable 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
- further work to develop pathways that transition traditional services to contemporary approaches in a sustainable way
- exploring increased flexibility of participant budgets in relation to outcomes.

Maximise the independence and safety of participants

This paper outlined four elements required to assist participants to seek and enjoy contemporary approaches for housing and support. These are support to maximise independence, build informal support, develop personal safeguards and a facilitator/ broker to help the participant develop and sustain the arrangement. All these elements are part of the NDIS discourse but their effectiveness will be proven as part of implementation of the Pathway Review.

The IAC recommends 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 around participants planning to move out of home.

Stimulate development of more contemporary options on the ground

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

The IAC recommends the NDIA:

- retains separation of housing infrastructure 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:

- determine an appropriate funding mechanism for informal/semi-formal supports in homeshare models
- include Support Coordination in the plans of self-managing participants who use arrangements alternate to 24/7 paid support
- promote 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 models
 - to locate people (other participants and people without disability) with whom they may want to home share.

Provide a clear pathway to transition traditional options

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

- reviewing the descriptor 'group homes' from housing for 4 and 5 residents in SDA housing types
- undertaking 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
- undertaking 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
- showcasing processes and practices that demonstrate choice of support providers in a property
- developing a strategy to support families and decision makers of group home residents to consider less restrictive options
- making representation to the NDIS Quality and Safeguards Commission in relation to:
 - requiring SIL providers to implement governance frameworks for decision making in shared accommodation

Improve practice in existing options

Currently, 17,000 people with disability live in group homes. Evidence presented in this paper supports the need for the NDIA to promote and improve practice. Areas for improvement include maximising independence of participants, implementing governance frameworks for shared decision-making, and by improving practice and ensuring safeguards.

The IAC recommends the NDIA:

- develops practice guides that establish clear expectations of required practice
- 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
- makes representation to the NDIS Quality and Safeguards Commission in relation to:
 - the development of ‘research into practice guides’ and training to promote quality practice
 - develops a set of minimum quality and safeguarding requirements for self-managing participants with SIL and SDA
 - utilising 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
 - require SIL providers to implement governance frameworks for decision making in shared living.

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 the NDIA:

- improves planning processes and supports to enable contemporary housing outcomes including by:
 - considering the role of a Housing Support Coordinator incorporating flexibility to draw on technical assistance that lies beyond the traditional disability sector
 - identifying the responsibility for coordination of the multiple elements of informal and paid support involved when a person with complex disability lives in their own home
- reviews price controls to remove barriers for the development of contemporary options of housing and support, including avenues to build informal support
- ensures the current review of the plan management policy supports the use of contemporary approaches including review of price controls when using a plan management provider
- showcases contemporary options and innovation in housing and support including:
 - content (e.g. new or emerging approaches designed to enhance accessibility, facilitate informal and community supports)
 - process (e.g. process and support to enable participants to take up the option).

Promote the implementation of the National Disability Strategy

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

The IAC recommends the NDIA makes representations to:

- Housing Ministers in relation to:
 - the National Construction Code (NCC) including the need for
 - minimum mandatory accessibility standards
 - uniformity in treatment of people with disability across states and territories
 - increasing 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
- the 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
- Building Ministers for a national commitment to an access standard in the NCC.

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Group homes

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