

Challenges in housing and support under the NDIS

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Introduction

At full Scheme roll out, NDIA costs for Supported Independent Living (SIL) and Specialist Disability Accommodation (SDA) will be approximately \$5 billion, will employ approximately 60,000 FTE staff ¹ and represent almost 25% of the cost of the Scheme. Predominantly delivered in group homes and larger forms of shared supported accommodation that do not produce positive outcomes, it is an area of high risk for the NDIS.

This paper provides insights into the need for change. Key NDIA policy issues that impede the provision of high quality options in housing and support include moves away from the separation of housing and support, challenges in SIL, the lack of widespread availability of contemporary living options, the lack of effective support for decision making and the lack of specialisation and independence in Support Coordination.

The need for change: why group homes are not desirable

Group homes bind housing and support into one unbreakable package so that if a resident is unhappy with the support, he/she must move homes. Both SIL and SDA vest control in the hands of the provider in ways that are contrary to the choice and control promised by the NDIS; when one provider delivers both SIL and SDA, the participant is subject to the same control as they experienced pre NDIS.

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, research indicates that the best group homes are 'not that good'. Many residents of group homes have profiles similar to participants living in less restricted and less costly options and group homes are associated with abuse. More contemporary alternatives are simply not widely available in most parts of Australia.

What do we know about group homes?

Group homes lack the benefits of other housing and support options²

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. Though the group home was at one time the leading-edge option for improving lives of people with disability, today group homes are seen as out-dated, harmful and inconsistent with the true-life potentials, human rights and social inclusion of persons with disability. The disability world has pressed onward with further innovation, leadership and updated concepts and standards of quality.³

¹ Summer Foundation

²Bigby, C., Bould, E., & Beadle Brown, J., (2015), Optimising outcomes for people with intellectual disability in supported living arrangements, p12

³ Kendrick, 2017, Why group homes are no longer optimal: A commentary



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. Moreover, the study found that there were significant reductions in staff costs across personalised arrangements and to a lesser extent group homes compared to larger 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-deinstitutional 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.

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.⁶

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."⁷

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 Inquiry⁸ and the Australian Senate⁹ 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.

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.

⁴ 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

⁵ 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

⁶ Bigby, C., Bould, E., & Beadle Brown, J., 2015, Op cit p11

⁷ Ibid p3

⁸ Parliament of Victoria, Family & Community Development Committee *Abuse in disability services* 2016

⁹ 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



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. ¹⁰

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.¹¹

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. ¹² Similar themes are very likely to be prominent among the findings and recommendations from the current Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

Factors in group homes that put people at risk

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 residents, reliance on others for intimate personal support, and receiving intensive support for challenging behaviour.¹³

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.¹⁴

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.*¹⁵ Judgements about compatibility of residents have 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.

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

¹⁰ Parliament of Victoria, op cit p36.

¹¹ ibid p36

¹² ABC News Group homes for people with disability must be phased out to prevent abuse academics say, 18 May 2017

¹³ Robinson, S, 2013, Safe at home? Factors influencing the safety strategies used by people with intellectual disability, Southern Cross University

¹⁴ Senate Inquiry Colleen Pearce, Public Advocate, Office of the Public Advocate, Victoria 🛭 Page 215

 $^{^{15}}$ Australian Parliament op cit Page 217



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 al¹⁶ documents the impact of staff practices on resident quality of life outcomes. The research concluded that even the better performing group homes were 'not that good' with none of the better houses performing strongly on outcome domains of personal development or interpersonal relations.

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 ¹⁷ 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 al¹⁸ 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.¹⁹

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	"It's her choice"

¹⁶ 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

 $^{^{}m 17}$ Australian Parliament op cit Page 236,

¹⁸ 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

¹⁹ reported in Bigby & Beadle Brown Culture in higher performing group homes



Dimension	Under performing group homes		High performing group homes	
			choice 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.

Isolation

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, Bigby²⁰ found that most group home residents had no more than a passing acquaintance with people other than staff or family. Relationships with people independent of a service provide a critical safeguard for vulnerable people. Robinson²¹ 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.

²⁰ 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

²¹ Robinson, S., 2013, Safe at home? factors influencing the safety strategies used by people with intellectual disability, Southern Cross University



The NDIS promise of transformation

The NDIS promised to:

- 1. separate the provision of housing from the provision of support
- 2. support participants to make decisions and be in control of their lives
- 3. promote the provision of high quality and innovative supports
- 4. provide expert guidance to enable participants to explore housing and support options best suited to their goals
- 5. provide expert guidance to 'make it all happen'.

Separation of housing and support

The IAC has long argued for the importance of the separation of housing and support being critical to participant choice and control to ensure that residents dissatisfied with support do not have to move homes. This remains a contested issue with many providers (including National Disability Services²²) exerting pressure to remove the requirement.

The Disability Reform Council commissioned the Social Policy Research Centre Research (SPRC) to conduct research into the *Effectiveness of Supported Living in Relation to Shared Accommodation* ²³ for people requiring 24-hour care.

Key elements of the most effective models identified included:

- separation of housing and support;
- support tailored to each person with a notional budget upon which they could call;
- support provided through a mix of formal and informal support with an investment in developing informal support.

Other research that evaluated individualised packages in NSW ²⁴ in which housing and support were separate, found that all participants experienced positive outcomes with increased choice and decision making about key domains of their lives at the core of the positive outcomes. Results showed that, in particular, self-determination, personal development, social inclusion and physical and emotional wellbeing improved.²⁵ Key facilitators of positive change for people with disability included adequate decision support and flexibility of funding from packages that were not tied to housing.

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
 Social Policy Research Centre, (2007) Effectiveness of Supported Living in relation to Shared Accommodation, at

²³ Social Policy Research Centre, (2007) Effectiveness of Supported Living in relation to Shared Accommodation, at http://www.sprc.unsw.edu.au/research-areas-and-strengths/effectiveness-of-supported-living-in-relation-to-shared-accommodation-56.html

²⁴ Jones A., Purcal C., Meltzer,A., Lutz D., Fisher K., Robinson S., Hill T., Kayess R (2015), Supported Accommodation Evaluation Framework Individual Packages, SPRC Report 10/2015, for the NSW Department of Family and Community Services, Ageing Disability and Home Care, Sydney.

²⁵Jones et al, op cit, p7



Support was provided through combination of paid and informal support and where funding was perceived to be inadequate, people tried to manage costs by sharing with friends and housemates and pooling support funding. Participants in the research reported that they felt happier, more confident and more independent than before (their receipt of the individualised package) and attributed this to both their ability to select preferred activities and support workers suited their age and life stage and the flexibility offered by packages.

The research found that in situations of *incomplete implementation:* where planning had not occurred in a timely way; where goals were not properly structured with support planning and where there was a lack of regular reviews, people were not able to achieve the accommodation arrangement of choice and were left confused and disappointed.

The research recommended that program implementation include the provision of information and decision support for people with disability and families including goal setting, arranging support and funds management, informed by people with disability, suggesting the use of Disabled Persons' Organisations and disability advocacy organisations.

Research by Fisher et al²⁶ exploring how people with disability made choices about who to live with and factors influencing these choices found that people with disability shared housing for three reasons including the economic savings from sharing housing and support costs, the social gains from living with friends and peers and the increased control over support arrangements. A combination of formal and informal support was reported as important for success.

Fisher et al found that people's choices were constrained by material and social circumstances aligning with recent research ²⁷ that people with disability preferred to live alone having had bad experiences of living with others. Not surprisingly, material, social and information resources of family also made a big difference to housing and support outcomes, consistent with the results of other studies. ²⁸

Most participants in the research had intellectual disability, a group most likely to live in group homes and larger congregate settings where they can be subject to lack of choice about who they live with and unsupportive attitudes from staff about moving to new arrangements. ²⁹ The research concluded that under the NDIS, people with high support needs are eligible for funded support but that without careful attention to individual housing needs, the risk remains of forced 'choice' due to lack of availability of suitable housing and inadequate independent support for planning.

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Fisher, K., Purcel C., Jones A., Lutz D., Robinson S., Kayess R (2019), What place is there for shared housing with individualised disability support? Disability and Rehabilitation, https://doi.org/10.1080/09638288.2019.1615562
 Bigby C, Bould E, Beadle-Brown J. Conundrums of sup- ported living: the experiences of people with intellectual disability. J Intell Dev

[&]quot;Bigby C, Bould E, Beadle-Brown J. Conundrums of sup- ported living: the experiences of people with intellectual disability. J Intell Dev Disab. 2017;42:309–319. Reported in Fisher et al (2019) op cit

²⁸ Harrison M. Defining housing quality and environment: dis- ability, standards and social factors. Housing Studies. 2004; 19:691–708. Bigby C. Transferring responsibility: the nature and effect- iveness of parental planning for the future of adults with intellectual disability who remain at home until mid-life. J Intell Dev Dis. 1996;21:295–312.

Wiesel I. Mobilities of disadvantage: the housing pathways of low-income Australians. Urban Studies. 2014;51:319–334.

Soldatic K, van Toorn G, Dowse L, et al. Intellectual disability and complex intersections: Marginalisation under the National Disability Insurance Scheme. Res Pract Intell Dev Disab. 2014;1:6–16. Reported in Fisher et al (2019) op cit

²⁹ Beresford P. Time to get real about personalisation. J Integrated Care. 2008;16:2–4.

Fisher KR, Lutz D, Gadow F, et al. A transformative frame- work for deinstitutionalisation. Res Pract Intell Dev Disab. 2015;2:60–72. Reported in Fisher et al (2019) op cit



Discussion

Separation of housing and support is very important to participants because separation gives the participant the ability to change support provider without having to move house. The Summer Foundation³⁰ argues that the separation of housing and support enables:

- Choice: Separation makes it easier to change, switch or remove supports or services that are not needed without needing to move house or fear that the provider will alter support service provision.
- Accountability: Separation makes it more likely that providers will deliver a good service as they know that tenants have the option of switching providers and that other providers are delivering services to the tenant at home and may advocate on the tenant's behalf to resolve an issue with the organisation.
- Clarity: Separation allows support providers to focus on their core business of supporting people, leaving a more administrative and potentially punitive role for tenancy managers.
- Specialisation: Separation makes it easier to develop expertise in either housing management or support services; allows each organisation to pursue an independent growth strategy that does not require prioritisation of investment across two different business lines; and delivers cost- efficiencies.
- Responsiveness: Separation makes it easier to respond to the needs of people with disability and their families, and being able to better adapt to changes in the chosen market (housing or support services).

The NDIA position on this issue has weakened over time from a previous clear commitment to separation in 2014 to the very weak proposition that service agreements must be 'separable'; not even separate but able to be separated.

Proviso

The aim of separation is to strengthen participant choice and control in an area of life that has the most significant impact on health and wellbeing. There are however limited circumstances in which separation may impede the beneficial impacts foreshadowed in research. These include situations in which separation is considered inappropriate for reasons such as cultural safety or situations in which the practice of separation would prevent houses being well positioned where participants want to live.

The research reported in this paper has implications beyond the issue of separation of housing and support. The research stressed the critical importance of decision supports and effective support with planning and implementation. IAC advice in relation to support for decision-making provides a framework for supporting the NDIA to ensure that participants have the support they need to make or contribute to the making of decisions. Whist good decision

³⁰ Crabb, A, (2017) Separating Housing and Support Services - A Toolkit for Providers. Melbourne: Summer Foundation Ltd.



support cannot completely compensate for the informational, material and social resources some families are fortunate to have, good decision support and good implementation support will ensure more equitable access to contemporary options for more participants.

In addition, IAC advice in relation to Support Coordination is relevant especially the importance of Support Coordinators having the specialised knowledge skills and experience to help participants plan and implement more contemporary approaches. Of equal importance is the independence of Support Coordination from the provider of SIL or SDA, noting the unsupportive attitudes from staff about moving to new arrangements. ³¹ The proviso noted above in relation to separation may also apply in relation to Support Coordination.

Other implications from the research relate to the importance of informal support and flexible funding in sustaining more contemporary arrangements. Whilst the NDIS promises assistance with both, reasonable and necessary support to build or strengthen informal support is not provided. It is hoped that current NDIA work on plan support flexibility will reduce current barriers.

SIL: Current operation

Confusion

Confusion surrounds SIL because participants with apparently similar support needs living in apparently similar arrangements are currently funded in different ways.

SIL is defined by the NDIA as "Assistance in Shared Living Arrangements". Confusion arises when some participants are allocated SIL when living alone which one would anticipate to be funded under "Assistance with daily living". Recent clarification with NDIA staff indicated that a participant living in their own home and funded by SIL is allocated SIL when they a) need 24/7 paid support AND b) are unable to share support because of the significant nature of their support needs. Conversely, 'Assistance with daily living' is allocated to participants living in their own homes with a combination of paid and informal support.

Table 2: Challenges with SIL process and practices

Participant	Process	Challenge
Participants in supported accommodation type programs transitioning into NDIS	Access to SIL: Business as usual because participants are part of a defined program and can document disability	If participant wants to transfer to another house, is treated as a new participant and requires plan review and new SIL quote. This is because SIL is linked to provider not participant.

³¹ Bowey L, McGlaughlin A. Assessing the barriers to achieving genuine housing choice for adults with a learning dis- [40] ability: the views of family carers and professionals. Br J Soc Work. 2005;35:139–148.

Fisher KR, Lutz D, Gadow F, et al. A transformative frame- work for deinstitutionalisation. Res Pract Intell Dev Disab. 2015;2:60–72. Reported in Fisher et al (2019) op cit



Participant	Process	Challenge
Participants seeking SIL for first time (those moving out of family home and those living in boarding houses and	Need evidence that proves eligibility for SIL. If participant supported by informed people, participant may get R&N support for necessary OT assessments Eligibility for SDA does not guarantee eligibility for SIL.	If not well supported may need a plan review for funds for OT assessment for eligibility for SIL. Long wait time for plan review.
SRSs)	Undergo assessment	Long wait lists for OT assessment
	Planner confirms eligibility for SIL	Sometimes additional evidence required but often participant and supporters are unclear of the nature of evidence required
	Once eligibility confirmed, participant seeks SIL provider interested in providing them a service and seeks quote	Can be difficult to locate a SIL provider, especially where participant has complex needs
	If participant wants to live independently or move into SDA but does not have a current offer of housing (into which support would be delivered), the planner generally does not include the person's eligibility for SIL in the plan.	Difficulty in finding a home. Participants require a plan review once they identify a better support arrangement (leads to more wait time)
	SIL provider develops a quote and submits to NDIA.	Participant generally unaware of details of what is covered in quote. VALID reports that their advocates have supported hundreds of people across Victoria who have had no involvement in the development of their SIL quote.
	NDIA assesses the quote and enters into negotiation with the SIL provider	Participants left out of negotiations about their support
	Quote accepted and place in participant plan	Dollar value of quote not documented. No transparency about what is in, what is out, funding is tied to the provider and



Participant	Process	Challenge
		participant must repeat the process if further change sought.
		in further change sought.
	Process is unnecessarily complex causing lengthy delays	Participants spend extended periods in hospital, homeless and with increased physical and chemical restraint while awaiting SIL.

Key additional challenges for participants arising from SIL include:

- The lack of choice and control with all power perceived to rest with the provider
- The lack of transparency of the SIL payment means that participants are unable to hold the provider to account. Examples of tensions related to the lack of clarity in the SIL payment include the availability of support for a holiday separate to house mates where the NDIA indicates that support for holidays is part of the quote and providers indicate they are unable to provide any support when the participant is not 'at home'.
- Support when in hospital

SIL providers developing outdated housing options

SIL providers are shaping the direction of the disability housing market by developing housing options that could never conform with SDA requirements in relation to size and density but can be financed off the back of SIL payments for residents. Importantly, residents in these facilities lack the safeguard of independent community visitors being able to visit. Examples of non-conforming housing include:

Head-leasing and sub-letting

In its submission to the Joint Standing Committee Inquiry on the NDIS into Supported Independent Living, the Office of the Public Advocate (OPA Victoria) reports 3 NDIS participants under guardianship living in properties leased by a provider of core supports. Similar examples have been reported at IAC meetings where in the context of a lack of affordable housing, support providers have purchased houses to serve as group homes for participants who could easily be supported in less restrictive and less costly options. There also appears to be evidence that some SIL providers who own non-SDA shared houses, use the SIL payment to cross subsidise the cost of housing.

Cluster housing and institution like environments

The IAC has heard of large cluster housing developments including St Michael's in Launceston where a provider of core supports is expanding an already large cluster housing environment to house, in one instance 91 residents with disability in many group homes on one property. These developments could never confirm to requirements for SDA builds. The providers however do not seek to enrol the dwellings because SIL and other core support payments enable a model that is financially viable for the provider, without the scrutiny



associated with SDA payments. These cluster builds are designed with an eye to profit more than an eye to the best outcomes of participants.

Proprietors of boarding houses and Supported Residential Services (SRS) become NDIS registered providers

There are a number of proprietors of SRSs and boarding houses who have become registered providers. Their residents tend to be participants with psychosocial disability and acquired brain injury for whom the concept of conflict of interest is not likely to be understood.

The Office of the Public Advocate reports that SRSs and boarding houses offer services of Support Coordination, community access, SIL, SDA and intensive supports for daily living with examples of undue influence on residents to 'choose' the proprietor's new NDIS businesses to spend their money. . SRS proprietors are known to attend planning meetings in which they can act as an advocate for the person without disclosing they are acting as an advocate for their own financial interest.

OPA also reports there may be evidence of SRS proprietors 'double dipping' by using a person's plan funding to pay for services that the participant has already paid for as part of their SRS room and board deducted from the DSP.

SIL providers engaging in anti-competitive practices

Third line forcing

There is an emerging trend of SDA providers pre-selecting the SIL provider for their project. Projects are then marketed to prospective SDA tenants on the basis that they engage the pre-selected SIL provider for their supports. Effectively participants can only choose the SDA house if they accept the pre-selected SIL provider.

SIL provider vacancy guarantees

Office of the Public Advocate notes that SDA providers pre-select SIL providers AND charge the SIL provider with the selection of residents reporting vacancy guarantees and exclusivity payments made by SIL providers to SDA providers.

Conflicts of interest

A very significant proportion of SIL providers also provide Support Coordination and SDA. The inherent conflict of interest is of significant concern. ³²

NDIA policy, reflected in the 'Request for Service: Support Coordination', indicates that it is the NDIA preference that *The Coordinator of Supports should not be the provider of any other funded supports in the plan;* However, this preference is usually waived: *The utilisation of First Plans means that the initial Support Coordinator may be employed by the same provider*

³² The IAC paper on Support Coordination (2018) argued the case for and against avoiding and managing conflict of interest drawing on experience in the UK, US and the Intermediaries Review undertaken for the NDIA by the Boston Consulting Group in 2017.



organisation as delivers other supports. Any potential conflict of interest must be managed by the provider and monitored by the NDIA.

In general, Support Coordination has not provided participants with adequate 'access to information, opportunities and choice and control' as a result of multiple factors. Support Coordination is generally provided to participants by the provider of core or SIL supports introducing a risk that alternatives are not given as thorough an exploration as may be required to contemplate an alternative.

The balance between requirements for independence and perceived constraints of the market has been a contentious issue. Participant advocates argue the avoidance of conflict of interest is essential because most participants with Support Coordination lack the capacity to identify and understand conflict of interest, are not aware of opportunities they have never experienced and feel loyal to what they know. In addition, participant advocates argue that independent Support Coordination is a safeguard that mediates the pressures of: participants who doubt the reliability of mainstream opportunities and hence maximise funded support; and providers who subtly and even subconsciously protect their clients from the uncertainties of mainstream and community services.

National Disability Services (NDS) and the NDIA have argued that the market is not yet sufficiently mature and that a requirement for independence may deplete the market, leading to additional risks for vulnerable participants. The view is put that interests are ubiquitous: the issue is to declare them, recognise the potential for bias and manage conflicting interests, as occurs in the health sector.

The choice and control offered by the NDIS can only make a difference to participants if they are supported to identify and try new options. Where the provider of core and SIL supports provides Support Coordination, most participants 'choose' the familiar, thereby handing their NDIS conferred authority in relation to choice, control and decision making to providers, without even being aware they are doing so.

In this context, the IAC is especially concerned that the NDIA practice of managing rather than avoiding conflict of interest has not been effective for participants who live in shared supported accommodation with few if any unpaid relationships in their lives. There is little evidence that these isolated and vulnerable participants have increased informal support or new mainstream and community opportunities.

Other challenges with SIL

There is a strong view in the advocacy community that the way in which SIL has been designed and implemented is in conflict with objects of the NDIS Act. SIL is seen to stifle:

 opportunities for participants to "exercise choice and control". Participants are generally excluded from meaningful participation in SIL conversations and have little control over decisions such as when they go to bed, take a shower, go to sleep or even have sex in their own bed.



• The SIL payment has thwarted more innovative approaches to support in home, inhibiting the use and acknowledgement of informal support in ways that were enabled in State and Territory systems pre NDIS.

The fact that SIL funds a provider rather than a participant puts it completely out of harmony with other forms of reasonable and necessary support. There is a <u>lack of transparency</u> to enable participants to know what is covered in the SIL quote. This prevents them holding the provider to account for what shared supports are delivered or from seeking recourse if they perceive they are not getting their 'fair share.'.

SIL impedes opportunities for participants to have <u>holidays</u> away from their housemates. The NDIA indicates that participants must use their SIL funding for holidays but practice on the ground indicates that providers are seldom willing or able to individualise the shared support to facilitate the break.

Contemporary options

In 2018, the IAC used a suite of papers to advice the NDIA Board on the topic of contemporary options of housing and support. The papers highlighted contemporary approaches that have some small presence in Australia but are widely used overseas to provide high quality 'innovative' supports that lead to positive, cost effective outcomes for participants. The papers outlined what is required to facilitate contemporary options, the way in which the options obviated the need for 24/7 paid support and the barriers to the development of each option in the NDIS environment.

Options showcased include:

- Home share: a person with disability who is the householder and requires some companionship and some assistance is linked to a homesharer, a person or persons who needs somewhere affordable to live. The links are planned, supported and monitored to ensure quality.
- Shared Lives: a 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.
- Key Ring: establishes 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.
- Approaches to irregular support: services that provide 'irregular support' through the combination of technology and support staff available for call out.

Separation of housing and support is a feature of all contemporary options described above.

In response to the IAC papers, the NDIA established a Contemporary and Innovative Approaches Strategy and is implementing a framework for Individual Living Options.



Support for decision-making

Support for decision-making is important because it enables participants with disabilities that impact on their decision-making ability to make and contribute to the making of decisions that affect their lives. The Objects and Principles of the NDIS Act promise to enable people to exercise choice and control in the pursuit of their goals and in the planning and delivery of their supports. The Intellectual Disability Reference Group and the IAC provided advice on this issue to the NDIA Board in 2016 but nothing was implemented. The issue of support for decision-making will go to the Board in December 2019 with an IAC approach and NDIA response to enable the NDIA to meet its obligations in this area.

Expert Guidance to explore housing and support options

Expert guidance is important because most participants and their families are not yet familiar with housing and support options beyond traditional shared supported accommodation models such as group homes. In the context that group homes are costly and do not deliver good outcomes for participants, the NDIA developed the Exploring Housing Options Package (EHOP), providing approximately 50 hours of Support Coordination to participants to explore and plan for options other than group homes.

The option is no longer available and the NDIS appears to lack a systematic approach to ensure participants seeking housing and support are made aware of options less restrictive and less costly than group homes.

Expert guidance to implement housing and support plans

Expert guidance is critical to assist a participant to establish a home of their own. The NDIA response is to allocate Support Coordination but key challenges relate to:

- Lack of specialisation in Support Coordination so that the provider may not necessarily have the knowledge, skills and experience to complete the work
- Conflict of interest: where participants currently live in group homes, the SIL provider is very often the provider of Support Coordination and experience demonstrates there is no motivation to assist the participant to explore alternate options that may be better suited to the goals and less costly for the NDIS.

Recommendations

The IAC recommends that the NDIA:

 Separates housing and support to strengthen participant choice and control and ensure that participants dissatisfied with support do not have to move. This policy position can be waived for reasons such as cultural safety or because the practice of separation would prevent SDA houses being well positioned.



- Avoids conflict of interest by requiring the provider of Support Coordination to be independent of the provider of SIL (or its affiliate) for participants in closed systems of housing and support in metropolitan areas except where no other suitably qualified Support Coordination provider is available.
- Moves away from SIL to approaches that genuinely support participants to live in a home of their choice: Reference Packages could be an appropriate vehicle to determine support for living and enable participants to use the funds in housing of their choice.
- Reinstates a planned approach to exploring options of housing and support (such as was available through the Exploring Housing Options Package) to ensure real consideration is given to non-shared supported accommodation.
- Takes steps to discourage use of SIL in non-conforming facilities.
- Commissions options for irregular support
- Improves reasonable and necessary support for living to be more transparent and flexible
- Reduces delays on SIL quotes and ensure that participants have an active role in their development
- Ensures access to funding for any assessments required for plan review
- Publishes examples of good practice such as the approach used by Summer Foundation.



References

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

Beresford P. Time to get real about personalisation. J Integrated Care. 2008;16:2-4.

Bigby C, Bould E, Beadle-Brown J. Conundrums of supported living: the experiences of people with intellectual disability. J Intell Dev Disab. 2017;42:309–319. Reported in Fisher et al (2019)

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

Bigby, C., Bould, E., & Beadle Brown, J., (2015), Optimising outcomes for people with intellectual disability in supported living arrangements. Accessed https://www.dss.gov.au/disability-and-carers/optimizing-outcomes-in-supported-living-for-people-with-intellectual-disability 28 October 2019

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

Bigby C. Transferring responsibility: the nature and effectiveness of parental planning for the future of adults with intellectual disability who remain at home until mid-life. J Intell Dev Dis. 1996;21:295–312.

Bowey L, McGlaughlin A. Assessing the barriers to achieving genuine housing choice for adults with a learning dis- [40] ability: the views of family carers and professionals. Br J Soc Work. 2005;35:139–148.

Crabb, A, (2017) Separating Housing and Support Services - A Toolkit for Providers. Melbourne: Summer Foundation Ltd.

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

Fisher, K., Purcel C., Jones A., Lutz D., Robinson S., Kayess R (2019), What place is there for shared housing with individualised disability support? Disability and Rehabilitation, https://doi.org/10.1080/09638288.2019.1615562

Fisher K, Lutz D, Gadow F, et al. A transformative frame- work for deinstitutionalisation. Res Pract Intell Dev Disab. 2015;2:60–72. Reported in Fisher et al (2019) op cit

Harrison M. Defining housing quality and environment: dis-ability, standards and social factors. Housing Studies. 2004; 19:691–708.



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

Jones A., Purcal C., Meltzer, A., Lutz D., Fisher K., Robinson S., Hill T., Kayess R (2015), Supported Accommodation Evaluation Framework Individual Packages, SPRC Report 10/2015, for the NSW Department of Family and Community Services, Ageing Disability and Home Care, Sydney.

Kendrick, 2017, *Why group homes are no longer optimal: A commentary*. Accessed https://www.family-advocacy.com/assets/d673bafd49/Why-Group-Homes-Are-No-Longer-Optimal.pdf 28 October 2019

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

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

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

Parliament of Victoria, Family & Community Development Committee *Abuse in disability services* 2016. Accessed https://www.parliament.vic.gov.au/file_uploads/FCDC - Inquiry into abuse in disability services HtW37zgf.pdf 28 October 2019

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

Social Policy Research Centre, (2007) *Effectiveness of Supported Living in relation to Shared Accommodation, at* http://www.sprc.unsw.edu.au/research-areas-and-strengths/effectiveness-of-supported-living-in-relation-to-shared-accommodation-56.html

Soldatic K, van Toorn G, Dowse L, et al. Intellectual disability and complex intersections: Marginalisation under the National Disability Insurance Scheme. Res Pract Intell Dev Disab. 2014;1:6–16. Reported in Fisher et al (2019) op cit

Wiesel I. Mobilities of disadvantage: the housing pathways of low-income Australians. Urban Studies. 2014;51:319–334.