What place is there for shared housing with individualized disability support?

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ORIGINAL ARTICLE

What place is there for shared housing with individualized disability support?

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ABSTRACT

Background: Individualized funding of disability support services has implications for people's choices about when to share their home. This paper examines how people with disabilities made choices about who to live with and the factors influencing these choices.

Methods: This paper discusses data from interviews with 30 people with mostly intellectual disabilities using individualized support services, 21 interviews with family members, four interviews with service managers, and a focus group with five support workers. The data come from a large evaluation of individualized housing support programs in New South Wales, Australia.

Results: Only some people had the opportunity to choose whether to share and with whom. Their choices were constrained by the range of housing options and their limited experience of them, even when they had support to make choices about shared housing or living alone. In some cases, the choices reflected a conceptualization of people with disabilities as different to other citizens in their rights and expectations about their social arrangements.

Conclusion: The results have implications for information sharing, housing stock, and the need to challenge the positioning of people with disabilities relative to other people regarding choices about where and with whom to live.

➤ **IMPLICATIONS FOR REHABILITATION**

- Many people preferred not to live alone, so as to improve their economic and social circumstances, and their choice and control.
- The choices about shared housing that many people and their supporters made were constrained by their limited experience of housing options or their familiarity with the range of choices made by other people with disabilities.
- Being able to draw on the material, social, and information resources of family made a big difference to their housing choices.
- It raises questions for policy implementation about whether individualized support may lock some people into shared housing arrangements by failing to include housing costs in the individual package.

Introduction

International trends in disability support are toward individualized plans and individualized funding [1]. The goals of this shift are to give people with disabilities more choice and control about their support and their life goals. This has implications also for their living arrangements and housing choices. In Australian states and territories, a variety of individualized funding programs have been introduced over the last three decades [2]. Currently, the Australian federal government is implementing the National Disability Insurance Scheme (NDIS), a new country-wide public entitlement system for disability support based on individual packages (https://www.ndis.gov.au/). The NDIS funds the support a person needs to live in their house – the housing support – but usually not the housing costs [2].

This article explores how people with disabilities in receipt of a pre-NDIS individualized funding package made choices about whether to share their housing and with whom – what were the factors and constraints determining their choices? The article is based on data from an evaluation of individualized housing support programs in New South Wales, Australia, which were intended to facilitate people with disabilities to live in a housing arrangement of their choice and with formal supports that suit their preferences and life goals. Data used for this article included interviews with people with disabilities, family members, and support service managers and workers. The majority of people receiving the housing support packages were people with intellectual disabilities.

The article analyses the data against rights to community living as stipulated in Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) [3] and considers whether programs to support people's options and choices are sufficient to meet the commitments under the CRPD.

The following sections introduce the background about the policy context of individualized funding packages, housing choices, and shared housing. They describe the qualitative methods and present the findings against the factors that shaped people's choices, before drawing conclusions about how program

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implementation considers people's right to community living choices.

Background

Countries around the world have introduced individualized funding programs for disability support [4,5]. Individualized funding usually consists of a personal budget, also called an individual package, which is a certain amount of money allocated to a person [6,7] so they can purchase services that support them to achieve their goals [8,9]. Through individualizing their funding, the person is meant to have more power in planning and customizing their support [8,10,11]. Support services are expected to take a person-centered approach, which places people with disabilities at the heart of decision-making [12]. There is considerable national and international experience of the benefits of an individualized entitlement approach [13], although implementation may be compromised [6,14,15].

The shift toward individualized funding can be interpreted as consistent with people's rights under the CRPD. The CRPD enshrines the right to equal recognition before the law and equal enjoyment of legal capacity of all persons, regardless of their mental or physical capacity [16], and the right to live full lives in their local communities [17]. Article 19 of the CRPD – "Living independently and being part of the community" – envisages that people with disabilities have housing choices. It suggests that people have the opportunity to choose their place of residence and the people with whom they want to live rather than be obliged to live in a particular arrangement. Consistent with this intent, one purpose of an individualized funding package is to support people to move away from group homes or congregate settings into their own home if that is their preference [18]. Like other citizens, they may choose to live alone or to live with an intimate partner, friends or housemates, with or without disabilities.

Despite the fact that many countries have signed and ratified the CRPD and are offering individualized funding packages, people with disabilities experience significant limitations and constraints on their right to housing choices [19]. This is because individualized funding mechanisms are not sufficient by themselves to ensure that all people with disabilities live in housing of their choice. The person may have an individual funding package and effective support services in place, but may not have access to the housing they want.

Researchers have identified a lack of choice for people with disabilities regarding housing options [13,20–22], although it needs to be acknowledged that many people without disabilities also face problems accessing affordable housing, due to low income or other socio-economic disadvantage [23]. Many people with disabilities live in disability-specific group homes, in large congregate settings or in the family home until mid-life or longer due to restricted access to affordable, secure, and appropriately designed housing in the community [13,21,24–26]. Wiesel [27] pointed out that some people with disabilities experience homelessness due to the financial difficulties of entering private housing. Other documented barriers to exercising housing choices are unsupportive attitudes, as well as lack of understanding of the potential of individualized funding, among support workers and family members [28–31]. On the other hand, people with disabilities who have financial and social support from families are often better able than others to pursue independent living goals, as they have the resources to access private rental properties and are less likely to face discrimination [32–34].

Restricted access to the housing market experienced by people with disabilities raises challenges for related programs, such as the Australian transition of disability support services to the NDIS. The NDIS, designed as a national public social insurance scheme, includes individualized funding packages for people with high disability support needs, and information and referral for other people with disabilities [35]. Estimates are that up to 10% of people with disabilities will receive individualized funding packages [36]. While the NDIS offers some funding for specialist disability accommodation (SDA) "for some participants who have an extreme functional impairment or very high support needs" (https://www.ndis.gov.au/specialist-disability-accommodation), most people are expected to find housing in the open market, like other citizens [30]. Shortage of affordable housing, due to progressive funding cuts to social housing – both public and community housing – and other policies that drive up housing costs, impact significantly on people with disabilities [37,38]. This is due to generally lower material resources among people with disabilities and often particular requirements for accommodation design, compared to people without disabilities.

Some people need additional support to make choices about where to live. In particular, people with intellectual disabilities may need the involvement of family carers and additional information and support during the development of housing and support plans [31,39]. Family carers often facilitate decision making [40], including the person's choices about whether or not to share housing after moving out of the family home. In these cases, the relationship between support professionals and family carers can be essential to shaping people's attitudes towards independent living approaches and facilitating choice [20].

While research has explored restrictions on housing choice, as summarized above, the process of how people with disabilities do make choices with regard to moving into their own home with or without someone else has remained largely unexplored. Hence, this article aims to shed light on the question: How do people with disabilities with individualized support packages make choices about who to live with, and what are the factors influencing these choices? The answers have implications for policy about the place of shared or single housing for people with disabilities.

Methods

This article draws on some of the qualitative data collected in 2013 for a broader evaluation of nine housing support programs for people with disabilities in the state of New South Wales, Australia. The broader evaluation used a mixed methods research design to assess the effectiveness of new housing support programs to empower participants to make choices about the supports they required to enable meaningful community inclusion [5]. The research methods of the broader evaluation included a review of program data provided by NSW Government Department of Family and Community Services, Ageing Disability and Home Care; surveys of people with disabilities, family members and service provider managers; interviews with people with disabilities, family members and service provider managers; and a focus group with support workers from the housing support programs.

This article draws on the interviews and a focus group conducted for two of the nine housing support programs: Supported Living Fund (SLF) and Individual Accommodation Support Packages (IASP). These two programs provided individualized housing support packages to people with disabilities. The article

Table 1. Number of interview and focus group participants by housing support program.

	Interviews			Focus group
	People with disabilities	Family	Manager	Support workers
Supported Living Fund	13	5	4	5
Individual Accommodation Support Packages	17	16	–	–

explores the perspectives of people with disabilities, family members and service provider staff about the housing choices and living arrangements available for the people receiving the individualized packages.

Both programs involved individualized recurrent funding and were designed to enable people to create living arrangements that suited their lives and preferences. A key difference between the programs was that the SLF was designed to primarily assist individuals with lower support needs who were interested in transitioning to living in a home of their own, with an average package cost of Aus$50 000 p.a. (£30 000), while the IASP was designed for people with a wider range of support needs who wished to live as independently as possible while maintaining existing support networks. The IASP had a wider funding range [41].

Semi-structured interviews were conducted with 30 people with disabilities receiving an individualized package, 21 family members and four support service managers, and one semi-structured focus group was held with 5 SLF support workers (Table 1). All interviews with people with disabilities and the focus group were done face-to-face, across six locations, both in Sydney and regionally. Some family member interviews were conducted during the fieldwork visits; the others and the manager interviews, by telephone. Fieldwork researchers were experienced in interviewing people with disabilities.

People with disabilities were asked about their current living arrangements, how they came to live there, the help they received and whether any aspect of their lives had changed since receiving the new housing support. Qualitative data collection focused on the experience of service users, included accessible communication, and was informed by a researcher on the team with lived experience of disability.

The interviews were conducted using participatory methods, which are increasingly regarded as best practice in evaluation research [42]. To promote accessibility and inclusiveness of communication, easy read recruitment and interview materials were used, and flexible methods used by the fieldworkers for people who needed or preferred more accessible approaches (e.g. walk-along interviews, conversational stimulus materials, and observation of daily routines). Participants could have a trusted support person with them at the interview.

Family members were asked about the process of changing to the new housing support, how it was working in practice, and any changes for their family member with disabilities or other family members since the support commenced. In addition, four service provider managers were interviewed, and one focus group was conducted with support workers. Data collection from managers and workers focused on their transition to providing individualized housing support and the impact of this change at both an organizational and individual level for the support worker, the person with disabilities and their family.

The recruitment of participants was at arm's length, organized by the funding agency. The research was approved by the University of New South Wales Human Research Ethics Committee (HC13001).

The sample sizes were small (Table 1) and participation was voluntary, limiting generalizability of the evaluation findings to other people with disabilities using these or similar funding packages. However, the cases provided rich experiential data, which is sufficient and appropriate to answer the research questions and inform program improvement.

While the data were collected in 2013, it remains relevant as the transition to the NDIS will continue for several years and will be required to address the implications of individual packages for people's housing choices.

Sample

Thirty people with disabilities participated in an interview, more men than women (Table 2). The age range was 19–59 years (average 33). One participant was from an Aboriginal or Torres Strait Islander background, and two participants spoke a language other than English at home. Most participants had received an individual funding package for less than 12 months (0–30 months; average 9 months). Most of the 30 participants had cognitive impairments, including learning difficulties, acquired brain injury, autism, and some physical impairments.

Most participants chose to have a trusted support person present to assist them to communicate during the interview, even though most of them could express their views verbally. Observational data in the form of non-verbal responses was collected for three participants who had difficulty communicating verbally.

Over half of the participants also had a family member (12) who participated in a family interview. The family interviews were intended to capture a different perspective and supplement the participant interviews. The interviewed service provider managers and support workers did not have known direct links to the people with disabilities sample.

All interview participants were directly asked about housing choices of the people with disabilities, whose experiences were the main focus of the study. Hence, the people with disabilities were asked about their own choices, the family members, about the choices of the person who received the funding, and the service providers, about the choices of people with disabilities who they supported or knew about.

The interviews were thematically coded and analyzed in QSR NVivo qualitative analysis software using a predetermined coding framework based on indicators in the evaluation framework and program logic [43]. These indicators included quality of life outcomes for participants, types of accommodation support provided, and characteristics of the housing support initiative. This paper draws largely from data coded to quality of life outcomes: 'live in the home of your choosing' (material wellbeing) or "live the way you want to" (rights, autonomy).

Limitations of the research were that no IASP service providers took part, and that many of the interview participants with disabilities and family members with an IASP belonged to parent governance groups, who may have unique experiences of the housing support initiative.

Table 2. Demographic characteristics of individualized package participants from interviews, number, and percent.

	n	%
Age		
Under 45 years	24	80.0
45 years and over	5	16.7
Not known	n.a.	n.a.
Total	*30*	*100.0*
Gender		
Male	16	55.2
Female	13	44.8
Not known	n.a.	n.a.
Total	*30*	*100.0*
Aboriginal and Torres Strait Islander background		
Yes	n.a.	n.a.
No	29	96.7
Not known	n.a	n.a
Total	*30*	*100.0*
Culturally and linguistically diverse background		
Yes	n.a.	n.a.
No	28	93.3
Not known	n.a.	n.a.
Total	*30*	*100.0*
Disability		
Intellectual	23	76.7
Other[a]	7	23.3
Total	*30*	*100.0*
Location[b]		
Major cities	26	86.6
Inner regional	4	13.3
Total	*30*	*100.0[c]*
Housing arrangement		
Family home		
Bedroom in house	13	43.3
Self-contained space	n.a.	n.a.
Living alone	3	10.0
Shared housing		
Partner	n.a.	n.a.
Sibling	3	10.0
Friend	n.a.	n.a.
Housemates	5	16.7
Supported housing	n.a.	n.a.
Total	*30*	*100.0*
Number of respondents	30	

Source: Interviews with people using accommodation support options February–August 2013.

Notes: n.a. = Cells smaller than 3.

[a]"Other" includes Specific learning/Attention Deficit Disorder, Autism, Physical, Acquired brain injury, Neurological, Sensory and speech, Psychiatric, Not known.
[b]In the Australian Bureau of Statistics remoteness structure, Major Cities of Australia are areas where geographic distance imposes minimal restriction upon accessibility to the widest range of goods, services, and opportunities for social interaction. In NSW, this includes Sydney, Newcastle, Wollongong and Tweed Heads. Inner Regional Australia is defined as areas where geographic distance imposes some restriction upon accessibility to the widest range of goods, services, and opportunities for social interaction. http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/6261.0.55.001Main%20Features22000–01?opendocument&tabname = Summary&prodno=6261.0.55.001&issue=2000-01&num=&view=.
[c]Percentages do not add up to 100 due to rounding.

Results

The findings describe the living arrangements and aspirations of people with disabilities in the evaluation study. They present the factors that shaped people's choices about where and with whom to live: their preferences about freedom and connections; the adequacy of their support package; family resources; support from service providers; control over the support; and housing affordability.

Living arrangements and aspirations

The people interviewed for the study had various living arrangements (Table 2). Half lived in the family home with their parents, although some had a self-contained, separate space, such as a studio apartment inside the house or a separate flat on the family property.

Others lived in separate housing in the community. This was a rental flat in either private or public housing, or their own apartment or house. People lived alone, with a sibling, a friend or with one or more housemates. Sometimes these living arrangements existed before the individual funding package commenced, while other people moved into their preferred housing after they started receiving the funding.

Most people who lived in separate housing in the community spoke of feeling happy about their housing arrangements, about where they lived and with whom. A few people were unhappy, usually because they lived in an arrangement that was not of their choosing, such as temporary housing, supported housing, or social housing arranged through a disability service.

Two people who lived in their family home spoke about this arrangement as the long-term plan. Both had very high support needs. All others who lived with their parents expressed a goal of moving into their own home, for example:

> [I want] my own house, me cop. Friends allowed. Family not [person laughed]. (SLF, lives in family home)

Some wanted to live by themselves, others were planning to share with their friends or with new housemates. People said they wanted to remain within their local area, where their family, friends and social supports were located. One parent said about their daughter:

> She doesn't want to live … with other people with disability …. She would like to live close to her sister so they can visit each other. (IASP, lives in family home)

Thus, most people in this study wanted to live away from their parents in the community, either alone or sharing with others. Their choices about where and with whom to live were shaped by several interacting factors discussed below, which related to personal preference, family circumstances and the wider policy environment.

Other factors, such as age and geography, were generally less important in shaping housing choices for the people in this study. A minority of interview participants were older (above 45) or lived outside major cities (Table 2). One person belonged to both groups. Overall, their aspirations and experiences were as varied as those of younger and more urban research participants. Some lived with family and some lived in their own place in the community. Most had family support, similar to the younger and more urban participants, and access to differing accommodation options was generally dependent on family circumstances rather than location or age. However, in this small sample, none of the four people who lived outside major urban areas reported difficulties in finding affordable accommodation, whereas several of the Sydney metropolitan residents did.

Factors influencing housing choices

Personal freedom and social connections

Most people had a personal preference about living alone or sharing with others. Some preferred to live alone because they wanted privacy and the freedom to arrange their daily home life however they wished. They spoke about how much they enjoyed their own space. For example:

> It's good [living on my own]. I get to choose what I watch on TV. [The person appeared proud of his flat, he answered the door and offered the researcher a cup of tea on their arrival.] (IASP, community housing)

I wouldn't want to move back home, I feel just free because I live here now. (SLF, private rental)

I like to sneak food and now there is no one to stop me [she smiled]. My Mum used to lock up cupboards in the kitchen, which she can't do anymore. (IASP, apartment purchased by parents)

On the other hand, a few people who lived by themselves felt some loneliness as they did not feel they were part of their local community. For example, the researcher asked an interviewee whether he spent a lot of time on his own, and he said he did, but liked to go out on his own. His mother added:

I feel that he sometimes gets a bit lonely and that it will be good for him to move into the [cluster housing model], so he will have other people around him. (IASP, townhouse purchased by parents)

Several people preferred to share their housing because they wanted the social contact and informal support that housemates could provide, as well as the collective experience of running a household together. For example, a woman had just moved into a three-bedroom apartment that her parents had bought for her to live in, and she was planning to find a flatmate once she was settled (IASP, apartment purchased by parents). At the same time, most people who were living with others felt they had enough privacy. They usually shared the main living areas, but had their own bedroom.

No-one was living with a partner, and most lived, or were planning to live, with long-term friends. Often this worked well. For example, two men had been living together for 20 years in a house that belonged to one of their families. Another young man was planning to move in with a school friend and his support worker. Some found housemates who they liked through advertisements, after they had moved into their home.

Some people who were living with housemates, rather than friends or siblings, wished to have a closer relationship with their housemate than they had; they hoped sharing a place would develop into a friendship, but they also recognized that this could not be forced. For example, a woman who had moved in with someone she knew from high school regretted that her housemate did not often engage with her socially (SLF, private rental).

Some people who aspired to live with others also expected that sharing would make it easier to forge wider social connections in the community. This was often possible with their individualized packages, which gave people flexible support that allowed them to pursue interests outside the home. A father noted how his son had become so busy since receiving his SLF package that the father now had to make a set time to see him:

It limits my options for seeing [my son and his flatmate], which is a good thing, not a bad thing – it's exercising his authority and independence. (SLF, private rental)

It is not clear whether people who expressed a preference for sharing did so because they had also lived on their own and could compare the two options, or whether they reported satisfaction with the only community living arrangement they had ever experienced or been offered. Such information would be available through collecting lifecourse data, which was not part of this methodology. It was clear, however, that some young adults in the study were still experimenting and learning – just like young adults without disabilities. For example, one young woman lived with a flatmate because she wanted companionship, but there was tension between them. The mother said they were trying to resolve the tensions:

We are just so new to this, and the flatmate has never lived away from home either. (SLF, private rental)

Housing support package

It was a common experience among people with lower support needs that their individualized package had made it possible to live more independently. Across both SLF and IASP, many people now had the funding to afford daily, practical support that enabled them to have their own home away from their families. The funding also helped them to develop the domestic and community skills they needed to live independently, including cooking, cleaning, budgeting, and joining educational and community activities outside their home. A few examples:

I always wanted to move out but couldn't do it without the funding … it has changed my life completely. (IASP, apartment purchased by parents)

My [package] is helping me to become independent with the help of support workers. (SLF, lives in family home)

I love doing Meals on Wheels. It's on Tuesdays. I have one of their T-shirts that I have to wear. (IASP, lives in family home)

One parent commented:

We built our house thinking our son would always be with us, and now that might not be the case. We never imagined it could be anything different, so it is quite amazing. (SLF, self-contained space in family home)

However, in preparing to arrange independent housing, many people and families said they needed more information from service providers and governments. For example, it was not clear to them whether extra funding would be provided in the support package to allow for the additional support required when people moved to their new home.

People with higher support needs often viewed the housing support funding as insufficient for living independently. The sister of a person with disabilities described that her brother had a lease on a social housing flat but he was currently living in a hospital mental health unit because the individualized package covered only about a third of the cost of his required 24 h support:

The funding program doesn't fit his needs as it doesn't cover the known cost of his care … now he is back in hospital. The funding was never going to provide a sustainable solution. (IASP, social housing)

One of the participants in the SLF worker focus group described a person with an individualized package who lived on their own for half of the week and moved back into the family home for the second half of the week. The person would love to live solely independently but could not do so due to funding constraints.

Some people considered the possibility of living with other people with disabilities and pooling their support packages in order to ensure everyone's support needs could be met. As one support provider explained:

One particular group [of three people] feel they need four lots of individual funding to have the services they require, but there are only three of them who know each other. So they are looking with trepidation into the process of how they would select another housemate. (SLF manager)

Family resources

Family resources were crucial for most people to achieve their goal to live independently and where and with whom they chose. Resources included financial support with housing costs, which were not covered by the individual funding package, and administrative support with arranging housing or finding flatmates. Parents with high financial capacity extended their home, bought a property for their family member to live in or supplemented

their rent. Some people bought housing with an inheritance. For example, one person said:

> My parents bought this house. I want to stay here for the rest of my life. I am happy here. (SLF)

Families also described how they applied their social skills and life experience to locate suitable rental properties for their family member, negotiate rental agreements, find compatible housemates or manage directly employed support workers. One family, together with their daughter with disabilities, had tailored the support package to facilitate social inclusion in preparation for moving out – she was attending fitness classes and a patchwork course and learning to use public transport – with the view to focus on practical support once she moved into her flat (IASP, apartment purchased by parents).

Support from service providers

Good support from service providers assisted some people to make choices about where and with whom to live, and to achieve and maintain their preferred living arrangement. Providers helped people organize their preferred housing, for example by filling in application forms for social housing or by accompanying people to meet prospective landlords. Support workers also lent practical assistance upon moving in, like unpacking and establishing housework routines. Some provider organizations made the effort to support people from different cultural backgrounds, by training workers in cultural competency and employing workers with compatible cultural heritage.

Where people with disabilities shared housing with others, support workers sometimes helped find housemates with similar interests, or they set up common activities in the shared house, for example having a cards night or watching a football game, to forge social connections.

However, these good practice examples were not common. Many people with disabilities and their families said they needed more information from their providers about housing choices and more support with decision making and administrative processes. As one family member noted:

> It is hard to make decisions when you are not provided with any options. (IASP, social housing)

Control over support arrangements

People with disabilities said an important reason for choosing shared housing was that they wanted more control over their support arrangements. If they shared, control over support became financially possible for these people. Increased control had several dimensions. First, when sharing, people could look for compatible informal support in a flatmate who they already knew and liked – a friend or a fellow student – or who they had purposely selected, like someone of a similar age with similar interests.

Second, if they shared with another person with disabilities they could pool their support packages and share support worker costs, making their funding packages go further. Pooling the cost of support was one reason for choosing parental governance housing arrangements, particularly for people with higher support needs. Numerous family members expressed concern that the amount of funding provided to people with higher support needs was not sufficient to enable the person to live on their own, and hence pooling funds was the only financially viable option (e.g. IASP, lives in family home). One service provider said:

> One client who lives in a 24/7 cluster model utilizes SLF funding for his accommodation but doesn't meet all the requirements, and therefore the service is pooling the funds. (SLF manager)

Third, when people lived in shared housing and had individualized packages, they said they could better control choices about their support workers and about the kind of support they received. A service provider described how two friends with disabilities living together used their SLF packages to choose their support workers, so they gained control over who entered their home. These friends also used their packages to individualize their support. Whereas before they had received the same kind of support at the same time, now they could arrange separate support worker time or separate support workers to pursue their different interests. One of the friends liked fishing, the other preferred going to concerts or football matches. One of their parents said:

> They have come along in leaps and bounds. (SLF, private rental)

Housing affordability

The individual funding packages did not provide a place to live, and many people with disabilities, family members, and service providers mentioned housing affordability as a major barrier to people living in their own home and where and with whom they chose.

Service providers said there was a general lack of affordable, suitable housing close to people's family and friends, especially in the Sydney metropolitan area:

> It has been difficult to implement SLF when housing options are so limited. I am currently working with a client who cannot find affordable rental and is on the Housing NSW wait list. The client has been looking for a home for more than 6 months. (IASP/SLF manager)

Likewise, several parents in Sydney saw housing affordability as a significant barrier to their family member's ability to move out of home, as social housing was limited and rent often unaffordable. For example, one parent said:

> I am worried that while the package provides support for people who live within their family home, I am not sure how people could move out of their family home, especially in Sydney. I feel that there needs to be significant investment into community housing for people with disability. (IASP, lives in family home)

Along with the findings above, this explains why 13 of 30 participants in the study remained in their family home despite receiving individual packages and having aspirations to more independent living.

As mentioned above, where parents had the economic means to manage the housing problem, they often built, bought, or were planning to buy, a private property for their family member, or they supplemented their rent. For example, two guardians bought a house for two men with disability (IASP), and parents bought an apartment for their family member to live in (IASP). Some other parents saw this as the ideal arrangement but could not afford it. Even if parents could afford a solution, this was complex. One mother had considered building a self-contained apartment in the grounds of the family home for her daughter, and she said:

> But the difficulty is, what would happen to my daughter should something happen to me? My daughter's flat would still be part of the property. (IASP, lives in family home)

Housing costs were an important reason for people to share with others. Some did not mind because they also appreciated the social and support advantages of sharing housing, as

described above. For example, the IASP funding had enabled a young woman to move out of home with support. Her parents had purchased an apartment for her, and once she was settled they were planning to find a flatmate to live with her.

Others shared only due to housing constraints. They said they could not afford to live by themselves as their package covered only disability support and their pension covered only living costs. A few people felt that sharing was their only option if they wanted to live independently and that it came at a cost to their privacy, control and available living space. This was particularly the case for people with higher support needs. For example, one young woman felt her flatmate invaded her privacy; and a man who had lived in temporary housing for more than 2 years due to a lack of appropriate long-term housing said he lacked privacy and control.

Discussion

Many people in this research preferred living with other people rather than by themselves. People shared housing because of the advantages they saw: economic savings from sharing housing and support costs; social gains from living with friends or peers; and benefits from having increased control over support arrangements. For sharing arrangements to work successfully, a combination of formal support from providers and informal support (largely from family members) was important.

However, many people made choices about their living arrangements differently to people in the wider community, and their decisions were subject to stronger constraints related to financial resources, suitable housing or disability support. Purchasing a property changed the nature of peoples' choices fundamentally – giving most of these people a sense of security and permanence, but for some it also raised questions about flexibility over time when their needs and preferences changed. These choices were often constrained by material and social circumstances, aligning with recent research findings that people with disability preferred to live alone, having had poor experiences of living with others [44]. One of the problems with the individualized funding models in this study is that most people, particularly those with higher support needs, were not funded at a level that made living independently feasible, and they were, therefore, forced into sharing or remaining in the family home. This has important implications for assessing funding levels under the NDIS and for considering support for families of people with disabilities.

Being able to draw on the material, social, and information resources of family made a big difference to the housing and support outcomes of people with disabilities in this research, consistent with earlier research findings [22,26,27,45]. The choices of people who did not have this level of resources [13] were heavily influenced by cost and availability of housing and support – either on the rental market or vacant places within specialist disability services. Declining availability of social housing (both public and community housing) meant that this option was not open to many people, limiting their options.

Some people with higher support needs reported needing to pool resources and share housing in order to receive an adequate level of daily support. This raises questions about program implementation – whether and how individualized disability support may lock some people into shared housing arrangements by failing to consider housing costs.

The research found that good practice examples from service providers that facilitate people's preferences about sharing were evident, but not routine. In this climate, it is unlikely that the service system will be able to fill the gap in support for people who do not have active family support or access to material resources to purchase housing of their choice [21,34].

Most participants in this research were people with intellectual disabilities. Of all people with disabilities, they are most likely to live in group homes and larger congregate settings, where they can be subject to a lack of choice about who they live with [21,27] and unsupportive attitudes from staff about moving to new arrangements [31,46]. Under the NDIS, people with high support needs are eligible for funded support. However, without careful attention to their individual housing needs, the risk remains of forced "choice" due to lack of availability of suitable housing and inadequate independent support for planning.

Implications

This paper has examined how people receiving individual support packages made choices about who to live with and the factors influencing these choices. The paper analyzed the data against rights to community living as expressed in Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD). Most people in this study wanted to live independently, either alone or sharing with others. Their choices about where and with whom to live were shaped by several interacting factors, which related to personal preference, family circumstances, and the wider policy environment.

The findings showed that not all people with disabilities were able to exercise their right to choose their place of residence and the people with whom they wanted to live, but were rather obliged to live in a particular arrangement. It found that some people chose to live with people they knew, and others were forced to do so. The choices about shared housing that many people and their supporters made were constrained by their limited experience of housing options or familiarity with the range of choices made by other people with disabilities. Even when they were supported to make choices about shared or single housing – be it by family, peers or service providers – availability of housing to meet their preferences continued to constrain their living arrangements. These constraints were largely historically driven, dependent on what was available under earlier disability and housing support systems. To some extent, the constraints continue to reflect a conceptualization of people with disabilities as different to other citizens in their rights, choices, and expectations about their social arrangements.

The findings have implications for program design and for support organizations working with people with individualized funding around their housing choices. Effective programs:

- are responsive to the person's context and preferences – this includes making appropriate housing options available across neighborhoods so people can choose to stay close to their family and community; a range of options allowing single or shared occupancy; and sufficient housing support package sizes to enable the person to live in the community if they choose
- are flexible – e.g. to allow pooling of support funds, or support at unusual times and for unusual activities, such as a fishing trip at dawn
- offer decision making support – ideally from an independent source and in addition to family support
- observe quality standards – e.g. provide easily accessible information about options for the use of funds so that

people and families know what the package can and cannot be spent on

- enable service provider organizations to support people to achieve their housing of choice – through training and funding so providers can e.g. help people fill in application forms, move, or navigate cultural differences
- address the shortage of appropriate, affordable housing for people with disability – this requires a whole of government approach; options include collaborations with public and community housing providers and exploring mechanisms for low-cost mortgages or rent assistance
- de-link housing support for people with disabilities from family support to maximize opportunities for independent living, especially for people without the resources to build or purchase accommodation to support their family member.

These implications are important for the sustainability of the NDIS, which attempts to move towards a universal rights approach to disability support.

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