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Conundrums of supported living: The experiences of people with intellectual disability

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ABSTRACT

Background Dissatisfaction with the inflexibility of the group home model has led to the growth of supported living that separates housing from support and is thought to have greater potential for better quality of life outcomes. Comparative studies have had mixed findings with some showing few differences, other than greater choice in supported living. By investigating service user experiences of supported living this study aimed to identify how the potential of supported living might be better realised.

Method Thirty-four people with intellectual disability participated in 7 focus group interviews and 6 people in an individual interview. Data were analysed using grounded theory methods.

Results Although participants experienced greater choice and control over their everyday lives, they did not feel they controlled the way support was provided and experienced restrictions on lifestyle associated with low income. Despite their use of community places and varied social connections to family, friends, and acquaintances, most experienced loneliness.

Conclusions If the potential of supported living is to be realised, shortcomings of support arrangements must be addressed by, for example, greater consistency of support worker skills, consumer control over recruitment and rostering, and more skilled support to build friendships and manage difficult relationships.

Introduction

Since the early 1980s, social policy in many western countries has sought to further social inclusion of people with intellectual disability and the choice and control they exercise over their own lives (Clement & Bigby, 2010; Mansell & Beadle-Brown, 2012). The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD; United Nations, 2006) effectively regenerated this policy intent in Australia and reframed social inclusion in a rights framework. Despite these policies, people with intellectual disability remain among the most disadvantaged group of people in society, whose overall quality of life is hardly comparable to the general population (Emerson, 2007; Walsh et al., 2010).

Deinstitutionalisation has been one of the most significant strategies to promote social inclusion, and although the closure of large institutions has been completed in the Scandinavian countries, it is yet to be finished in the United Kingdom (UK), United States (US), and Australia (Wiesel & Bigby, 2015). In Australia, small group homes have been the primary model of

service to support people moving from institutions to the community, or moving away from their parents' home (Clement & Bigby, 2010). Although small group homes have superior outcomes to institutions and larger clustered models of supported accommodation, quality of life outcomes have been shown to be variable (Mansell & Beadle-Brown, 2012). The size of group homes (4–6 people), and combination of housing with 24-hour support, means the model has the potential to be inflexible when a person's support needs change, provide more support than necessary, and limit choice about who to live with. In Australia it is clear that some current residents in group homes have the potential to live more independently with comparable quality of life outcomes, and significantly cheaper support costs (Bigby, Bould, & Beadle-Brown, in press; Mansell, Beadle-Brown, & Bigby, 2013; Stancliffe & Keane, 2000).

Dissatisfaction with the cost and inflexibility of group home models, together with reform of service systems in the search for more effective and efficient services, has focused attention on supported living (Productivity Commission, 2011). This is an umbrella term, originally

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conceptualised by Kinsella (1993) as housing and support models with greater potential than small group homes for person-centred support, choice, and control. Kinsella suggested that at the personal level supported living enabled choice about how, with whom, and where to live, and from where and how support is provided; and at the service or system level, supported living separated the provision of housing and support thus providing more flexibility, focused on one person at a time, could be tailored to anyone regardless of their level of disability and was concerned with building social connections. Supported living encompasses a wide variety of different types of housing tenure and support options. For example, in the US it is known as semi-independent living and refers to 1–4 people living together with drop-in paid support from a disability support agency that does not extend to 24-hour support (Stancliffe & Keane, 2000), whereas in England, it can include provision of 24-hour support (Mansell, 2010). Supported living models are increasingly becoming an option in the US (Larson, Salmi, Smith, Anderson, & Hewitt, 2013), UK (Emerson et al., 2001; McConkey, Keogh, Bunting, Garcia Iriarte, & Watson, 2016; Perry, Firth, Puppa, Wilson, & Felce, 2012), and Australia (Stancliffe, 2002). The progressive introduction of individualised funding mechanisms in all Australian states through the National Disability Insurance Scheme (NDIS) between 2016–2019 is widely expected to increase availability of supported living for existing service users in group homes and people on accommodation waiting lists (Productivity Commission, 2011).

There is little evidence about outcomes or the support arrangements that make supported living a better model (Mansell & Beadle-Brown, 2010). Research in the UK and US comparing supported living to group homes and controlling for individual differences of service users found it to be advantageous on quality of life domains of choice and some aspects of social inclusion (most often frequency and variety of community activities), as well as being significantly more cost effective (Emerson et al., 2001; Felce et al., 2008; Howe, Horner, & Newton, 1998; Perry et al., 2012). On other domains, such as safety, regular structured activities, health and money management, research has found poorer outcomes for people in supported living compared to those in group homes (Emerson et al., 2001; Felce et al., 2008; Perry et al., 2012).

An Australian study had similar findings about advantages of supported living compared to group homes (Stancliffe & Keane, 2000). Findings have been mixed about the advantages of supported living for more subjective aspects of social inclusion such as loneliness. Stancliffe and Keane (2000) suggested that early studies in the US indicated that loneliness posed a particular concern for people in supported living, but their study found similar high levels of loneliness in group homes and supported living. However, Stancliffe et al.'s (2007) survey of 1,002 people with mild to moderate intellectual disability in the US found that although loneliness was an issue for half the sample, people living in very small settings (1–3 people) or who had more contact with family and friends reported less loneliness.

In contrast to most other studies of supported living, a large Canadian survey found few differences, other than greater choice and control, between quality of life outcomes for residents in supported living and group homes (Stainton, Brown, Crawford, Hole, & Charles, 2011). The authors suggested inadequate support could explain the failure to realise advantages of supported living found in other studies (Stainton et al., 2011).

Stainton et al.'s (2011) conclusion echoes earlier research in group homes about the significance of support quality to good service user outcomes. Very little research has canvassed the perspectives of people themselves about their experiences of supported living, in terms of what works well, what goes wrong, why, and what might be improved. This paper presents qualitative data from a mixed methods study of supported living in Victoria, Australia. The aim was to explore the experiences of people with intellectual disability in this type of housing and support arrangements to identify how the potential of supported living might be better realised. The research question was: How do people with intellectual disability experience living in supported living arrangements?

Method

Approach

The meaning that individuals give to their experiences of supported living arrangements was the primary concern of this study, which had its foundations in social constructivism, and an interpretative theoretical perspective (Crotty, 1998). The methodology drew on constructivist grounded theory (Charmaz, 2014), and two methods were used to collect data: focus groups and individual interviews. Focus groups provide opportunities for participants to exchange views about common experiences, which can generate more data than an individual interview, particularly where group members are known to each other (Pranee, 2011). Although focus groups also provide the opportunity for peer support, they are less well suited to in-depth exploration of more personal or difficult experiences (Cambridge & McCarthy, 2001). To gain further depth to themes emerging from the focus group discussions, a small number of individual interviews were included in the design.

Recruitment and participants

Word-of-mouth invitations and advertisements were circulated through self-advocacy groups, social housing, and disability support organisations to recruit participants. A letter, inviting participation, was also forwarded by the Victorian Department of Human Services to their clients whose records suggested they had moved from a group home to supported living in the 5 years prior to the study. The advertisements asked organisations to circulate the information among the people they support and to assist anyone interested to contact the researchers. The inclusion criteria were based on Kinsella's (1993) conceptualisation of supported living, as separating housing and support, and Emerson et al.'s (2001) definition as being a household of three or fewer people. Participants were required to be aged over 18 years, self-identify as having an intellectual disability, in receipt of some type of disability service funded through the Department of Human Services, and living in supported living (i.e., living alone, or with a maximum of two other people who were not parents or siblings), in a situation where housing was separated from receipt of support. Following the focus groups six people were selected, to reflect the diversity of participants, and were invited to participate in an interview.

Data collection procedures

Thirty-four people participated in seven focus groups, each with three to eight participants, and six people participated in an individual interview. The focus groups were held in familiar places, such as a common space in an apartment block or the offices of a self-advocacy group, at various locations across metropolitan Melbourne and in two Victorian regional towns. Each was organised to include people who lived in the same locality; many knew each other, either through using the same service provider, or living in the same block. Interviews were held at a place chosen by each participant, which in most instances was their home.

A schedule of open-ended questions was prepared for the focus groups to prompt discussion when necessary. Following introductions, participants were invited to share their experiences and perspectives on supported living arrangements, with prompts such as what was working well and not so well, how their current arrangements compared to previous living situations, how they spent their time and their connections to the community. Questions did not seek detailed information about individuals' circumstances. The groups were co-facilitated by two members of the research team and each lasted between 60 and 90 minutes.

The interviews used a similar open-ended approach and prompts were used to elicit more detailed information about participants' experiences and their support and living arrangements. The interviews were conducted by one member of the team and lasted between 15 and 60 minutes.

The study was approved by the Human Research Ethics Committee of La Trobe University (HEC 2013-007) and conducted in accordance with this approval. Plain English versions of information sheets were provided and a brief verbal explanation of the study. The process of consent was explained prior to focus groups and interviews, and all participants gave either written or verbal informed consent to participate in the study.

Analysis

Both focus groups and interviews were digitally recorded and transcribed. The inductive analysis used grounded theory methods (Charmaz, 2014) and NVivo as a data management and coding tool. The initial coding schema and emerging categories were discussed among all members of the research team and with the project reference group, and refined as the analysis progressed. The reference group included staff from disability service organisations, a housing advocacy group, and two members of their board who had intellectual disability. The focus group data were analysed first, and then the interview data separately, using the a priori analytic codes from the focus groups, although with the possibility of adding additional codes and categories if necessary. Data from the two sources are combined in this paper. To ensure confidentially all names of locations, service users, and staff have been changed.

Findings

The findings are organised into four sections; the first describes participants and their living situations, and the following sections describe their experiences in the three life areas they talked most about: having choice and control, being supported, and being connected.

Characteristics and living situation

Tables 1 and 2 set out sociodemographic data about the participants. The recruitment process did not find any potential participants with high support needs, which meant the participant group was a relatively able group of people who self-identified as having an intellectual disability. There were equal numbers of men and women, who ranged in age from 22 to 70 years, with an average age of 42 years. Most people lived on their

Table 1. Service user focus groups – location and participant numbers.

Location	Participants	Female	Average age (years)
FG 1. Regional – south east	5	3	48
FG 2. Regional – south east	3	2	44
FG 3. Inner west	3	1	55
FG 4. Northern	6	1	41
FG 5. Inner south	4	2	45
FG 6. Regional – north east	8	5	38
FG 7. Outer south Melbourne	5	3	43
Total	34	17	42

own or with one other person. Five people lived with a partner and one person with their child. Their housing arrangements varied and most rented some form of social housing. Private rental and payment of market rent was the least common form of tenure. Twelve people rented housing that had loose ties to a disability service provider and was part of various sized clusters of apartments or units specifically for people with disability. However, even for these participants, support was not provided by the same organisation who managed or owned their housing. For example, several people lived in a block of six units built on the grounds of the day service that provided them with support, but the units were owned and managed by a separate community housing organisation.

Having choice and control

Participants all talked about the greater choice and control they had over their own lives compared to other living situations. Their sense of freedom to make decisions about their lives and do things for themselves seemed to outweigh the restrictions imposed by low income or others controlling their finances, which were mentioned almost in passing by many people and did not feature strongly in the discussions.

Sense of freedom to do your own thing and make up your own mind

All participants were enthusiastic about the freedom supported living situation provided. They had a strong sense they could do their own thing without interference from family or workers. Phrases such as "you can do what you want," "no-one can order me around," and "you don't have to ask" reverberated through the discussions. Participants who had previously lived with either parents or in group homes had similar views about the relative freedom of supported living, saying, for example,

> I've enjoyed it more than anything … even living with my mum 'cause my mum was always telling me to do this, do that, you can't do this, you can't wear that, telling me what I can do and what I can't do and things like that, she was always bossing me about. [FG2, person previously at home with parents]

> I live on my own now and I like it, it's better. Freedom, there's no people dictating to me and telling me what to do … I don't want anyone dictating to me. That's what I like about life. I can come and go as I please … you can live and do what you like. [FG3, person previously in a group home]

As well as enjoying the freedom to make up one's own mind about what to do, participants spoke about their enjoyment of being independent. Rather than resenting having to do things such as domestic tasks, they valued doing tasks for themselves, saying, for example,

> I'm pretty good doing everything for myself, I'm pretty independent and get to work and go to Melbourne, do my own shopping, go to the bank on my own, the Trustees put the money in the bank. [FG1]

> I'm independent and I do everything … Well, I do my own shopping; I just do things. [FG3]

Experiencing restricted options

Despite a unanimous sense of more choice and control over their lives, many people talked about their experiences of restricted options. Reliance on the disability support pension as their main source of income meant participants had little money for discretionary spending on leisure, clothes, or holidays. For example, one participant said,

> Very tight so we don't go out, we don't really do anything, we have to stay home and what little money we do have has to be spent on food … As for clothes

Table 2. Interview participants.

Participant	Location	Gender	Age	Mental health needs	Physical disability	More than three chronic health conditions	Primary support hours a week
Anna	Inner north	F	56	No	Yes	Yes	Up to 2
Sam	Inner west	M	54	Yes	No	No	3–8
Steven	Outer south	M	23	Yes	No	No	3–8
Max	Regional – south east	M	50	No	No	No	Up to 2
Helen	Regional – north east	F	31	No	Yes	No	3–8
Wendy	Outer south	F	57	No	No	No	3–8

shopping everything I wear I bought them years ago and I just have to keep on wearing the same clothes. [FG7]

Steven, who had been employed in the past, and was actively seeking work with the support of a disability employment agency, expressed the frustrations associated with having no job and a low income more forcefully than other participants, saying,

> I used to do karate and go to the gym and do boxing and a bunch of other things, and I was relaxed when I got home because I would then watch some TV and then go to bed. But since I don't have a job I don't do all those hobbies and stuff. I don't relax. I'm stuck here watching crap TV all the time … most of the time I'm just stuck by myself, bored.

Very few participants controlled their own finances fully, and relied on a family member or, in most cases, the State Trustees to manage them. One young woman said, for example,

> I used to have a card but mum took it away from me and said I can't do it anymore because I buy mostly rubbish for myself. Yeah, I want my bank card back. [FG5]

Another person complained about the amount of money that he was allocated from his pension each week, saying,

> Do you know how much I get a week? … every Tuesday, $130 that's spending money and food money … that's all they [State Trustees] are giving me. [FG1]

Being supported

Although most people were generally confident about the support available to them, they also had concerns, that it could be inconsistent, uncertain, abusive, or frustrating. Most were supported informally by family members and used formal services. They relied on both mainstream services, such as general practitioners and local government Home and Community Care services, and disability-specific services, such as "outreach support," day programs, and employment services. Everyone talked about the support worker who "dropped in" at a regular time once or twice a week to help with things such as practical housekeeping and reading correspondence. For example, Ann had a weekly 1-hour visit from a support worker, a cleaner for 2 hours every fortnight, and annual maintenance check from the Home and Community Care service, attended a monthly social group, and was about to have the last of a series of psychologist consultations she had accessed at no cost through her GP's care plan.

Sense of security and help being available

Most participants had positive relationships with support workers, valuing their company as well as practical support. For example, Max said that he had "good support" and liked being able to access his support workers by phone whenever he needed to "chat." He liked his newest support worker being a man because he had a lot of questions about being in a relationship and felt that it was useful to discuss these with another man. Listening was consistently highlighted as a characteristic of good support workers. As Sam said, "they've got to listen to you. If they don't listen to you they're not doing their job properly."

All participants had a strong sense of security – that help would be available from either family or paid support workers should they need it, naming at least one person they could contact to sort out any difficulties. For example, Anna said she generally rings the coordinator of the drop-in service about three times a week, and said, "if I have any problems I usually ring up Kerry." Other participants said,

> I've got family around Victoria; they always help me with everything I want. If I do get some problems I just call mum or dad or I could call Donna and Hatty [workers] to discuss things. [FG6]

> I do a lot of cooking … I do my own clothes shopping. Shoe shopping can be a hassle but my mum helps with that and I guess that's mainly it, but if I need help with something it's either mum or Susie or Roger [workers]. Roger usually does the maintenance around the unit. [FG7]

Uncertainties about support

Participants also had negative experiences of support, many referring to problems with the behaviour of support workers. For example, Sam said in the past he had had "bad ones [who] don't care" and had to complain about one who had fallen asleep at his home. Helen described her worker as her "friend" but said she would like to do more tasks for herself and make more decisions, and that she did not feel listened to. Wendy was positive about her current worker but critical of "strict" and "controlling" previous ones.

Several participants had concerns about the way support arrangements could change, without their knowledge or involvement. Common concerns were not knowing which worker was coming or that it may be someone they had never met. For example, one participant talked about the support she and her co-tenant received:

> They help us with the menus, cleaning, cooking, shopping, any appointments and we just lost a really good support worker … there's a bit up and down at the moment, we don't know who is coming and who is not … so it's been really unsettling … Really they need to ring the day before [tell us] who is going to be on and who's not working … I think this organisation is

not really good enough because we need to know, my housemate and I need to know who is coming. [FG1]

Participants talked about incidents when they had been poorly treated or abused by support workers. Although many of these related to past experiences in institutions or group homes, some were more recent, such as one women who said,

> But I just don't want this carer … She did something that she, which I didn't like, and I had bruises from it and she digged her nails in really hard and I had bruises. [FG1]

People had experienced change to support arrangements without consultation or their agreement. For one man, a reduction of 30 minutes a week meant his shopping had become rushed and some domestic tasks were left undone. The withdrawal of another man's drop-in support between the focus group and interview had left him without practical support to negotiate with another agency. This may have exacerbated the difficulties he experienced that culminated in loss of rent assistance. He said,

> I couldn't fill in the form properly so they said since I didn't fill in the form they can't give me rent assistance … I hate that place … You go in there. They say you have to be there at a certain time. You go there and you'll sit for 40 minutes to get somebody who is trying to rush you as far up as possible and then no help.

Participants whose financial affairs were managed by the State Trustees[1] were frustrated with this body. They had difficulties contacting the office and no consistent person to talk with. One person said, for example,

> [There is a] contact person at Trustees … but now see there's another number and I can't get them, I get [support worker] to ring them … because I can't get them, I can't ring them up, it's different, a hard number too. [FG3]

Overall experiences of support were characterised by inconsistency with support workers changing over time; some of whom were highly valued, while others were controlling, lazy, or did not listen. Although people had a sense help would always be available should they need it, their experiences were of uncertainty, change, and at times frustration.

Being connected

Participants were positive about their social contact with family, people in their locality, at regular activities, or through the use of social media, such as Facebook. On the other hand, many also talked about being lonely, bored, feeling unsafe, and having some difficulties with social relationships.

Diverse weak and strong social ties

Most people were in regular contact with family members, who might be parents, siblings, nieces, nephews, their own children, or a partner. They valued both their concrete help and emotional support. For example, participants said,

> My oldest nephew is 21 next year and my godson was 20 last year and my nieces and nephews are 18 in October so I see them quite often, they pop round and put stuff together. [FG4]

> My brother is coming to do some work for me, my sister asked him. [FG3]

> Elizabeth and I got married in May last year and we both enjoy our work … we enjoy living independently and want to keep doing that … We enjoy being on our own and doing our own thing. [FG4]

Anna was one of the few people with a long-standing relationship to someone without an intellectual disability who was not a paid staff member or family. She spoke to her advocate at a regular time each week, but was clear she was not a friend. Others spoke about their regular connection with friends or acquaintances with intellectual disability:

> I'm good friends with all my work colleagues … They treat me as equal … Sometimes my friend who also works at Safeway come and visit and my other friend he works for the Shire, he comes and visits … My boyfriend, he's just fun to hang around with and he really cheers me up when I'm having a down day. [FG1]

> I might talk to a couple of people throughout the day, on the phone, but I know a lot of people but they're not necessarily friends but acquaintances. [FG4]

Participants were recognised or had brief friendly encounters with neighbours or others in their immediate locality. Sam said that some of his neighbours were friendly and he chatted to one lady in particular about "recycling the rubbish and other stuff." Other people said,

> I say good morning when I go to work, say hello … a bloke said g'day to me the other day, I don't know his name. [FG1]

> At church … well, they are like friends to me, they're really nice and we had a morning tea and really lovely people, really nice. [FG3]

Participation in a mix of regular activities, such as paid or volunteer work, part-time attendance at a disability day program, or membership of a self-advocacy gave shape to people's time, a sense of purpose, and opportunities

for contact with a range of people with and without disability. Talking about how they spent their time, participants said, for example,

> Two days a week in a catering crew … I've got my Salvation Army stuff Thursday, bowling Friday, and three times a week I do my own thing. [FG6]

> I work two days a week at the op shop … I go to mosaic classes two times a fortnight. [FG5]

Their use of public and private facilities, such as gyms, bowling or social clubs, coffee shops, pubs, and churches, also gave people a chance to meet other people. They said, for example,

> I prefer to go out and see people, I don't like hanging around the house all the time, I like to be out and go for a walk or have a drink. [FG1]

> I go out to the local café or go and see a live band or something like that, one of the pubs here or something like that. [FG6]

Being lonely

Despite their presence in community places and a range of activities, many participants talked about being lonely and bored, particularly in the evenings. For example, one participant said,

> I look at telly but I'm sick of being by myself in the night, I'd like to go out for a change, like dancing or singing. [FG3]

Anna described her life as being "very lonely" and talked about how hard it was to go out to social places alone:

> I try to get out but I can't go into the hotel on my own all the time because it's too lonely … Be nice if I could have one or two friends. I'm not asking for too many … Just company. Someone to talk to … It'd be nice if I could talk to someone really nice but ones that are not going to abuse you or be controlling.

She, like several others, had negative experiences of trying and failing to make friends, and being rejected and excluded by the negative attitudes of others:

> I've got a stepbrother but he doesn't want to see me … makes me feel awful because he doesn't really speak to me, he thinks he is better than me … I just feel I want to be wanted. Want people to like me and want to be needed in the world, I just don't want to be with people and friends that don't like me, that's all. I don't ask for much. [FG3]

> I don't have many friends … I used to go to this church … but I had to stop going there because they wouldn't accept me … I tried everything to go up and say hello to them and get mixed up with them and they just don't want to know me. [FG4]

Feeling unsafe and difficulties negotiating social relationships

Both men and women talked about feeling unsafe going out in the evening when it was dark, although no-one gave examples of adverse incidents. They said, for example,

> I just don't like going out too late … you don't know who is hanging about. [FG3]

> I'm not supposed to go out at night it doesn't feel safe. Even going in a taxi, I will not do that at night. [FG1]

Apart from those living in cluster settings, everyone had examples of difficult encounters with door-to-door or telephone sales people. Support workers had provided strategies for dealing with such situations, from blowing a whistle down the phone to pretending they were only a visitor to the house. Participants said, for example,

> Oh, I feel sometimes nervous … They are trying to sell things, I just say no we don't want that, no … and then we get these telephone calls … like they want to sell things. [FG3]

> I had somebody come to the door trying to change the electricity company and I made a fib saying I don't live here, I'm just minding the house. [FG1]

Dealing with neighbours also posed difficulties for some people, who complained about their rudeness and noise. They said, for example,

> I don't like them [neighbours], one stole one of the bins of mine and I said you stole one of the bins, you want to put it back into unit one, she said no, she said that's my bin. [FG3]

> Well, there's a mixture of good and bad neighbours at the flats, bad ones … they stomp on people's ceilings and keep them awake all night … One time I went up there and spoke to him about it, and he threatened to punch me in the face. [FG4]

Participants who had previously lived with a partner, spouse, or co-tenant talked about their difficult experiences of sharing and the benefits of living alone. They said, for example,

> I prefer living on my own but I don't mind sharing, it depends on who I'm actually sharing with because if you're only sharing, you got to make sure that the other person pays their share of the bills otherwise it is not worth sharing. [FG6]

Untapped potential of technology

Everyone had a mobile phone, though not often a smartphone, and knew how to use an iPad and the internet. They talked about using programs such as Skype,

Facebook, and email at various venues such as their parents' home, self-advocacy groups, public libraries, or day programs. One person said,

> I got one [computer] at mum and dad's … I don't have the internet. Yeah, I learnt a bit more [using the internet] when I went to self-advocacy group … We got Skype now … … we can get in contact with people on the computer. [FG1]

Few people had a computer or an internet connection in their own home, apparently due to the cost and difficulties of setting up systems. For example, people said,

> No, I haven't got the internet at home; I think it costs about $100. [FG2]

> We used to have a computer but we used to deal with Dodo [internet provider] and each time we were using it, they'll still charge you though, even though it was turned off and we thought that wasn't right so we had it off altogether. [FG4]

Discussion

Participants were unequivocal about the greater sense of autonomy, independence, and freedom from control by others they experienced in supported living compared to other arrangements. These findings reflect previous studies that have found greater choice and control, the hallmark of supported living in Australia (Stancliffe & Keane, 2000), Canada, (Stainton et al., 2011), the UK (Emerson et al., 2001; McConkey et al., 2016; Perry et al., 2012), and the US (Howe et al., 1998; Tichá et al., 2012). Unlike Emerson et al. (2001), however, we found that most people participated in regular structured activities as well as community activities. We also identified an undercurrent of more negative experiences, tempering people's control over their lives and compromising their quality of life. Some of these, such as vulnerability to exploitation, are similar to previous research about supported living (Emerson et al., 2001; Felce et al., 2008). Our findings are similar to other research that suggests loneliness is an enduring issue for people with intellectual disability (Sheppard-Jones, Thompson Prout, & Kleinert, 2005; Stancliffe et al., 2007). They do not reflect Stancliffe et al.'s (2007) finding that very small-sized living arrangements or social contacts may be associated with less loneliness.

The distinction made between everyday choice and support-related choice used in the US National Core Indicators project (Tichá et al., 2012) is useful in thinking about the experiences of participants in this study. Similar to Tichá et al. (2012), we found higher levels of everyday than support-related choices among people in supported living. Control over their direct support was limited, and its scope and personnel were likely to change. Potentially negative experiences of workers changing were compounded by their inconsistent skills and attitudes. Few people controlled their own money, and many were frustrated about those who supported them to manage it. Low income, and consequent reliance on social housing, restricted choice about where people might live, if they had to share accommodation, and about other aspects of their lives such as leisure or clothing.

The balance and tenor of the focus group discussions suggested choice about everyday life overshadowed or compensated for less support-related choice. Nevertheless, individual choice and control over support forms the bedrock of service system reforms that have introduced markets and individualised funding mechanisms, and lies at the heart of the Australia's NDIS; clearly, there is a long way to go in realising this aim. The present study, like other research, suggests that supported living has greater potential than other models to deliver some aspects of choice, but identified challenges in optimising support-related choice. Disability service systems are unlikely to make significant inroads into the high rates of poverty experienced by people with intellectual disability that mediates some choices (Emerson, 2007), but can address the consistency and quality of support and support worker skills. Participants knew what constituted "good" support: someone who listened, was not controlling, and had high expectations of their capacity to live independently. Reform in the sphere of support for financial and other types of decision-making is likely to occur in response to the rights imperatives for supported decision-making generated by the UNCRPD (United Nations, 2006; Douglas, Bigby, Knox, & Browning, 2015). For example, the state of New South Wales is currently trialling a new approach to support for financial decision-making for people with intellectual disability (http://www.publicguardian.justice.nsw.gov.au). In respect of other types of support, strategies such as more rigorous quality auditing of services, mandated training requirements, and staff selection that draw on the expertise of service users may help to address these issues.

Most but not all people felt they had sufficient practical support with daily living and had a sense of security that help was available anytime they needed it. Whether this latter perception was grounded in reality is not knowable, but no examples were given of it not being fulfilled. This suggests that on-call support is a necessary element of support packages for people in supported living.

Costs of technology and/or lack of support to manage home internet connections were issues not raised in

earlier studies, which is likely due to rapid advances in technology. The implications of poor access to technology stem from a normative perspective of need (Bradshaw, 1972), rather than being strongly felt by participants. Nevertheless, this is important to consider for various reasons: increasingly basic information and transactions such as train and bus timetables, medical appointments, enquiry services, or ticket booking systems are moving online; the availability of programs and apps designed to compensate for cognitive disability, particularly low literacy, is growing, and social media is becoming an important vehicle for socially connecting to others. Support that enables people with intellectual disability to access technology in their homes, as do the majority of Australia's population (Australian Bureau of Statistics, 2013), and use it optimally should be considered in the design of individualised support packages. Support should also raise awareness and enable adults to manage the risks associated with the use of social media as a tool for building social relationships (Caton & Chapman, 2016).

Unlike some other studies of supported living, participants not only made use of community facilities but also were regularly engaged in structured activities. Although frequently present in community and places with opportunities for social interaction, few participants had close friends or people with whom they could go out socially to less structured activities, and many felt lonely. This study suggests that one shortcoming of current support arrangements was the availability of facilitative assistance to enable people to build and maintain close personal relationships or friendships. As Reinders (2002) suggested, a rights perspective has enabled people with intellectual disability to claim formal status as citizens, but much more is required to facilitate friendships, particularly close ones that are important to wellbeing and a vehicle for social inclusion. Although various promising practices are emerging, such as dating services (Ward, Atkinson, Smith, & Windsor, 2013), self-authored spaces (Anderson, & Bigby, 2015), circles of support (Hillman et al., 2013), and local neighbourhood networks (Bigby, Anderson, & Bould, 2015), they lack a strong evidence base about processes used and cost. This type of support, potentially the responsibility of both individualised funding and community capacity-building programs in the NDIS, may run the danger of falling through gaps or may benefit from greater attention in the future.

Finally, negotiating difficult social encounters with a range of people from co-tenants to sales people emphasises the continuing need for individual support and skill development, but also for attention to community attitudes and codes of conduct for sales people. This is something that has been exemplified by exploitative practices of vocational training providers in Victoria, who have used aggressive sales techniques, such as free laptops, to sell educational courses that are likely to be beyond the capacity of many people to complete (Bachelard, Cook, & Knott, 2015).

Conclusion

This small study, conducted in one state of Australia, cannot take account of the different ways support services have developed in different states. Using qualitative methods to explore experiences of people who could communicate using language, it only included people with a mild or moderate level of intellectual disability. The intention was to identify patterns in experiences of supported living to develop propositions about needed improvements to support that can be tested through larger scale research, and with other stakeholders.

This study adds to others that identify the advantages of supported living in terms of choice and the preference of people with intellectual disability to run their own lives. It gives more nuanced insights into issues of choice, highlighting the greater potential of supported living for choice about everyday living compared to choice about support. The finding suggests many people are lonely, lacking close friends despite their community presence and engagement in regular activities, and draws attention to the importance of person-centred support to develop and maintain social relationships. Finally, it identifies the need for support to access and use internet technology at home so that people with intellectual disability are able to access information about essential services in the future, and use social media safely to make social connections and navigate communities.

Note

1. The statutory body that administers finances for people for whom an administrator has been appointed under Victorian Guardianship legislation.

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References

Anderson, S., & Bigby, C. (2015). Self-advocacy as a means to positive identities for people with intellectual disability: 'We just help them, be them really.' *Journal of Applied Research in Intellectual Disabilities*. Advance online publication. doi:10.1111/jar.12223

Australian Bureau of Statistics. (2013). *Household use of information technology, Australia, 2012–13*. Canberra: Author.

Bachelard, M., Cook, H., & Knott, M. (2015, September 16). Vocational education, the biggest get-rich quick scheme in Australia. *The Sydney Morning Herald*. Retrieved April 20, 2016, from http://www.smh.com.au/national/vocational-education-the-biggest-getrich-quick-scheme-in-australia-20150916-gjnqwe.html#ixzz3yWKLQRnl

Bigby, C., Anderson, S., & Bould, E. (2015). *"I might need a hand with that": Enabling mutual support & social connections for people with intellectual disabilities: A report on the Marillac Neighbourhood Connections Programme*. Bundoora, Australia: Living with Disability Research Centre, La Trobe University. Retrieved from http://hdl.handle.net/1959.9/319804

Bigby, C., Bould, E., & Beadle-Brown, J. (in press). Comparing costs and outcomes of supported living with group homes in Australia. *Journal of Intellectual & Developmental Disability*.

Bradshaw, J. R. (1972). The concept of social need. *New Society*, *496*, 640–643.

Cambridge, P., & McCarthy, M. (2001). User focus groups and best value in services for people with learning disabilities. *Health and Social Care in the Community*, *9*, 476–489. doi:10.1046/j.0966-0410.2001.00328.x

Caton, S., & Chapman, M. (2016). The use of social media and people with intellectual disability: A systematic review and thematic analysis. *Journal of Intellectual & Developmental Disability*, *41*, 125–139. doi:10.3109/13668250.2016.1153052

Charmaz, K. (2014). *Constructing grounded theory* (2nd ed.). Thousand Oaks, CA: Sage.

Clement, T., & Bigby, C. (2010). *Group homes for people with intellectual disabilities: Encouraging inclusion and participation*. London, UK: Kingsley.

Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. St Leonards, Australia: Allen & Unwin.

Douglas, J., Bigby, C., Knox, L., & Browning, M. (2015). Factors that underpin the delivery of effective decision-making support for people with cognitive disability. *Research and Practice in Intellectual and Developmental Disabilities*, *2*, 37–44. doi:10.1080/23297018.2015.1036769

Emerson, E. (2007). Poverty and people with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, *13*, 107–113. doi:10.1002/mrdd.20144

Emerson, E., Robertson, J., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., … Walsh, P. N. (2001). Quality and costs of supported living residences and group homes in the United Kingdom. *American Journal on Mental Retardation*, *106*, 401–415. doi:10.1352/0895-8017(2001)106<0401:QACOSL>2.0.CO;2

Felce, D., Perry, J., Romeo, R., Robertson, J., Meek, A., Emerson, E., & Knapp, M. (2008). Outcomes and costs of community living: Semi-independent living and fully staffed group homes. *American Journal on Mental Retardation*, *113*, 87–101. doi:10.1352/0895-8017(2008)113[87:OACOCL]2.0.CO;2

Hillman, A., Donelly, M., Dew, A., Stancliffe, R. J., Whitaker, L., Knox, M., … Parmenter, T. R. (2013). The dynamics of support over time in the intentional support networks of nine people with intellectual disability. *Disability & Society*, *28*, 922–936. doi:10.1080/09687599.2012.741515

Howe, J., Horner, R. H., & Newton, J. S. (1998). Comparison of supported living and traditional residential services in the state of Oregon. *Mental Retardation*, *36*, 1–11. doi:10.1352/0047-6765(1998)036 < 0001:COSLAT > 2.0.CO;2

Kinsella, P. (1993). *Supported living: A new paradigm*. Manchester, UK: National Development Team.

Larson, S., Salmi, P., Smith, D., Anderson, L., & Hewitt, A. (2013). *Residential services for persons with intellectual and developmental disabilities: Status and trends through fiscal year 2011*. Minneapolis, MN: Research & Training Center on Community Living, Institute on Community Integration/University Center for Excellence in Developmental Disabilities.

Mansell, J. (2010). *Raising our sights: Services for adults with profound intellectual and multiple disabilities: A report by Professor Jim Mansell*. London, UK: Department of Health.

Mansell, J., & Beadle-Brown, J. (with members of the Special Interest Research Group on Comparative Policy and Practice). (2010). Deinstitutionalisation and community living: Position statement of the Comparative Policy and Practice Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities. *Journal of Intellectual Disability Research*, *54*, 104–112. doi:10.1111/j.1365-2788.2009.01239.x

Mansell, J., & Beadle-Brown, J. (2012). *Active support: Enabling and empowering people with intellectual disabilities*. London, UK: Kingsley.

Mansell, J., Beadle-Brown, J., & Bigby, C. (2013). Implementation of active support in Victoria, Australia: An exploratory study. *Journal of Intellectual & Developmental Disability*, *38*, 48–58. doi:10.3109/13668250.2012.753996

McConkey, R., Keogh, F., Bunting, B., Garcia Iriarte, E., & Watson, S. F. (2016). Relocating people with intellectual disability to new accommodation and support settings:

Contrasts between personalized arrangements and group home placements. *Journal of Intellectual Disabilities*, *20*, 109–120. doi:10.1177/1744629515624639

Perry, J., Firth, C., Puppa, M., Wilson, R., & Felce, D. (2012). Targeted support and telecare in staffed housing for people with intellectual disabilities: Impact on staffing levels and objective lifestyle indicators. *Journal of Applied Research in Intellectual Disabilities*, *25*, 60–70. doi:10.1111/j.1468-3148.2011.00647.x

Pranee, L. (2011). *Focus group methodology: Principles and practice*. London, UK: Sage.

Productivity Commission. (2011). *Disability care and support* (Report No. 54). Canberra: Australian Government.

Reinders, J. S. (2002). The good life for citizens with intellectual disability. *Journal of Intellectual Disability Research*, *46*, 1–5. doi:10.1046/j.1365-2788.2002.00386.x

Sheppard-Jones, K., Thompson Prout, H., & Kleinert, H. (2005). Quality of life dimensions for adults with developmental disabilities: A comparative study. *Mental Retardation*, *43*, 281–291. doi:10.1352/0047-6765(2005)43[281:QOLDFA]2.0.CO;2

Stainton, T., Brown, J., Crawford, C., Hole, R., & Charles, G. (2011). Comparison of community residential supports on measures of information & planning; access to & delivery of supports; choice & control; community connections; satisfaction; and, overall perception of outcomes. *Journal of Intellectual Disability Research*, *55*, 732–745. doi:10.1111/j.1365-2788.2010.01378.x

Stancliffe, R. J. (2002). Provision of residential services for people with intellectual disability in Australia: An international comparison. *Journal of Intellectual & Developmental Disability*, *27*, 117–124. doi:10.1080/13668250220135079-1

Stancliffe, R. J., & Keane, S. (2000). Outcomes and costs of community living: A matched comparison of group homes and semi-independent living. *Journal of Intellectual & Developmental Disability*, *25*, 281–305. doi:10.1080/13668250020019584

Stancliffe, R. J., Lakin, K. C., Doljanac, R., Byun, S.-Y., Taub, S., & Chiri, G. (2007). Loneliness and living arrangements. *Intellectual and Developmental Disabilities*, *45*, 380–390. doi:10.1352/1934-9556(2007)45[380:LALA]2.0.CO;2

Tichá, R., Lakin, K. C., Larson, S. A., Stancliffe, R. J., Taub, S., Engler, J., … Moseley, C. (2012). Correlates of everyday choice and support-related choice for 8,892 randomly sampled adults with intellectual and developmental disabilities in 19 states. *Intellectual and Developmental Disabilities*, *50*, 486–504. doi:10.1352/1934-9556-50.06.486

United Nations. (2006). *Convention on the rights of persons with disabilities*. Retrieved from http://www.un.org/disabilities/convention/conventionfull.shtml

Walsh, P. N., Emerson, E., Lobb, C., Hatton, C., Bradley, V., Schalock, R. L., & Moseley, C. (2010). Supported accommodation for people with intellectual disabilities and quality of life: An overview. *Journal of Policy and Practice in Intellectual Disabilities*, *7*, 137–142. doi:10.1111/j.1741-1130.2010.00256.x

Ward, K. M., Atkinson, J. P., Smith, C. A., & Windsor, R. (2013). A friendships and dating program for adults with intellectual and developmental disabilities: A formative evaluation. *Intellectual and Developmental Disabilities*, *51*, 22–32. doi:10.1352/1934-9556-51.01.022

Wiesel, I., & Bigby, C. (2015). Movement on shifting sands: Deinstitutionalisation and people with intellectual disability in Australia, 1974–2014. *Urban Policy and Research*, *33*, 178–194. doi:10.1080/08111146.2014.980902