


Please cite the Published Version

Blood, Lauren, Ribenfors, Francesca, Hatton, Chris  and Marriott, Anna (2024) Moving house: how much choice do people with learning disabilities have about where they live? *British Journal of Learning Disabilities*, 52 (1). pp. 140-149. ISSN 1354-4187

DOI: <https://doi.org/10.1111/bld.12558>

Publisher: Wiley

Version: Published Version

Downloaded from: <https://e-space.mmu.ac.uk/633192/>



Usage rights:  [Creative Commons: Attribution 4.0](https://creativecommons.org/licenses/by/4.0/)

Additional Information: This is an open access article which originally appeared in *British Journal of Learning Disabilities*, published by Wiley

Enquiries:

If you have questions about this document, contact openresearch@mmu.ac.uk. Please include the URL of the record in e-space. If you believe that your, or a third party's rights have been compromised through this document please see our Take Down policy (available from <https://www.mmu.ac.uk/library/using-the-library/policies-and-guidelines>)

Moving house: How much choice do people with learning disabilities have about where they live?

Lauren Blood¹  | Francesca Ribenfors² | Chris Hatton²  | Anna Marriott¹

¹Research & Evaluation Team, National Development Team for Inclusion, Bath, UK

²Department of Social Care and Social Work, Manchester Metropolitan University, Manchester, UK

Correspondence

Lauren Blood
Email: lauren.blood@ndti.org.uk

Funding information

National Institute for Health and Care Research (NIHR), Grant/Award Number: 20069

Abstract

Background: People with learning disabilities have the right to choose where they live. However, evidence suggests people's choices are limited due to a shortage of housing.

Methods: 200 Lives was a mixed methods research project, which evaluated supported living and residential care for people with learning disabilities in England; 107 people with learning disabilities took part, 77 from supported living and 30 from residential care.

Findings: Two-thirds of people in supported living compared to half of those in residential care chose the place they were currently living in; however, less than half of all participants looked at another property before moving to their current house. People in supported living were significantly more likely to have chosen who they lived with. Reasons for moving mainly consisted of reactive moves following an issue with the previous living situation. Many people had not considered moving in the future.

Conclusion: Findings suggest that people's choices about where to live were constrained regarding the properties on offer and who to live with. This suggests that people's housing rights were not being upheld. Support and housing providers should ensure that housing can adapt to people's changing needs and wishes over the course of their lives.

KEYWORDS

independent living, learning (intellectual) disabilities, residential services

Accessible Summary

- People with learning disabilities have the right to choose where they live.
- We spoke to 107 people with learning disabilities living in supported living or residential care.
- Not everyone had the chance to choose where they live. People in supported living were more likely than people in residential care to choose who they lived with.

This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

© 2023 The Authors. *British Journal of Learning Disabilities* published by John Wiley & Sons Ltd.

- People tended to move house when they had a problem with their current house, rather than moving because they wanted to.
- There needs to be more housing available for people with learning disabilities to choose from. People should be supported to think about where they want to live in the future.

1 | INTRODUCTION

People with learning disabilities have the right to decide where and with whom they wish to live (Article 19 of the UN General Assembly, 2006). Choice over housing features in several UK government policies aiming to improve outcomes for people with learning disabilities (e.g., DHSC, 2021, 2022; HM Government, 2009). Housing has been identified as a priority for self-advocacy organisations, showing that this continues to be important to people with learning disabilities today (Learning Disability England, 2022). However, the most recent in-depth research about housing for adults with learning disabilities in England was carried out over 20 years ago (Emerson et al., 1999).

This is noteworthy as there have since been several key policy updates. A key objective of the UK government strategy valuing people now (HM Government, 2009, p. 20) is that all people with learning disabilities have an 'informed choice about where and with whom they live'. The United Kingdom ratified the United Nations Convention on the Rights of Persons with Disabilities in 2009, which recognised that disabled people have the right to an adequate standard of living, including adequate food, clothing and housing (Article 28). Within The Care Act (2014) housing forms part of the definition of wellbeing for people who have care and support needs. Housing is also a priority for reducing the number of people with learning disabilities living in long-stay hospitals (Building the Right Support, DHSC, 2022). The recent social care reform white paper (DHSC, 2021) sets out the ambition that people who draw on social care will have a 'good choice of alternative housing and support options' (p. 16) along with a £300 million investment intended to broaden the range of supported housing on offer.

One mechanism intended to give people in the United Kingdom more rights and control over their housing and support is supported living. Supported living is a housing model in which a person owns or rents their home, with housing and support provided separately so that the person can change their support provider without affecting their housing or vice versa (Harflett et al., 2017). Support may range from around-the-clock, sleep-in staff to a few hours of support per week (NDTi, 2010). In contrast, within residential care housing and support are provided together by the same organisation (Harflett et al., 2017). A fundamental principle of supported living is choice over how, where and with whom to live (Duffy, 2012) which is embedded within the REACH standards, a nationally recognised set of standards for supported living (Paradigm, 2020).

Despite these policy intentions, the reality for many disabled people in the United Kingdom is starkly different. Recent decades have seen a sharp increase in the cost of housing, alongside a volatile housing market and a decline in the quality of housing (Robertson, 2017). The privatisation of social housing through the 'Right to Buy' scheme introduced in the 1980s has contributed to a shortage of social housing. More recently, the British government has capped housing benefits and introduced the 'bedroom tax', which penalises social tenants with an additional bedroom, even when this is needed for equipment or support staff. These policies have reduced the number of properties available to people on housing benefit (Robertson, 2017). Disabled people have been disproportionately impacted, with a 2018 inquiry finding a 'chronic shortage' of suitable homes for disabled people (Equality and Human Rights Commission, 2018; cited in Ryan, 2019). Inequalities in the housing market have been further compounded since the start of the COVID-19 pandemic, with a significant decline in the construction of new houses leading to increased housing costs (Blundell et al., 2022). As discussed by Glendinning (2008, p. 14) 'choice is only possible if there is an accessible and affordable supply of appropriate service options'. Therefore, a lack of suitable homes in the United Kingdom has constrained people with learning disabilities' options when it comes to finding somewhere to live (Learning Disability England, 2020).

Research has found that people with learning disabilities feel that they have little choice when moving (McGlaughlin & Gorfín, 2004). The study found that 40% of people would like to move either now or in the future, but few people had active plans in place. A 'Big Conversation' self-advocacy project hosted by Learning Disability England and the Housing Learning Improvement Network (2020) found that few people got to choose who they lived with, and decisions were often based on the limited suitable housing available, meaning that it could be a 'postcode lottery'.

Salmon et al. (2019) interviewed 35 people with learning disabilities in Ireland who had moved house. One-third of people said they had no choice over whether to move and where to move. For those who did have a choice, important considerations included the location, accessibility, cost, and opportunities to be independent. Almost everyone had viewed their current house before moving in; however, it is not clear whether they viewed a range of properties or just one. Therefore, this may have been assent rather than a true choice. There may be pressure to accept a property even if it is unsuitable, as people who decline a property offered by the council risk being found 'intentionally homeless' and ineligible for further support (Ryan, 2019).

Research is needed to explore the extent to which people with learning disabilities have a true choice when moving into a new home, as this forms an important but sometimes overlooked component of their housing rights. Choice is a dynamic process and not simply a one-off event (Glendinning, 2008) so research must explore people's future aspirations and how their housing preferences may change, otherwise it risks placing people with learning disabilities in a perpetual present. This paper draws on data from the 200 Lives project to examine people's experiences of moving house and the extent of choice available to them when moving now or in the future. Given that people in supported living would be expected to have greater choice over their housing than people in residential care (Harflett et al., 2017; Paradigm, 2020), differences between the two models are explored.

2 | METHODS

This paper reports data collected as part of the '200 Lives: Evaluating Supported Living and Residential Care for Adults with Learning Disabilities' research study, funded by the National Institute for Health Research. The project was informed by an advisory group comprising people with learning disabilities, family members, and service providers who met with the research team at key junctures throughout the project. Furthermore, a member of the core research team had a learning disability.

While data were collected from people with learning disabilities, their support staff, provider organisation and family members, this paper focuses solely on the interviews with people with learning disabilities.

The research was conducted during 2020–2022, coinciding with the COVID-19 pandemic, which had a considerable impact on people with learning disabilities and their routines (Flynn et al., 2021). Full details of the study and procedures are reported in (Hatton et al., 2022). The project received a favourable ethical opinion from the Social Care Research Ethics Committee (REC reference 20/IEC08/0041).

The interview questions were devised through consultation with people with learning disabilities. Participants were free to take breaks or skip questions that they did not want to answer and could choose to have a support person present during the interview. In the case of a participant becoming distressed, the researcher would check in with them, offering signposting to resources and an aftercare phone call where appropriate. Participants were aware that their responses would be confidential unless there was a safeguarding concern. Some of the ethical complexities of this research are explored further in Ribenfors & Blood (2023).

2.1 | Recruitment

Residential care home providers or organisations providing support to people in supported living were contacted through social media and networks known to the research team. They were asked to share an easy-read information booklet and a YouTube video about the project

with people they support. Eligible participants were people in supported living or residential care with a learning disability, aged 18–74 years old, who had lived in their current home for at least 6 months.

People who were interested in taking part consented to be contacted by the research team. The researcher then went through the consent process and arranged an interview with them. In line with Dobson (2008) and the Mental Capacity Act, a consultee process was followed to enable people who were unable to consent for themselves to take part in the research.

2.2 | Participants

In total, 107 participants with learning disabilities took part. Ninety-three participants had the capacity to consent to take part in the project and 14 participants were included via the consultee process. Seventy-seven participants lived in supported living and 30 lived in residential care. The 107 participants were recruited from 16 different organisations (range 1–19 people per organisation). Table 1 shows the age, gender and ethnicity of participants, as well as the total number of people in the household where they live.

2.3 | Data collection

Semistructured interviews were conducted with people with learning disabilities over a video call, phone, or face-to-face during a home visit and recorded with participants' consent. There were 200 questions in total, split across multiple sessions depending on individual preference. Not all questions were applicable to every person, and some questions were skipped depending on participants' level of engagement and fatigue.

Concerning the topic of moving house there were eight quantitative questions and four open-ended questions (with prompts) to explore how the person was involved in choosing where they live, their experience of moving, and whether they would like to move in the future. Where participants lacked the capacity to answer these questions for themselves, a member of staff who knew them well answered these questions on their behalf using a Proxy-Participant Questionnaire.

2.4 | Analysis

Statistical analysis was conducted using SPSS. Where differences between supported living and residential care are described throughout these findings, they are all statistically significant differences at $p < 0.01$ (this has been set due to the number of comparisons conducted). The data presented below includes responses from both participants and proxy participants.

Purposive sampling was used to analyse the qualitative data for 21 participants in residential care (including 7 proxy-participants) and 21 participants in supported living (including 2 proxy-participants). Participants were chosen to ensure that a range of support needs and housing set-ups were represented.

TABLE 1 The people who took part.

	Supported living	Residential care	Test and statistical significance
Age (years)			
Mean (SD)	42.8 (12.1)	41.5 (13-2)	$t = -0.44; df = 96, p = 0.658$
Range	23–70	19–72	
Gender			
Men	56.0%	63.3%	(Men vs. Women) Fisher's exact test $p = 0.506$
Women	44.0%	33.3%	
Other	0.0%	3.3%	
Ethnicity			
White (all groups)	87.1%	93.3%	$\chi^2 = 1.36; df = 3; p = 0.715$
Asian/Asian British	1.4%	0.0%	
Black/Black British	8.6%	3.3%	
Mixed heritage	2.9%	3.3%	
(People with capacity only) Number of people in the household (including participant)			
1 person—live alone	25.0%	4.8%	Recoded 1–3; 4–6; 7–10; 11+; $\chi^2 = 38.16; df = 3; p < 0.001$
2 people	19.4%	0.0%	
3 people	22.2%	0.0%	
4 people	19.4%	0.0%	
5 people	5.6%	19.0%	
6 people	4.2%	23.8%	
7–10 people	4.2%	47.6%	
11–20 people	0.0%	4.8%	

Responses to the open-ended questions were transcribed verbatim and names pseudonymised. Relevant extracts of data were collated into a framework matrix (as described in Gale et al., 2013) based on key topics of interest, for example, the experience of moving, what participants like about their home and so forth.

Extracts were coded within these topics by two members of the research team (F. R. and L. B.). An inductive approach to coding was used (Braun & Clarke, 2012), although there were elements of a deductive process as the data had already broadly been organised into topics. The codes were grouped into themes through discussion among the research team.

3 | FINDINGS

Sixty-six percent of participants in supported living compared to 48% in residential care said that they chose the place they were currently living in (Table 2). Fewer people in supported living (37%) and residential care (40%) had looked anywhere else before moving to their current home.

There were statistically significant differences between supported living and residential care in the extent to which people chose who they lived with. Most people in supported living had chosen who

they lived with (46%) or were involved in the process somewhat (14%), whereas no one in residential care had chosen who they lived with (0%) and very few were involved in the process (6%).

Thirty percent of people in supported living and 74% of people in residential care reported that someone new had moved in since they started living there, a statistically significant difference. Few people in supported living (14%) or residential care (15%) were involved at least a little in choosing who moved in.

3.1 | Qualitative findings: The experience of moving

Participants were asked about the process of moving into their current home.

3.2 | A proactive or reactive move?

Reactive moves were common across both housing models. They took place in response to an issue with the previous living situation. This was either due to an emergency, such as the death of a co-habiting family, or a longer-term issue such as difficulties with housemates or support staff.

TABLE 2 Choosing a place to live.

	Supported living	Residential care	Test and statistical significance
Did the person choose the place where they live?			
Yes	66.2%	47.6%	$\chi^2 = 3.46$; $df = 2$; $p = 0.177$
No	23.9%	28.6%	
Don't know	9.9%	23.8%	
Did the person look anywhere else before moving here?			
Yes	37.3%	40.0%	$\chi^2 = 0.30$; $df = 2$; $p = 0.858$
No	43.1%	46.7%	
Don't know	19.6%	13.3%	
Did the person choose who they live with?			
Yes	46.0%	0.0%	$\chi^2 = 20.00$; $df = 4$; $p < 0.001$
Was involved in the process where possible	14.0%	6.3%	
No	26.0%	87.5%	
Don't know	4.0%	0.0%	
Not Applicable	10.0%	6.3%	
Has anyone new moved in since the person started living there?			
Yes	30.4%	73.7%	Fisher's exact $p = 0.001$
No	69.6%	26.3%	
Did they have any choice about who moved in?			
Yes, fully involved	2.8%	0.0%	$\chi^2 = 22.00$; $df = 4$; $p < 0.001$
A bit, involved a little	11.3%	15.0%	
No, no choice	9.9%	55.0%	
Don't know	7.0%	5.0%	
Not Applicable	69.0%	25.0%	

I used to live in another bungalow for 3 years. I didn't like it as much. [The support provider] changed and it went downhill... there were staff I didn't get on with there ... the other clients put me off there... I wanted to get out of there! (Grace, Supported Living)

Other reactive reasons given by people, typically in supported living, included poor living conditions in their privately rented home, crime, and issues with neighbours. For example, one person moved in response to mate crime, which is exploitation or abuse by someone that the person considers to be a friend (Thomas, 2011).

I was getting bullied 24/7. I had my friends coming over and stuff like that and they was asking for a lot of money and food...they were taking the mickey out of me and they were taking all my food out my flat and money as well. (Liam, Supported Living)

Proactive moves were less common than reactive moves. They were associated with personal progression or pre-empting future issues, such as future health needs. For example, one person moved to develop independence after finishing education; 'Before I moved in I used to live at my mum's house...my mum wanted me to be independent' (Stacey, Supported Living). There were also examples of moving from shared housing to living alone and enjoying the benefits this brings, 'I had been sharing and I wanted to get my own place and you can watch what you want on TV' (Chris, Supported Living). Another person moved from a large residential home into a smaller self-contained bungalow on-site as a stepping-stone to living alone in the future. These examples suggest participants associated living alone or with fewer people with increased levels of independence.

3.3 | A bumpy road until settled

Whatever their reasons for moving, many people experienced difficulties at first and took a while to feel settled in their new home.

Some people had to move twice as they moved initially into respite or an interim home before moving into their current home. One person described a process of 'trial and error' as he moved into a supported living home and quickly realised it was not for him before moving into a larger residential home, which he preferred.

Participants described feeling apprehensive when they first moved. It took some time to get used to the staff and other housemates, and to adapt to their new living arrangements, 'I found it difficult at first. I wouldn't talk much' (Zack, Residential Care). For some participants, this included adapting to differing sensory environments:

After a few weeks I got used to it. It helped because everybody hadn't moved in at that time, so I was able to get used to a few people and then a few more and then it got noisier, and I slowly got used to the level of noise. (Andrew, Residential Care)

Even when participants knew their housemates previously, there were mixed emotions. For example, one person, who was moving from a residential home to a supported living home with two fellow residents, said the following:

All different emotions, excited, nervous, worried.... if it didn't go quite right and that if I wasn't suited to the place? (Jamie, Supported Living)

Feelings of unease were particularly prominent when the move was due to an emergency, as one staff member explained:

At the beginning he struggled with the move due to it being so sudden, he protested with not eating food or only eating certain foods, his behaviour was very challenging. (Proxy response on behalf of George, residential care)

For people in supported living, there were some additional 'bumps in the road'. Some people faced delays due to issues with funding, having to apply for housing with the council bidding system and a lack of suitable homes or properties falling through as in the following example:

We had a look round there, but our social worker at the time had a message from them saying they couldn't give us a place there, but they never told us why or anything. (Roy, Supported Living)

Once a property was found, there were sometimes challenges relating to the condition and the expense of furnishing the property, with one person saying that their home was dirty and smelly when they first moved in.

3.4 | Smoothing the bumps

Despite the difficulties associated with moving, participants spoke about good practices that helped to ease the process.

Timing was important so that the move could happen at their own pace. For example, the person who moved from a large residential home into their own bungalow on-site was able to make the move when she felt ready rather than when staff first suggested it several years before. Another participant appreciated having time to make numerous transition visits at his own pace:

When they moved me in here, they did it slowly, so first of all I had a couple of day visits and then, this is what I requested because I don't do change very well so if something changes and I am not used to something I like to take my sweet time and do it in my own time. So, I asked for a few weeks where I just go for the day and then it turned into a night and then it turned into two nights and then it turned into three and then I said 'right, now I am used to the staff and everything, now I can move in'. (Aaron, Supported Living)

Friends, family and staff were all important sources of support during the move for both practical and emotional reasons. For example, participants appreciated being able to discuss their options and share the decision-making process with trusted staff and family:

There were different options. I looked at different places and we talked about my mum moving out and I staying with more support. (Leanne, Residential Care)

So, I spoke to our manager and had a really long conversation with her and decided yes, I would go for it. (Amy, Residential Care)

The presence of familiar people helped them to settle in, for example, friends and family visiting them in their home shortly after the move, or someone from their existing support team who they had a good relationship with continuing to work with them in their new home:

We had a tour of our house and chose our bedrooms. But then we did travel training from [old house] lots of times to here, on public transport and walking to here...We had a few staff members from [the old house] come here to help us. (Rory, Supported Living)

Moving to a home in a familiar location helped ease the process for people in both supported living and residential homes, as participants felt part of the community and knew they had friends and family close by, for example:

My family were a bit worried about it because they thought I would get very lonely. But at the time I had my partner living up the road and I got very good friend that lives down the road. (Sam, Supported Living)

When talking about the process of moving, participants' language hinted that they may not have had much control over the process. Phrases such as 'they thought it would be best I moved' (Jack, Residential Care), 'I just got put here' (Adam, Residential Care), and 'I just got told I was going to live with them' (Holly, Supported Living) were common. Participants appreciated small elements of choice and control, for example, over the spacing of transition visits described above. Furthermore, confidence was gained from a belief that staff were acting in their best interests as, ultimately, their wishes to move were respected by the move taking place.

3.5 | Moving home in the future

Participants were asked whether they would like to stay in their current home or move in the future. Many people had not considered moving, as they felt happy with their current arrangements. Some people found it difficult to discuss this. For those who had thought about moving, their reasons mirrored the proactive and reactive reasons noted in the previous section.

Participants who were planning to move were all living in supported living and wished to move for reactive reasons, relating to issues with space and feeling unsafe. These tended to be participants who had minimal support and lived in council housing. However, as previously explored in the theme 'a bumpy road until settled', moving was not a straightforward process. For example, one participant stated:

I just want out...I have spoken to [support provider] and they are going to ring up the council to see what the conclusion is going to be... I have to go to the doctors to get more forms. (Joe, Supported Living)

Another participant explained recent difficulties he had encountered with applying for council housing via the bidding system:

I have had my banding demoted a few months ago so I had to re challenge that to get my banding put back to where it is and that's because I didn't have an understanding of the area and if [my support provider] supported the area because if you go out of the area they won't support you. (Ali, Supported Living)

Other considerations for this participant were his mental health, possible racism and proximity to his family with which he had a difficult relationship. Despite thinking of ways to mitigate potential

issues in the future, he remained concerned about how it would pan out.

Participants in both supported living and residential care described sporadically toying with the idea of moving. This was usually due to a desire to escape particular situations, such as difficulties with housemates. However, the desire to move was not always continuous, as there were good days and bad days:

I have been thinking about it and then I change my mind and then I been thinking about moving out and then I change my mind again. One day you have a bad day and think 'I'm moving out I am' and the next day you think 'no it's fine you can cope it's fine, carry on with it, it's fine'. (Megan, Residential Care)

Similarly, one participant described previously using the thought of moving as a coping strategy. He explained he would contact his social worker whenever things were not working well at home:

I used to email them quite a bit or phone up if I was in trouble and say I would like to go, but I've not done that for 2 nearly 3 years now. (Dave, Residential Care)

However, as the issues for the participant above were now resolved he was happy to stay where he was and referred to that period of time as 'a doolaley moment':

I had a bit of a doolaley moment but it's out of the way now. I hit the nail on the head, we are happy where we are now and no I don't want to move anywhere else... I've done really well and I've not asked social services to be moved on any more. (Dave, Residential Care).

Participants who discussed the possibility of moving due to progression tended to live in supported living. Reasons included moving in with their partner, 'My next place would be a downstairs flat with my girlfriend' (Luke, Supported Living), owning their own home or moving out to live alone or with fewer housemates. For example, one person explained:

I would like to have my own place whether it be a flat or a house. Whether I organise it with a company and have some support, like a set amount of hours where they come in and do some bits or just check on me to make sure I am ok...I would like to have it where there is literally just one other person, like a friend or something, or my own tenancy by myself. (Jamie, Supported Living)

This reiterates that living alone or with fewer housemates was seen to reflect progression and higher levels of independence.

3.6 | Having to compromise

While some people wanted to move, they knew how difficult this could be, often based on prior experience. They were aware of the different hoops they might have to jump through and the potential upheaval to different areas of their life as the following participant expressed:

It means getting hold of the social workers and then getting hold of this and then changing everything, if I move house I have to change doctors and if I change doctors, I have to change clinics. The thing is I have that much set up that I would need to readjust, it's not practical to move at the minute. (Aaron, Residential Care)

This highlights the precarity of people's situations, with one change such as moving house potentially disrupting other networks and support systems.

In addition, participants were aware of the complexities of their living situation. For example, one participant who was in residential care wanted to move because of difficulties with her housemates, however she knew that if she moved she would lose her support staff, as the member of staff supporting her in the interview explained:

Sometimes she does want to move but because she can't take her keyworkers with her it stops it as she does like us all, but unfortunately she can't take us with her. (Staff member on behalf of Megan, Residential Care)

There was a sense that participants were weighing up whether moving would be worth it as while they may escape one issue they may encounter many more. As a result, many participants appeared accepting of their situation as the following participant summed up:

It can be a bit tricky at times but it is what it is, you just gotta bear with it. We're not gonna get any better place than living here I'm afraid. The grass isn't always greener on the other side. (Dave, Residential Care)

4 | DISCUSSION

In principle, the model of supported living is expected to offer people with learning disabilities greater choice than residential care over whether to move, where to move and who to live with. However, findings from this research suggest this is not necessarily the case. It is striking that only 66% of people in supported living and 48% of people in residential care said that they chose the property they were currently living in. This fits with Salmon et al.'s (2019) findings that a

third of people had no choice over whether or where to move. Less than half of people in either setting had looked at anywhere else before moving into their current home, calling into question the extent to which this was a true choice.

A significant difference between supported living and residential care was observed regarding the choice of housemates. Participants in supported living were more likely than those in residential care to be fully or somewhat involved in the process of choosing who they live with. However, very few people in either housing model were involved in deciding when someone new moved in, suggesting that this aspect of choice was overlooked. Service providers may be under pressure to fill voids left by vacant tenancies, which may impact the rights of existing tenants, if financial concerns take precedence over compatibility and choice.

The qualitative findings give further insight into the complexity of moving. Participants' reasons for moving into their current home tended to be either reactive moves in response to an issue with the previous living situation or proactive moves associated with planning ahead. Reactive moves were more common, in keeping with Essex et al.'s (1997 as cited in Grey et al., 2015) finding that most decisions about housing are driven by unplanned circumstances. The language that people used when talking about their move further indicated disempowerment, with people commonly saying that they were 'put' somewhere or they were 'told' that someone else would be moving in. This echoes the findings of McGlaughlin (2004), suggesting that many people continue to experience powerlessness nearly two decades later.

Many people found the process of moving to be a bumpy road involving many stops and starts. Particularly in supported living, there were issues with finding suitable properties and navigating the council housing system. People also spoke about good practices that helped to ease the process of moving, such as time to get used to the idea of moving and being allowed for transition visits. Practical and emotional support from friends, family and staff was invaluable, and staying local where possible also helped. Many people found that they needed a while to adjust after moving house; this supports Learning Disability England's (2020) recommendation that people should have access to additional support while moving, if they wish.

Few people had considered moving in the future as most felt happy with their current arrangements. People who did want to move tended to give reactive reasons such as issues with housemates or antisocial behaviour in the area. Some others spoke about aspirations to move in the future, such as getting their own place or moving in with a partner; however, few people were actively working towards this.

While it is positive that people felt happy where they are, it could be that some people were reluctant to discuss moving because they were afraid that they might be moved against their wishes if they voiced any dissatisfaction. McGlaughlin (2004) noted that people with learning disabilities tend to discuss their present home favourably in comparison to previous homes, however, they may find it difficult to talk about things that they did not like about their current home. Some people may also have a limited frame of

reference if they have experienced poor housing in the past; for example, one person felt his current home was much better as he was allowed to watch what he wanted on TV. The complexity of the moving process could also put people off even thinking about moving, resulting in a sense of compromise, with people accepting things that were less ideal about their current housing situation as it was not seen to be worth the hassle or risk of moving.

Finally, significant capacity issues, underfunding and staff shortages within social care (King's Fund, 2023) may limit the ability of social care staff to have conversations about planning ahead, causing them to prioritise urgent issues instead. This risks placing people with learning disabilities in a perpetual present, where personal progression and aspirations are discouraged. Proactive conversations and forward planning are needed to prevent the need for moving in a crisis.

5 | LIMITATIONS

The data reported in this paper were collected during the COVID-19 pandemic, which limits how the findings can be interpreted. The project recruited 107 participants rather than the 200 participants planned, as supported living and residential care services were operating under extreme pressure during this time. These reduced numbers mean less statistical power for direct comparisons between housing models. The service providers evaluated in this project were self-selecting so may not be representative.

The lockdowns and restrictions associated with COVID-19 caused immense disruption to the lives of people with learning disabilities, alongside impacts on the housing market, so people's experiences of moving house may have been different depending on whether they moved before or during the pandemic.

6 | IMPLICATIONS

- Findings suggest that a considerable number of people did not have a genuine choice about where to live or who to live with. Providers and commissioners need to ensure that people are fully involved throughout the moving process as this forms part of their housing rights. This may include the provision of advocacy and creative approaches to involve people who do not use words to communicate (e.g., Mencap's Involve Me Project, 2010).
- People with learning disabilities and their families should receive accessible information about their housing rights so that they know what to look for when considering a move and can challenge if their rights are not being met. For example, the Equality and Human Rights Commission (2018) has created an easy-read guide to rights about social housing.
- When monitoring housing provision, services should consider how well people's rights are being met. Quality Checks conducted by people with lived experience from an independent organisation

can offer a more meaningful and in-depth consideration of choice, compared to satisfaction surveys.

- It can take people a while to adjust to moving somewhere new, so there should be flexibility for people to access additional support during the transition if they need to.
- Limited accessible housing stock constrains people's choices and control over where they move. Addressing this should be a key priority for local authorities.
- It is crucial that housing has the capacity to adapt to people's changing needs and wishes across their life course, to enable them to stay in their home (if they wish to) and reduce the need for unplanned reactive house moves. Discussions about future housing needs could be supported by the person-centred future planning guide produced by the National Institute for Health and Care Excellence (2019).
- Services should provide opportunities to engage in proactive planning for moves in line with people's aspirations, for example, during Community Care Act reviews. This is vital to respect the right of people with learning disabilities to a meaningful life course through adulthood, rather than assuming a perpetual present for people. The Planning Ahead cards created by Tuffrey-Wijne (2023) could be used to support these conversations.

7 | CONCLUSION

Findings suggest that people with learning disabilities faced limited choice in terms of where to live and who to live with. Despite policy mandates that stress the importance of choice and control over housing, it appears that a considerable number of people in supported living did not have their full housing rights upheld. The broader political context of austerity and the housing crisis, which disproportionately affect disabled people, means that there is very limited suitable housing for people to choose from.

It appears that few people had conversations about planning ahead when it comes to housing, even though people's wishes and needs may change over the course of their lifetime. To address this, there needs to be an urgent investment in increasing available housing stock. Local authorities, commissioners and service providers should also encourage proactive planning and conversations about people's aspirations when it comes to housing in the future.

ACKNOWLEDGEMENTS

The authors would like to thank the people who took part in the research and the staff that supported them, as well as the organisations who put us in touch with the people they support. Thank you to Dr. Victoria Mason-Angelow and Annie Smith for their comments on earlier drafts of this article. This study is funded by the National Institute for Health and Care Research (NIHR) (20069). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

ORCID

Lauren Blood  <http://orcid.org/0000-0002-0609-5237>

Chris Hatton  <http://orcid.org/0000-0001-8781-8486>

REFERENCES

- Blundell, R., Costa Dias, M., Cribb, J., Joyce, R., Waters, T., Wernham, T., & Xu, X. (2022). Inequality and the COVID-19 crisis in the United Kingdom. *Annual Review of Economics*, 14, 607–636.
- Braun, V., & Clarke, V. (2012). *Thematic analysis*. American Psychological Association.
- Care Act. (2014). Parliament: House of Commons. <https://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>
- Department of Health and Social Care (DHSC). (2021). *People at the Heart of Care: adult social care reform white paper*. <https://www.gov.uk/government/publications/people-at-the-heart-of-care-adult-social-care-reform-white-paper>
- Department of Health and Social Care (DHSC). (2022). *Building the right support for people with a learning disability and autistic people*. <https://www.gov.uk/government/publications/building-the-right-support-for-people-with-a-learning-disability-and-autistic-people>
- Dobson, C. (2008). *Conducting research with people not having the capacity to consent to their participation: A practical guide for researchers*. https://www.ed.ac.uk/sites/default/files/atoms/files/bps_guidelines_for_conducting_research_with_people_not_having_capacity_to_consent.pdf
- Duffy, S. (2012). The limits of personalisation. *Tizard Learning Disability Review*, 17(3), 111–123. <https://doi.org/10.1108/13595471211240951>
- Emerson, E., Robertson, J., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., Knapp, M., Järbrink, K., Netten, A., Walsh, P. N., Linehan, C., Hillery, J., & Durkan, J. (1999). *Quality and costs of residential supports for people with learning disabilities: A comparative analysis of quality and costs in village communities, residential campuses and dispersed housing schemes*. Hester Adrian Research Centre, University of Manchester.
- Equality and Human Rights Commission. (2018). *Housing and disabled people: Britain's hidden crisis*. <https://www.equalityhumanrights.com/en/publication-download/housing-and-disabled-people-britainshidden-crisis>
- Flynn, S., Hayden, N., Clarke, L., Caton, S., Hatton, C., Hastings, R., & Todd, S. (2021). *Coronavirus and people with learning disabilities study, wave 3 results*. University of Warwick. https://pure.ulster.ac.uk/ws/files/92511950/Coronavirus_and_People_with_Learning_Disabilities_Study_Wave_3_Full_Report_v1.0_FINAL.pdf
- Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*, 13(1), 117.
- Glendinning, C. (2008). Increasing choice and control for older and disabled people: A critical review of new developments in England. *Social Policy & Administration*, 42(5), 451–469.
- Grey, J. M., Griffith, G. M., Totsika, V., & Hastings, R. P. (2015). Families' experiences of seeking out-of-home accommodation for their adult child with an intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities*, 12(1), 47–57.
- Harflett, N., Pitts, J., Greig, R., & Bown, H. (2017). *Housing choices*. https://www.ndti.org.uk/assets/files/Housing_Choices_Discussion_Paper_2.pdf
- Hatton, C., Ribenfors, F., Blood, L., Marriott, A., Woodward, E., Dunstan, L., Nadat, S., Taylor, J., Knapp, M., King, D., & Zhang, K. (2022). 200Lives: Evaluating supported living and residential care for adults with learning disabilities. <https://www.ndti.org.uk/assets/files/200-Lives-Full-report.pdf>
- HM Government. (2009). *Valuing people now: A new three-year strategy for people with learning disabilities. Making it happen for everyone*.
- Learning Disability England. (2020). *Finding our own way home: A 'big conversation'*. <https://www.learningdisabilityengland.org.uk/wp-content/uploads/2020/11/Finding-our-own-way-home-report-Final-1.pdf>
- Learning Disability England. (2022). *Good lives: Building change together*. https://www.learningdisabilityengland.org.uk/wp-content/uploads/2021/02/The_Good_Lives_Framework-9.3.22.pdf
- McGlaughlin, A., & Gorfing, L. (2004). Enabling adults with learning disabilities to articulate their housing needs. *British Journal of Social Work*, 34(5), 709–726.
- Mencap. (2010). *Involve me: Increasing the involvement of people with profound and multiple learning disabilities (PMLD) in decision-making and consultation*. <https://www.mencap.org.uk/sites/default/files/2017-05/Involve%20me%20Summary%20Booklet.pdf>
- National Institute for Health and Care Excellence. (2019). *Person-centred future planning: A quick guide for practitioners supporting people growing older with learning disabilities*. <https://www.nice.org.uk/Media/Default/About/NICE-Communities/Social-care/quick-guides/person-centred-future-planning-quick-guide.pdf>
- NDTi. (2010). *Supported living—Making the move*. https://www.ndti.org.uk/assets/files/Supported_Living-Making_the_Move2C_May_2010.pdf
- Paradigm. (2020). *A practical guide to the REACH standards*. https://paradigm-uk.org/wp-content/uploads/2020/11/REACH_STAGE_07-1.pdf
- Ribenfors, F., & Blood, L. (2023). To report or not to report: The ethical complexity facing researchers when responding to disclosures of harm or illegal activities during fieldwork with adults with intellectual disabilities. *Ethics and Social Welfare*, 17(2), 175–190.
- Robertson, M. (2017). The great British housing crisis. *Capital & Class*, 41(2), 195–215.
- Ryan, F. (2019). *Crippled—Austerity and the demonisation of disabled people*. Verso Books.
- Salmon, N., Garcia Iriarte, E., Donohoe, B., Murray, L., Singleton, G., Barrett, M., & Dillon, M. (2019). Our homes: An inclusive study about what moving house is like for people with intellectual disabilities in Ireland. *British Journal of Learning Disabilities*, 47(1), 19–28.
- The King's Fund. (2023). *Adult social care funding and eligibility: Our position*. <https://www.kingsfund.org.uk/projects/positions/adult-social-care-funding-and-eligibility>
- Thomas, P. (2011). 'Mate crime': Ridicule, hostility and targeted attacks against disabled people. *Disability & Society*, 26(1), 107–111.
- Tuffrey-Wijne, I. (2023). *Growing older, planning ahead cards*. http://www.tuffrey-wijne.com/?page_id=860
- UN General Assembly. (2006). *Convention on the rights of persons with disabilities*. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/238405/7905.pdf

How to cite this article: Blood, L., Ribenfors, F., Hatton, C., & Marriott, A. (2023). Moving house: How much choice do people with learning disabilities have about where they live? *British Journal of Learning Disabilities*, 1–10. <https://doi.org/10.1111/bld.12558>