Inclusion Australia

Home and Living Supports

Background Paper – NDIS Review Engagement Project

August 2023

This paper was prepared by Tracy Wright to support Inclusion Australia's engagement with people living with intellectual disability, their families and allies, and other stakeholders as part of consultations to inform the NDIS Review.

Introduction

Australia is a signatory to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which sets out the fundamental rights of people with disability, including living independently. As a signatory, Australia is obliged to ensure that:

(a) *Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;*

(b) *Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;*

(c) *Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.*

Article 19, UNCRPD

Despite this, people with disability are still at significant disadvantage in choosing where they live, who they live with and who provides their supports.

Inclusion Australia has previously noted in its submission to the NDIS Review on Safeguarding[1] that the people who experience the highest rates of violence, neglect, abuse and exploitation are people with an intellectual disability who have very high support needs. This includes those with complex communication needs, who very often have a range of unmet needs and subsequent experiences of dysregulation, and who very often experience segregation in group homes.[2]

The promise of a better life under the NDIS has not turned into reality for many people with disability. There are clear steps that can be taken to reverse this situation and deliver on the promise. Delay will mean some people will die without having experienced the true benefits of the Scheme. We must ask ourselves and our leaders —if not now, then when?

Working with young people with an intellectual disability earlier to support them in their future planning is crucial to embedding positive outcomes and change about how supports can be delivered in a more proactive approach in the longer term. As well as delivering better participant outcomes, this intentional approach will also increase the sustainability of the Scheme.

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[1] Inclusion Australia. Submission to the NDIS Review—Participant Safeguarding Proposals, p.2. Accessed on 15 July 2023 at https://www.inclusionaustralia.org.au/wp-content/uploads/2023/07/Final-copy_Submission_Participant-safeguarding-proposals-paper_NDIS-review.pdf

[2] McVilly, K., Ainsworth, S., Graham, L., Harrison, M., Sojo, V., Spivakovsky, C., Gale, L., Genat, A., Zirnsak, T. (2022). Outcomes associated with 'inclusive', 'segregated' and 'integrated' settings: Accommodation and community living, employment and education. A research report commissioned by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. University of Melbourne, Australia. Accessed on 15 July 2023.

The problem

People with disability are highly disadvantaged when it comes to accessing suitable home and living supports. In communities across the country there is a lack of accessible and affordable housing, and contemporary/innovative models have been slow to develop. People with an intellectual disability often don't have a voice or choice about where they live or how their support is delivered.

This lack of innovation and its consequential impacts on people with disability was emphasised in the recent *What we have heard* report, a paper detailing the interim findings from the NDIS Review. The paper also highlighted the concerns about the safety of participants, particularly for those who live in Supported Independent Living (SIL) arrangements, and the need for more regulation to ensure the quality of supports. This echoed the findings of the NDIS Quality and Safeguard Commission's own motion inquiry report released in early 2023.

The current ineffectiveness of home and living supports for people with disability also impacts the sustainability of the NDIS, with the cost and number of participants accessing SIL exceeding expectations.

Fundamentally, in its current form housing and living supports are not-for-purpose and are failing people with disability.

SIL providers are 'capturing' participants

After transitioning to the NDIS, most people either remained in their existing group home or moved to another group home, though it is unclear whether this was by choice. SIL quickly became unofficially packaged, where rooms were offered on conditions that residents agreed to purchase SIL services from the provider that leased, or in some cases owned, the building. Some providers also 'vertically integrated' their services, with residents also receiving support coordination, community participation and other services from the same provider.

While in theory individualised funds through the NDIS are intended to provide flexibility and move away from the historical block funding model, in practice participants are effectively 'captured' and locked into services from a specific disability provider.[3]

Lack of genuine choice and control

Many people with an intellectual disability continue to live in 'group home' settings which often replicate small institutions, compounding the barriers to accessing the private market.

People often have little choice and control about where they live or who provides their personal supports, often without regular contact with people other than provider staff. Information about their lives, hopes and dreams, and support needs are communicated via the provider to key people such as NDIS planners, doctors, guardians, support coordinators, behaviour support specialists and allied health practitioners. Many people with an intellectual disability are voiceless.

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[3] Royal Commission into violence, abuse, and exploitation of people with disability, 'Public Hearing Report' Public Hearing 3-The experience of living in a group home for people with a disability

Anyone wishing to change providers or change their home and living supports must overcome multiple barriers and, in many cases, this makes any changes impossible.

Failure to holistically understand and support participants

While the supply of disability accommodation, NDIS SIL funding, and other funded supports are all, ostensibly, directed at helping people with disability to live as independently as possible and enjoy an ordinary life in the community, we know that there is a lack of coordination between these elements or monitoring of if they are working in tangent to help achieve goals important to the individual.

Ensuring the person is an active participant at their planning meeting is critical when decisions about their home and living arrangements are being made. However, we know that in many cases for people with an intellectual disability other people, both formal and informal supports, make these decisions regardless of the capability and capacity of the person. Supported decision-making practices are inconsistently and seldom used in planning, with the NDIA releasing its first Supported Decision Making Policy in April 2023, 10 years after the Scheme commenced.

Further, there is also currently nowhere for participants and their families to go to explore their options and structure their housing which doesn't have a conflict of interest in their decision.

Not only does this disjointed approach prevent opportunities for people with disability, it also undermines the insurance-approach underpinning the NDIS and impacts is ongoing sustainability. For instance, if the right supports are allocated in a young person's plan early enough to investigate options, this would reduce the transition into more expensive models and allow more choice and control, greater independence, and less restrictive living options in the future.

Disjointed systems

Planning by state and territory governments for supply of disability housing occurs independently of the NDIA, and there is no formal link between housing suppliers and support providers. The NDIA supplies funding for housing to about 6 per cent of participants who receive SDA, however supply of SDA accommodation is left entirely to the market. Those who are building SDA houses do not know where participants want to live, and participants have no input as to where SDA houses are being built. This has resulted in both a high level of SDA vacancies in some areas and thin markets in others.

This has the potential to decrease the inclusion of people in their community or mean they need to move away from their community if they have support needs that require a specific accommodation model design.

The NDIA has, until now, relied on the market to identify where vacancies exist. Neither the NDIA nor the NDIS Commission, the market steward under the *NDIS Act*, are otherwise involved in the supply of accommodation. The NDIS Commission found a number of concerning findings in their own motion inquiry which highlighted concerns about the lack of regulation, skills of the workforce to deliver quality services limited contemporary options and flexibility and the lack of consultation with people living in group home models about their home and living preferences.

There are no incentives for either housing suppliers or providers of supports to try new approaches, and no possibility of them coming together to try new combined approaches. Increases in the

supply of disability housing do not necessarily result in increased availability of housing options for people with disability, nor increase their choice and control.

Where to from here?

Expectations must be clear to achieve outcomes

Any new approaches to home and living supports, or the design and funding of supports, would need to offer an attractive value proposition to all stakeholders:

- State and territory governments (as the suppliers of disability housing)

- The NDIS (as the funder of supports)

- Providers delivering the supports (who are integral to the market)

- Participants and their supporters (who will live in the housing and rely on services to meet their support needs and who need quality, choice and control).

There will need to be a cultural change in the thinking of all these stakeholders for the system to change, as well as strong leadership at all levels of government and provider level.

The mindset of everyone in the person's circle of support will also need to change to achieve the outcomes for the person. Family and friends need to have expectations of what the Scheme can deliver – that their family member or friend will receive active supports, be supported to make decisions, and will be included in all aspects of their life and future. This will be especially true for our children and young people. The expectation of having every aspect of your life funded by your NDIS plan is not realistic. So, helping young people to be more independent will be key if the Scheme is to be sustainable.

Providers need to ensure their staff have the right skills, knowledge, and capability to ensure they understand how to implement strong person-centred approaches in their practice, and staff need to understand how to practically include people in decision making on a daily basis.[4] Currently, providers are not expected to show evidence as to how they are actively supporting the person to utilise their abilities and skills in their lives. Passive practice is paid at the same rate as active practice and there is little incentive for providers to switch up to achieve good outcomes for people.

For example, a passive approach would be ensuring a person can access a peer group once a fortnight. An active approach would include ensuring staff are trained in how to communicate with the person and use their skills to communicate with the person and encourage them to be more independent in all aspects of their lives.

An active approach is vital for young people to develop living skills, rather than a 'doing for' approach. It will be important to make sure that funding for community access, participation and capacity building supports are used in ways that young people build their capacity to be more

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[4] Beadle-Brown, Julie, Leigh, Jennifer S, Whelton, Beckie, Richardson, L, Beecham, Jennifer, Bäumker, Theresia and Bradshaw, Jill. (2015). Quality of life and quality of support for people with severe intellectual disability and complex needs. *Journal of Applied Research in Intellectual Disabilities*, online.

independent. We know that if this is done when people are young, the cost of supports later in life will be lower.

There should be expectations on providers to plan and deliver, as well as report on outcomes demonstrating strong links to increased capacity building for young people, otherwise we will continue to see a reliance on paid supports. This approach will have flow-on impacts in other areas of people's lives, including increasing independence and employment opportunities.

What does the evidence say?

Active support
There is strong evidence that staff using active support approaches positively influences the quality-of-life outcomes across the domains of personal development, emotional wellbeing, autonomy, interpersonal relationships, and social inclusion.[5]

Mansell and Beadle-Brown[6] argue that active support is one of the building blocks which need to be in place no matter who is being supported. While this is not always easy to implement, we need to build the capacity of the workforce to use active support and person-centred approaches. This should not be reliant on the number of staff or the amount of money available, but more about how resources are used and how staff are supported to use these approaches in their practice.

We should recognise the importance of appropriately skilled staff, particularly where people are identified as having behaviours of concern and complex needs, emphasise the importance of providing active support consistently, and draw on positive behaviours support strategies if and when active support is not enough to eliminate the behaviour.

Active support for young people is critical in developing their life skills, increasing their opportunity for more independence both in the home and community. This needs to be linked to all aspects of the person's life.

Peer support
Peer support has been researched around the world for several decades and various forms of peer support applications have been credited with a range of beneficial effects. It has become a significant element in the search for improved outcomes that matter to people, and a move towards solution-based approaches that engage them to meet their needs.

The Independent Advisory Council[7] recommended the NDIA consider commissioning Disabled Persons Organisations (DPOs) to deliver activities such as individual planning, capacity building, supporting people to participate and belong and removing barriers in community and mainstream services. We know that most people with an intellectual disability do not have access to individual capacity building supports.

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[5] Bigby, C. (2022) Evidence about Best Practice in Supported Accommodation Services: What Needs to be in Place? A literature review for the NDIS Quality and Safeguards Commission.
[6] Mansell, J., & Beadle- Brown, J. (2012). Engagement in meaningful activity and relationships: an observational measure, Canterbury: Tizard Centre
[7] The Independent Advisory Council in their paper to the NDIA – regarding Peer Support and Disabled Persons and Family Organisation 2017

Peer support models are low cost in comparison to other interventions using paid professionals, however they require some investment. Peer support groups support people with an intellectual disability, the deaf/blind community and others needing support to build self-advocacy skills, knowledge and other social supports. They are active in supporting peers through their lived experience to understand how to navigate the housing, health, and the justice systems. Linking young people to a strong peer network increases their inclusion in the wider community, especially after they leave school and are needing information affecting their future.

A review conducted by the Social Policy Research Centre at UNSW[8] found that despite various approaches to peer support, common values and principles of good practice emerged from the review. The key benefits identified:

- Opportunities for information and knowledge sharing

- Confidence and capacity building

- Social connection and emotional support

- Access to a safe space to share experiences and problem-solve

- Access to positive role modelling and leadership from peers

- Increased participation in community life.

Innovation in the NDIS

Since 2018 the Independent Advisory Council[9] has highlighted the need for innovation in the Scheme, stating that there needed to be a targeted innovation strategy which would:

- Demonstrate new approaches that facilitate, social and economic inclusion, choice, and control.

- Stimulate mainstream and community services to respond to increased demand.

- Support the transition of existing traditional services to services that demonstrate a contemporary approach.

Many participants and families have little or no information about innovative options in home and living supports at the moment. They are likely to confuse concerns for certainty and safety with the bricks and mortar of shared options for day support and home and living arrangements and discount less restrictive options as 'not for their son or daughter'.

People with an intellectual disability and their supporters need accessible information about what alternative options are available for them to consider, otherwise we will continue to see the transition into group home type models.

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[8] NDIS Peer Support Final Report (2019) Ayah Wehbe, Laura Davy, Karen R. Fisher, Sally Robinson, Rosemary Kayess, Christiane Purcal
[9] Independent Advisory Council to the NDIS – Innovation in the NDIS March 2018

Possible solutions

In considering possible solutions or new approaches, we need to ensure there is a holistic approach to services and outcomes for people's lives – looking only at home and living supports without looking at the wider system will limit possibilities and solutions.

Capacity building supports/ community participation – focus on young people

Young people with an intellectual disability need to be supported to explore options for their future independence. They need to be part of their planning meetings, and home and living conversations should be front and centre if that is a goal they wish to explore.

In many cases young people with an intellectual disability have limited opportunities to build life skills using their capacity building and community participation supports. Families and supporters have indicated that they want their young people to develop more independence in their lives, and this will also reduce the reliance on more intensive models of home and living supports.

Employment goals – particularly for young people

Despite the investment by government, the open employment rates for people with an intellectual disability remains low. There should be more conversations with young people at their planning meetings about how they can be supported to gain employment. If people have greater opportunities to gain employment, this provides other alternatives to secure housing in the market, reducing the reliance on more expensive models of home and living supports.

Peer support

Peer support should be seen as a critical aspect of any future model. The benefits of peer support are well known, and the cost is low. If done well, peer mentoring can provide safeguarding, supported decision making, planning support and the development of self-advocacy skills. This provides opportunities for people to explore options through the sharing of local information about housing options are available in their community. Using the lived experience of peers to support others can lead to increased participation in community life and, therefore, reducing a reliance on paid supports.

Currently the NDIS does not fund peer support except through the ILC grants, with no ongoing funding. Local peer support groups should be funded as an additional safeguarding mechanism and support to people.

Active support

Embedding active support approaches into the Home and Living framework will result in increased participation and positive outcomes. If staff are well trained in active support and where needed, positive behaviour support, and use these tools regularly in their practice, there will be positive outcomes for people and a decrease in the number of staff needed to deliver quality services. Strong leadership is also needed to support these practices and achieve long-term outcomes.

Case management

There are times when participants need extra help to manage complex situations in their life. This is especially the case for those whose needs increase suddenly, or who are confronted with crises or disruption in their lives, such as abuse or homelessness.

The NDIA has avoided funding case management until now, largely because it is seen reducing choice and control. However, where a participant needs more intense support this will reduce future costs to the scheme and be more person centred and responsive for the person.

Innovative models

There needs to be a review of what innovation really is in the NDIS context. The use of assistive technology needs to be front and centre of future design thinking. There are missed opportunities if the new technologies are not a requirement of any new property proposals, especially for young people who use technology in their everyday lives. Providers of SDA also need to engage with people with an intellectual disability earlier so that accommodation models can be more thoughtful and fit for purpose.

Conclusion

Although many participants have experienced greater outcomes and increased independence since the commencement of the NDIS, people with an intellectual disability are not necessarily experiencing the same positive outcomes. For people with an intellectual disability still living in group homes their quality of life is still in question so it is critical that the changes needed to ensure the scheme is not only sustainable but delivers on the outcomes for people to live an 'ordinary life'.

We need a considered focus on young people and how the current planning and identified supports are more intentional in their outcomes to support independence in the future.