



The Role of Adult Social Care in Supporting People with Learning Disabilities Who Rent Their Own Homes in England

RESEARCH

EPPIE LEISHMAN

DAVID ABBOTT

DEBORAH QUILGARS

BECCA COOPER

ANDY POLLIN

STEPHEN LEE HODGKINS

PAUL SCARROTT

SAM CLARK

LOIS BEECH



*Author affiliations can be found in the back matter of this article

ABSTRACT

Context: Evidence suggests that very few people with learning disabilities in England rent their own homes through the private or social housing rental sector. This is despite the fact that this group of people routinely say they would like more choice and control over where they live. We hypothesise that support from adult social care may benefit people to take up and sustain tenancies in this sector.

Objective(s): This paper draws on original and empirical research with people with learning disabilities who do rent, and who are at the margins of social care eligibility, to understand more about their support needs from adult social care in relation to renting a home.

Method(s): Qualitative, on-line interviews with 35 people with learning disabilities who rent their own homes in England.

Findings: Renting a place to live was working relatively well for the people in the study. There were, however, some important and often unmet needs in relation to managing a tenancy. The amount of social care support people received relating to their housing and tenancy varied with no apparent reason for the variation. Some people described a decline in support and others referenced the cost of social care support charges. Housing and social care support was only very rarely joined up. The paper suggests that there is a potentially untapped source of housing options in the rented sector, but that social care support could play a greater role in supporting renters over time.

Limitations: We did not manage to recruit many people who rented in the private rented sector compared with renting from social housing organisations. Our recruitment resulted in a majority of white respondents and a more diverse group would have been beneficial. Most of our respondents were recruited via self-advocacy organisations and it is conceivable that their links with groups that offered support meant that their experiences might not be representative of the wider population of people with learning disabilities.

CORRESPONDING AUTHOR:

David Abbott

School for Policy Studies,
University of Bristol, UK
d.abbott@bristol.ac.uk

KEYWORDS:

Social Care; Learning Disability;
Housing

TO CITE THIS ARTICLE:

Leishman, E., Abbott, D., Quilgars, D., Cooper, B., Pollin, A., Hodgkins, S.L., Scarrott, P., Clark, S. and Beech, L. 2024. The Role of Adult Social Care in Supporting People with Learning Disabilities Who Rent Their Own Homes in England. *Journal of Long-Term Care*, (2024), pp. 403–413. DOI: <https://doi.org/10.31389/jltc.309>

Implications: Choice about where to live – and where to call home is as important as ever but barriers remain for people with learning disabilities. We suggest that there is an important and preventative role for adult social care in offering, even sometimes quite small, packages of support to enter into and maintain a tenancy agreement.

I always say to myself, this is my first home, and I tell everybody this, this is my first, this is my first home, I've never ever had a home, never ever had a home of my own and this is my first home. This is my, this is my dream come true, this is my dream; hold on, let me rephrase that. This is my dream come true, oh God, this is, my dream, my dream come true cos this is, this is my first home. (Ellen)

INTRODUCTION

Where we live and where we call home is, fairly undeniably, of utmost importance. Home can, in the right circumstances, bring comfort, happiness, security, belonging. Two major reviews of research priorities in learning disability research, which both highlighted the views of people with learning disabilities (Williams, Marriot and Townsley, 2008; Hassiotis, 2015), cited housing as one of the top, and in the latter review, the top priority for research. This review remarked upon how few studies about housing actually included the views of people with learning disabilities themselves. Additionally, the *Good Lives Framework* produced by self-advocates and Learning Disability England (a partner in the project described in this paper) foreground home as its first chapter with key principles, including people having the right to choose where they live and who they live with (Smith, 2022). And so, we start with the quote from one of our participants to remind us, if we should need reminding, of the crucial importance of feeling like we have a place we can call home; and of hearing from people with learning disabilities themselves.

These ideas are not new. Forty years ago, *An Ordinary Life* (Kings Fund, 1980) promoted the principle of people with learning disabilities, ‘...living ordinary lives, in ordinary houses, in ordinary streets.’ Sadly, this vision of ‘ordinariness’ seems like a distant utopia and as Kaley et al., (2022, p. 319) write, ‘...for many people with learning disabilities, achieving a true sense of belonging is a hope that remains “just out of reach”, an ever elusive and unattainable goal’. These authors describe the ‘perfect storm’ of reductions in social care budgets, a tightening of eligibility criteria and the disproportionate impact of austerity on people with learning disabilities including those on the edges of social care eligibility. Again, we have been here before, as nearly twenty-five years ago Simonds and Watson (1999, p. 52) wrote about issues which this paper will go on to explore:

The financial pressures on UK local authority spending... has led many to introduce a system of explicit eligibility criteria to aid with the ‘prioritisation’ of community services, and then to subsequently tighten those criteria... Of course some people with learning disabilities have always lived with little or no support from specialist services. However, there is some tangential evidence that the number of people in this situation is increasing, including people who would have been able to get support in the past. Where individuals who have previously managed run into a crisis, it can mean an expensive and difficult move into some form of residential service. As a result there is an increasing interest in ‘preventative’ services. By definition these will have to be cost-effective ‘low support’ options designed to help people remain independent. By and large, there has been little consideration of these options for people with learning disabilities.

Analysis of the ‘Living situations of adults with learning disabilities aged 18–64 receiving long-term social care (NHS Digital SALT dataset) – England’ data shows (as per Table 1) that in 2019/20 there are a number of possible categories in which we might find people who rent their own homes (to reiterate, not in supported accommodation settings). These figures represent *only* people with learning disabilities with a social care support package and as we shall see, our research included people who were renting with no social care support so these figures will not capture or include those people. Obvious categories include the two ‘tenant’ categories but there may well also be people renting in the category of ‘settled mainstream housing including flat sharing.’

We are not aware of research that focuses on people with learning disabilities who rent their own homes. Subsequently, our research was a three-year study which explored the experiences of people with learning disabilities who rented their own homes in both social housing and the private rented sector and who received either no or quite small amounts of social care support. The study was funded by the National Institute for Health and Care Research, School for Social Care Research and was a collaborative effort between academics, disabled people’s organisations, providers and policy influencers. The overall study research questions were:

	2019/20
Rough sleeper/squatting	10
Night shelter/emergency hostel/direct access hostel (temp accomm accepting self-referrals)	50
Refuge	5
Placed in temp by council (inc homelessness settlement) eg B&B,	175
Staying with family/friends in short term	670
Acute/long stay healthcare residential facility or hospital	370
Registered care home	20095
Registered nursing home	970
Prison/young offenders institution/detention centre	25
Other temp accomm	580
Owner occupier/shared ownership scheme	2955
Tenant-LA/arms length mgt org/registered social landlord/housing assn	12635
Tenant-private landlord	3600
Settled mainstream housing with family/friends (inc flat-sharing)	49070
Supported accomm/ supported lodgings/ supported group home	31160
Shared lives scheme	3450
Premises for offenders released from prison or under probation	35
Sheltered housing/ extra care housing/ other sheltered housing	1805
Mobile accomm for Gypsy/Roma & Traveller community	20
Unknown accommodation	6770
TOTAL RECEIVING LONG-TERM SOCIAL CARE (from 2014/5)	134450

Table 1 Living situations of adults with learning disabilities (18–64) receiving long term social care support in 2019/20. (NHS England, 2020).

1. What are the current, and future potential ways in which people with learning disabilities, who are on the edges of social care, might be supported to access and enjoy living in independent housing, particularly their own tenancies, when this is their choice?
2. What are the current respective roles of social care providers, housing providers, other agencies, and informal support in supporting people with mild/moderate learning disabilities to live in their own tenancies?
3. What are the experiences of people with mild/moderate learning disabilities living in their own tenancies in social housing and the private rented sector? To what extent do the housing and support options available provide 'suitable accommodation' for people?
4. What is the current role of adult social care in supporting people with learning disabilities with tenancies in the social housing and private rented sector?

We have written about different aspects of the research elsewhere – on our approach to coproduced working (Leishman et al., 2023), on the overall experience of being a renter, and findings from the first two components of the research (see below and Quilgars et al., 2024). To contextualise this paper, it is worth noting that the main overall finding from our research was that renting a home in the social housing sector can be a very positive and enjoyable housing option for people with a label of mild or moderate learning disabilities and, that while barriers remain (including issues of support – the focus of this paper), our view was that a larger scope to consider is that the housing market warrants more attention. Here we write about the role of support from adult social care in helping people with learning disabilities access and maintain a tenancy. The research has three components.

1. A review carried out in 2020 of local authority learning disability strategies to assess their focus on housing.
2. A national consultation undertaken in 2021 consisting of one national and eight regional roundtable events held online to discuss renting in the social housing and private rented sectors and the support available. The events were attended by about 100 professionals and experts by experience including: people with learning disabilities, family carers, advocates, support workers, social and private housing providers, representatives from local authorities, the NHS and voluntary and community organisations, and key national policy experts.
3. In 2022 we undertook on-line/telephone (due to COVID-19 restrictions) interviews with 35 people with learning disabilities who rent their own homes in England. Twelve of these renters also contributed creative methods booklets to the project. The qualitative interviews are the part of our data that we will focus on in this paper.

METHOD

This paper highlights data collected in the qualitative interview component of the study. The majority of renters were recruited for interviews through self-advocacy organisations across England who contacted renters directly, shared our information sheets at meetings and through emails/newsletters. Academic members of the research team alongside self-advocacy experts from the advisory group also attended a number of online self-advocacy meetings to speak about the research and recruit renters. A very small amount of snowball sampling took place with renters sharing the information sheet with friends and fellow self-advocates. Finally, recruitment information was also shared on social media though to the best of our knowledge no renters were actually

recruited from this. Renters were screened to ensure that they held their own tenancy and were receiving no or small amounts of social care support (this was understood to be 20 hours or under a week). An interview topic guide was co-created with the whole research team, with an initial draft having been produced in light of a literature and policy review and wider consultation (components 1 and 2 above). Interviews lasted between one and three hours with the majority being around one hour and were carried out on-line. They had been originally planned to be face-to-face, but this was not possible because of the then COVID-19 restrictions. Participants received a £30 voucher as a thank you for taking part in the interviews.

An easy read version of the topic guide was sent to participants in advance so that they could have a chance to prepare or think about the questions. The interviews were semi-structured, each addressing the following main topics, whilst leaving time to allow participants to talk about anything they thought was relevant: How did you find this place/your home?; Where did you live before?; Who (if anyone) helped you find this place?; What do you like/not like about living here?; How do you organise paying to live here and other bills and money matters?; Who supports you to live here including social workers, housing officers, friends and family, etc.?; What kind of information do you get/need and is it accessible?

During the interview, participants were asked if they would prefer to choose a pseudonym or for the interviewer to do so for them, these are used for quote attribution in our findings section. All those interviewed were also asked if they wanted to take part in a creative methods part of the project and 12 did so. The creative methods involved sending participants an instant polaroid camera and an easy-to-read booklet (to complete with photos and a range of supplied pens, drawing materials, stickers, etc.). The booklet gave people a range of prompts about, for example, what they liked and did not like about where they lived, things they might like to change, advice they might give to other people. This part of the data collection was also made more complicated by COVID-19 restrictions, but still produced rich and interesting material discussed later in our paper about people's overall experiences of renting (Quilgars et al., 2024).

Most of the renters we interviewed (30) were tenants of social housing providers. A small minority (5) rented in the private sector. Time renting their current property ranged from 6 months to 30 years. Most participants described themselves as White or White British although participants also identified as Black, Black Caribbean, and British Mixed Asian. Renters ranged in age from late 20's to 66. In terms of formal social care support, 14 renters had no paid support on a weekly basis, while 21 had between one and 20 hours per week. Most support was fixed hours and determined by an assessment, a small number of renters (3) had more flexible support which did not always happen weekly. A number of participants

were in either part-time paid employment (12), some volunteered (9), and some described themselves as unemployed (11). Renters had a range of family and household arrangements including living alone, living with a partner or spouse, and/or living with children. While the majority of renters preferred not to tell us about their sexual orientation, eight told us they defined as straight/heterosexual, one as asexual, and one as bisexual.

Analysis of the interview data took place in a number of ways. Firstly, two of the academic researchers did a 'traditional' thematic analysis (organised using Nvivo) in which the data was interrogated to see how it spoke to and/or were 'salient' to the study's main research questions (Buetow, 2010). The principles of thematic analysis described by Braun and Clarke (2023) were adopted in this process. Next, and in keeping with the way in which the research team was working more inclusively, we approached the wider team to take part in analysis – although not from a blank slate, to discuss the main themes that had already been identified. In practical terms, attempting this process on Zoom, even in accessible ways, was very challenging. The transcripts themselves were often very long and the stories people shared, non-linear. While we did hold a one-hour Zoom meeting to focus on themes relating to renting, and listened to short audio clips from the data, the process was difficult for everybody. However, this stage of the research coincided with the lifting of COVID-19 restrictions, and we were able to meet in person (for the first time) to have a whole day, data analysis workshop. On that day, we listened to short clips about support with context about who these renters were. We covered tables in paper, wrote notes, and drew pictures to show what the clips said to us. We then embarked upon a shared 'sense-making' of the data. We collected all of the notes and discussion from the day and used it to supplement the thematic analysis that had already taken place. Although this approach highlighted the ways in which people with learning disabilities can take part in data analysis, it is clear that the non-disabled, academic researchers, very obviously set certain parameters by doing the first stage of thematic analysis on their own (an issue we reflect upon in more detail in Leishman et al., 2023).

The research project began its life by adopting a quite traditional approach by having an advisory group made up of people from policy, practise, and lived experience backgrounds. As is evident from the description of our approach to data analysis above, this changed relatively quickly, and quite radically, when the people with learning disabilities involved in the advisory group made it very clear that they wanted a much more enhanced, active, and paid role – a process of change and learning which we discuss in more detail in Leishman et al., 2023. Meetings of the whole research team – the terminology we adopted in place of 'advisory group', were held throughout the project. These meetings occurred approximately every two months and were facilitated by the main academic

researcher on the project, who liaised closely with the members and supported the group in preparing easy-read material for all documents, agendas, etc.

Ethical approval for the fieldwork was given by The Health Research Authority (HRA).

LIMITATIONS AND CAVEATS

Our study is qualitative in nature and therefore will not be representative of all people with learning disabilities who are renting. In addition, our study, like so much research with/about people with learning disabilities, is dominated by White people, even though we know that being from a minoritised ethnic community exacerbates most key health and social inequalities (O'Dowd, 2023). It was also difficult to recruit private renters, so the majority the experiences reported are mainly about living in social housing. In addition, setting a cap of 20 hours will have (unintentionally) excluded people who had low support needs, with regard to renting, but higher personal care support needs. Finally, our reliance on remote methods due to COVID-19 gave us concerns over people's access to the internet. We built flexibility into our approach to account for this. Participants could do an interview using their chosen method of a video call (Zoom, teams, Facetime, Skype, Google Meet, etc) or take part via phone, if necessary. However, we still may have excluded people with less digital access.

FINDINGS

In this section we focus upon what participants told us about their main support needs in relation to renting and how/if these were met by people working in adult social care (in which we include housing staff employed by local authorities).

WHAT SUPPORT DID PEOPLE WANT?

Participants described relatively obvious and modest needs for support to make 'home' work. We say 'home' instead of 'tenancy' because, of course, the supports needed to make the whole thing work are often closely related and not reducible to, for example, just understanding a tenancy agreement. That said, the most commonly reported needs related to money, finance, and bills; accessible information; support for when things go wrong; support to find a place and move in.

In terms of support to rent, in the first place, we heard about the general level of complexity in the system and the lack of accessible information about tenancies, bidding systems, and tenancy agreements. One person said that they had found using the bidding system complicated and had initially made some bad decisions:

I found it difficult at first because with me not being very good at geography, there were some places I didn't know where they were and if there were like any convenience stores around to get your essentials and if any of my friends were around there either. So I mistakenly bid on two areas, you know, accidentally. I said to council, 'Can I remove these please cos I kinda don't know where they are.' So they did, thankfully. (Holly)

Some people had to navigate the system largely alone and said that they did not really understand the contractual details of their tenancy:

Looking back I think I needed someone to help me understand things in the contract. My social worker at the time wasn't available to come with me on the day I went to pick up the keys. I pretty much had to go and do that myself. (Matt)

The general inaccessibility of renting a home, buying insurance, paying bills, and managing money was the main source of concern and the greatest articulated need. We heard no more than one or two examples of information being presented in easy-read or accessible formats. People described the paperwork they received about bills and their tenancy as, 'confusing', 'intimidating' and 'complicated.' Please make it plain English like so we can actually (laugh) understand it! (Val)

We cannot overstate the importance people gave to the need for help with money and other tenancy-related matters and the stress it could cause:

Form filling, I find difficult. I find that difficult. All you want is to move in, live the life you want to lead and enjoy the surroundings without the paperwork. (David)

I need someone to help me manage my bills and like issues with the housing. Had a social worker ring me last week and not a clue. 'Have you tried going to Citizens' Advice?' Not a clue. (Mathew)

We heard a lot of examples when people wanted support to make complaints or contact people about repairs or financial matters. Sometimes participants felt they were not getting anywhere themselves and/or were being 'fobbed off' (Andrew). One person highlighted that the system for complaining or logging a problem had gone from an in-person process to solely on-line. They had endured a faulty boiler for over a year:

I can't speak to them directly. The office is closed now. So it's all on the computer, but I haven't got a computer. (Janet)

One person said he would give his social housing provider a 3 out of 10 for communication. He was aggrieved that despite paying a service charge it was very hard to get hold of anybody to do a repair and he and his wife had been without a working cooker for several months – ‘... they said, if it goes wrong again it’s your problem, and I said, ‘No, because we are disabled!’ (Donald)

DO ADULT SOCIAL CARE PROFESSIONALS/SERVICES HELP?

All but two participants in the study said that they did not have as much support to manage a tenancy as they would like. Given the focus of our research, we asked people specifically about who, if anybody, was helping from adult social care. Housing officers were the most commonly cited source of support, including those employed by the local authority and social housing providers. This is an interesting finding to us given that housing officers are sometimes regarded as somehow tangential to *mainstream* social care. People renting from private, individual landlords did not, as we might expect, have access to a housing officer. Of the 30 people renting from social housing, seven referenced the existence, input, and support from housing officers:

A: I’ve got the email address to the housing officer, so yeah I’m alright.

Q: You can get hold of them?

A: Yeah. (Jane)

However, of these seven, five said that the support had dwindled to almost nothing over time and one person had been allocated a housing officer but had never had any interaction:

A: We never see the housing officer.

Q: Do you have a housing officer or not?

A: We do but we, we never see her. (Lucy)

A: I met the housing officer about three times. That was back then. (Ellen)

A: We was having the housing officer round; we saw her about four times, and she’s never been back since. (Val)

Q: Do you have a housing officer helping?

A: Yes, but I don’t know who it is because the one I was under left, so now I don’t have a clue who my housing officer is. (Steph)

Q: Do you have a housing officer still?

A: I don’t know really, cos I think she retired; so I don’t know who took over her place. (Bill)

A: Trying to talk to the housing officer is a nightmare, he’s a nightmare to get hold of... we got told in our contract, every couple of months the housing officer will ring you and see how everything’s going. Nothing. Nothing. (Holly)

Social workers were directly referenced just a couple of times including positively by one person who had help from their social worker to find the place they rented but no longer had any engagement. In the other instance the communication had lapsed – ‘I’m supposed to have a social worker, she said she’s a social worker, but I haven’t seen her.’ (Bill)

The role of formal and statutory social care was more visible in the assessed support packages that some people had to support them in their day to day lives. So, we heard about the role that support workers (sometimes employed as personal assistants with a direct payment) but more commonly as agency support staff. The support varied in nature and quantity but included:

Someone comes round once a week for an hour. At the moment I’m shredding...trying to get rid of old papers...I’m not quite sure about it, so she told me, just keep the recent ones. (Anne)

Staff come in in the evenings and if we get letters saying that the rent’s gone up or whatever, then staff go, ‘Ooh that sounds a bit dodgy, I’ll go and talk to your social, or to your direct payment person.’ (Mr Sunshine)

I get 8 hours tenancy related support, so if like I have a problem with like bills, shopping, that kinda thing. It’s in me support plan. (Ian)

We also heard about instances of support from a local housing charity, a citizens advice bureau and one person’s social housing provider, who employed a tenant liaison worker the person valued. Neighbours, employers, friends and family, and self-advocacy groups were also mentioned as important sources of help. One person’s neighbour helped them organise and put out their recycling – ‘It’s really good when you’ve got neighbours like that.’ (Mary-Lou)

There were people in our study who received no social care support at all. A small number of people had been offered a few hours a week but were going to be charged for them and this cost was usually prohibitive.

They wanted to charge me £14 for a couple of hours which I couldn’t afford at the time, so I

stopped. I always get money worries and especially if like utility companies, like electric companies, they get folded; mine's gone through liquidation, what do they call it? When it comes to finances I do need help, even though I've got a mild disability I do need help and I don't get that. (David)

Concerns about the cost of support extended to those who would have liked more:

Q: Would you like more support or is it about the right amount?

A: I'd have some more...but they restrict yer, don't they, financially? Like we're all equal except you have to pay for it to be more equally. (Andrew)

Reviews of support plans were described as stressful as people anticipated cuts – 'I get two hours a week but that might change in the future because, as I said, there's a meeting.' (Jane). One person had their support cut from six to two hours during the COVID-19 lockdown, and two people had had their support needs reviewed and cut completely:

I did have support and now they stopped it. Sometimes I want support and they say, 'Oh you don't need it, you don't need it, you don't need it.' (Donald)

Two people were happy with the amount of support they got – 'I think I'm happy with the support I get' (Christopher); 'It's about right, yeah' (Ian), and one person found that they had too much support at one point and wanted it decreased – 'One support worker was enough. I definitely didn't want two coming in.' (Ellen)

The provision or absence of social care was significant and was shaping choices, sometimes in helpful but sometimes in constraining ways. We did not get a strong sense of many people self-directing their social care. Some people reflected on how in fact they felt that the operation of social care served to control aspects of their life. We think these quotes tell us important things about how support issues can run as a thread across people's lives and time and identity. Good support which is empowering has a ripple effect and the same is true when that support (or lack of) acts to disempower:

So I've got to somehow explain... I've realised, in social care I've realised that all my decisions are made by someone else, cos if you think about it I only moved into this flat because someone else said so, you only get extra hours if someone else says so, you only get community supported living if someone else says so, you only get to do your favourite activities if your support worker wants

to do them... making your own home is quite a responsibility; you, you have to be an adult and I'm not sure (laughs) I'm not sure I'm ready to do that just yet. Yeah, the good days are good, but it can be quite scary, and I think there's that, you know, you know, I'm not afraid to say that it's scary, because you want to try and be as independent as you can but actually you realise that you need a bit of help, everybody needs a bit of help but just some people need more than others. (Joshua)

Q: What sort of things do you do with your support workers?

A: No, no, they, they do for me and that's one of my big bugbears. They do it for me not with me. They wouldn't know what person-centred meant. It's been so bad that there have been times when I've wanted, when I've wanted to end it all because...I have...I have given up... cos I'm just so worn down. (Michael)

A: I think the staff you get now are less person-centred and there's no way of complaining or owt. It's like you get this on one day and you'll get that on another day. Like Monday is shopping.

Q: It's not your choices?

A: No, it in't. (Lucy)

DISCUSSION

We have presented findings which are fairly uncomplicated. Having found that people in our research were, overall, very positive about renting their homes, we have more disappointing data to report about the amount and dwindling amount of support afforded by adult social care in order to maintain a tenancy. Social workers were directly referenced just a couple of times. There are challenges in common across our participants relating to getting enough, and getting good enough, support, especially in relation to money, information, and paperwork relating to renting a home. Our findings echo those of Bowey et al. (2005, p. 146) not just in relation to the seemingly obvious need to restate the importance of, '...a real home', but also in relation to the barriers that prevent people with learning disabilities having say and choice in relation to where they live.

Most people were getting small amounts of social care support and whether it was too much or too little (usually the latter) it met a very direct set of needs relating to having a tenancy. The provision of housing related support from social housing providers appeared inconsistent; in addition, this had reduced over time and people regretted

this change (we link to the start of the paper and the decades old concern from [Simons and Watson, 1999](#) about the dangers of losing so-called low-key support.).

As with many research studies that collect data on ‘who gets what’ there was no remotely obvious pattern as to why some people got two hours of support and some got twenty ([Thorlby et al., 2018](#); [Victor, 2010](#)). We mostly seem to accept this as a quirk and/or failing of our current system. In the same way we are mostly resigned to the absence of consistent social work support for people with learning disabilities with relatively low levels of support needs ([Roets et al., 2019](#)). We also see the dramatic creep of charges for social care ([Bolderson, 2023](#)), which as one participant pointedly remarked, ‘Like we’re all equal except you have to pay for it to be more equally’ (Joshua).

The false moral and financial economy of squeezing support or offering none at all is, we think, pretty obvious. When we read of the abuse and killing of people with learning disabilities in ‘specialist placements/units’ ([Willis, 2020](#)) we think that the much wider population of people with learning disabilities are, if unsupported, only a few life-steps away from falling into crisis: whether that be accumulating arrears, facing eviction, being exploited in their homes, or struggling with mental health. We know for example that the number of people with learning disabilities in the homeless population is increasing ([Hatton, 2023](#); [McKenzie et al., 2023](#)) and that a lack of housing choice in the community prolongs unnecessary stays in wholly inappropriate settings ([Ince et al., 2022](#)). We also hear the widespread concerns of ageing family members about where their son or daughter will live after their deaths ([Anderson-Kittow et al., 2024](#)). The gap in financial costs in ‘low-level support’ and ‘high-cost crisis management’ is incomparable. There should also be imaginative ways to support people who might find bills and money, or their landlord or repairs problematic. We heard about self-advocacy groups who were proactive in supporting members with these kinds of problems ([Fenn and Scior, 2019](#)). We also heard about community hubs which brought together support services and offered flexible, reliable support. Capacity building funding to make that kind of offer more sustainable could be one way of preventing problems spiralling.

It is hard to imagine that people at the edges of social care eligibility will face anything other than more moves to cut support to save money. We may use words like ‘austerity’ or ‘cost constraint’ but these are not politically neutral things or objective realities but represent political choices. These choices will, as [Kayley et al. \(2002\)](#) write:

...impact people with mild and moderate learning disabilities in particular, as strict eligibility criteria constrain access to local authority day services and individuals do not have the resources to purchase private provision.

The latest statistics ([NHS England, 2022](#)) indicate that over a third (37%) of working age adults (18–64) with learning disabilities who receive social care support are living with family or friends ([Hatton, 2023](#)). We cannot help but wonder if the opportunities to rent their own place afforded to those who began renting 30 years ago have somewhat dissipated. The centrality of social care and housing support at the time of moving into their own place raises the question as to whether future cohorts will or will not have this support to achieve their goal of their own home.

Recommendations from research carried out by Housing LIN ([Beech et al., 2023](#)) included that local authorities should undertake regular housing needs assessments and publish a relevant strategy every five years. Nationally, there is relevant policy but little in the way of strategy or action and the focus remains on options around supported living – which will suit many, but not all. The *Adult Social Care Reform White Paper* ([Department of Health and Social Care, 2021](#)) includes a focus on housing, new models of care, digital, and technology. NHS England has recently published an action plan *Building the Right Support for People with a Learning Disability and Autistic People* ([Department of Health and Social Care, 2022](#)) which also concentrates on supported housing but does restate the crucial role of suitable housing for people with learning disabilities. The Supported Housing (Regulatory Oversight) Act 2023 obliges local authorities to develop strategic supported housing plans which quantify existing supply and local need, and which may reveal information about the scope of local private rented options for a range of different populations including people with learning disabilities.

The arguments being made here about the possibilities of the rented housing market need contextualising against a backdrop of a general worsening of position for those who rent their homes (as opposed to homeowners), and the well-established precarity of being a renter in the UK. As [Hick et al. \(2024, p. 24\)](#) argue:

.... the evidence of a deteriorating relative position of market renters in many countries, when combined with falling homeownership amongst low-income households, gives rise to concern about housing tenure as becoming an increasingly important social division requiring direct policy attention. This might come about through more stringent rent regulation or by increasing housing allowances, or by increasing housing supply, especially of reduced rent and affordable homes, in an attempt to depress costs.

This is not to be resigned about the possibilities for more growth, investment, and consideration of renting for people with learning disabilities. Whilst the links between social care, housing, well-being, and health outcomes seem to diminish rather than strengthen – conceptually,

as well as in policy, provision, practise, and research (Power and Mee, 2020), we instinctively know about the potentially transforming effect of feeling at home. Social Work Cats and Rocket Science (2023) write:

People want a place called home, a real home, a home that looks like where we all live. A place that is safe and provides sanctuary and is a happy place and is not dependant on rotas, availability, or the disposition or mood of staff who work there. A home that is the most relaxed place on earth, a place that is understanding, compassionate and where conversation and humour prevails. A place where people have their own front door. A door that they choose to open and close to whoever they want and without question.

Our participants reminded us time and again of the positive aspects of having their own front door and a place to call home:

It's okay because we've got our own thing. I've got control. I can turn our heat up and I can turn our heat down. It's everything. (Donald)

ACKNOWLEDGEMENTS

We are grateful to everybody who took part in this research.

FUNDING INFORMATION

This study was funded by the National Institute for Health and Care Research, School for Social Care Research. The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

COMPETING INTERESTS

The authors have no competing interests to declare.

AUTHOR AFFILIATIONS

Eppie Leishman  orcid.org/0000-0002-1100-1784
University of York, UK

David Abbott  orcid.org/0000-0002-3447-5368
School for Policy Studies, University of Bristol, UK

Deborah Quilgars  orcid.org/0000-0003-4167-5947
University of York, UK

Becca Cooper
York People First, UK

Andy Pollin

York People First york, UK

Stephen Lee Hodgkins

York People First, UK

Paul Scarrott

My Life My Choice, Oxfordshire, UK

Sam Clark

Learning Disability England, UK

Lois Beech

Housing LIN, UK

REFERENCES

- Anderson-Kittow, R.J., Keagan-Bull, R., Giles, J. and Tuffrey-Wijne, I.** (2024) "There's a timebomb": Planning for parental death and transitions in care for older people with intellectual disabilities and their families', *Journal of Applied Research in Intellectual Disabilities*, 37(2), pp. e13174. Available at: <https://doi.org/10.1111/jar.13174>
- Beech, L., Copeman, I. and Ghadiali, D.** (2023) *Supported housing for people with learning disabilities and autistic people in England*. Available at: https://www.housinglin.org.uk/_assets/Resources/Housing/Support_materials/Reports/Supported-housing-for-people-with-learning-disabilities-and-autistic-people-in-England.pdf (Accessed: 29 August 2024).
- Bolderson, C.** (2023) "It's the fairness isn't it?" *Experiences of social care charging for disabled adults of working age and their families*. Summary of a dissertation. UCL. Available at: <https://www.inclusionlondon.org.uk/wp-content/uploads/2022/01/Social-Care-Charges-Research-Summary.pdf> (Accessed: 10 February 2024).
- Bowey, L., McGlaughlin, A. and Saul, C.** (2005) 'Assessing the barriers to achieving genuine housing choice for adults with a learning disability: the views of family carers and professionals', *British Journal of Social Work*, 35(1), pp. 139–148. Available at: <https://doi.org/10.1093/bjsw/bch167>.
- Braun, V. and Clarke, V.** (2023) 'Toward good practice in thematic analysis: Avoiding common problems and becoming a knowing researcher', *International Journal of Transgender Health*, 24(1), pp. 1–6. Available at: <https://doi.org/10.1080/26895269.2022.2129597>
- Buetow, S.** (2010) 'Thematic analysis and its reconceptualization as "saliency analysis"', *Journal of Health Services Research & Policy*, 15(2), pp. 123–125. Available at: <https://doi.org/10.1258/jhsrp.2009.009081>
- Department of Health and Social care.** (2021) *People at the Heart of Care Adult Social Care Reform White Paper*. London: The Stationary Office.
- Department of Health and Social Care.** (2022) *Building the Right Support for People with a Learning Disability and Autistic People Action Plan*. London: The Stationary Office.
- Fenn, K. and Scior, K.** (2019) 'The psychological and social impact of self-advocacy group membership on people with intellectual disabilities: A literature review', *Journal*

- of *Applied Research in Intellectual Disabilities*, 32(6), pp. 1349–1358. Available at: <https://doi.org/10.1111/jar.12638>
- Hassiotis, A.** (2015) *Engaging service users in identifying priorities for research on intellectual disabilities*. Available at: <https://www.ucl.ac.uk/intellectual-developmental-disabilities-research/sites/intellectual-developmental-disabilities-research/files/finalreport21jan2015.pdf> (Accessed: 9 February 2024).
- Hatton, C.** (2023) *What do the latest statistics say about social care and adults with learning disabilities? 8 key messages (and 0 graphs)*. Available at: <https://chrishatton.blogspot.com/2023/10/what-do-latest-statistics-say-about.html> (Accessed: 30 January 2024).
- Hick, R., Pomati, M. and Stephens, M.** (2024) 'Housing affordability and poverty in Europe: on the deteriorating position of market renters', *Journal of Social Policy*, pp. 1–24. Available at: <https://doi.org/10.1017/S0047279423000703>
- Ince, R., Glasby, J., Miller, R. and Glasby, A.M.** (2022) "'Why are we stuck in hospital?'" Understanding delayed hospital discharges for people with learning disabilities and/or autistic people in long-stay hospitals in the UK', *Health & Social Care in the Community*, 30(6), pp. e3477–e3492. Available at: <https://doi.org/10.1111/hsc.13964>
- Kaley, A., Donnelly, J.P., Donnelly, L., Humphrey, S., Reilly, S., Macpherson, H., Hall, E. and Power, A.** (2022) 'Researching belonging with people with learning disabilities: Self-building active community lives in the context of personalisation', *British Journal of Learning Disabilities*, 50(3), pp. 307–320. Available at: <https://doi.org/10.1111/bld.12394>
- Kings Fund.** (1980) *An Ordinary Life: Comprehensive Locally-based Residential Services for Mentally Handicapped People*. London: The Kings Fund.
- Leishman, E., Quilgars, D., Abbott, D., Clark, S., Cooper, B., Pollin, A., Hodgkins, S. and Scarrott, P.** (2023) 'Working collaboratively with an online advisory group of people with learning disabilities in covid-times: carrier pigeons, cats and drones', *Research Involvement and Engagement*, 9(1), p. 79. Available at: <https://doi.org/10.1186/s40900-023-00494-7>
- McKenzie, K., Murray, G., Metcalfe, D., Robson, R., Kaczmar, M. and Shirley, A.** (2023) 'Using the learning disability screening questionnaire to help identify people with an intellectual disability in homeless services', *Journal of Applied Research in Intellectual Disabilities*, 36(6), p. 1319–1325. Available at: <https://doi.org/10.1111/jar.13150>
- NHS England.** (2020) *Adult Social Care Activity and Finance Report, England - 2019–20*. Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2019-20#resources> (Accessed: 15 October 2024).
- NHS England.** (2022) *Adult Social Care Statistics in England: An Overview*. Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-statistics-in-england/an-overview#chapter-index> (Accessed: 16 October 2024).
- O'Dowd, A.** (2023) 'Life expectancy of minority ethnic learning-disabled people is half that of white counterparts', *BMJ: British Medical Journal (Online)*, 382, p. 1713. Available at: <https://doi.org/10.1136/bmj.p1713>
- Power, E.R. and Mee, K.J.** (2020) 'Housing: An infrastructure of care', *Housing Studies*, 35(3), pp. 484–505. Available at: <https://doi.org/10.1080/02673037.2019.1612038>
- Quilgars, D., Leishman, E., Abbott, D., Clarke, S., Cooper, B., Hodgkins, S., Scarrott, P., Pollin, A. and Beech, L.** (2024) "'I wouldn't change my flat for anything'" Is there scope for more people with learning disabilities to rent their own homes?', *British Journal of Learning Disabilities*, 52(2), pp. 362–370. Available at: <https://doi.org/10.1111/bld.12584>
- Roets, G., Dean, H. and Bouverne-De Bie, M.** (2019) 'Disability rights and disability studies in social work: Uncovering different interpretations of rights and needs of people with learning disabilities in social work practice', *European Social Work: A Compendium*, pp. 201–224. Available at: <https://doi.org/10.2307/j.ctvscxsrf.14>
- Simons, K. and Watson, D.** (1999) *The View from Arthur's Seat: A Literature Review of Housing and Support Options' Beyond Scotland*. Scottish Executive Central Research Unit.
- Smith, S.** (2022) *The Good Lives Framework*. Birmingham: Learning Disability England.
- Social Work Cats & Rocket Science** (2023) *Why Social Work?* Available at: <https://socialworkcatsandroketsscience.com/2023/10/15/why-social-work-2/> (Accessed: 16 October 2024).
- Thorlby, R., Starling, A., Broadbent, C. and Watt, T.** (2018) *NHS at 70: What's the problem with social care, and why do we need to do better?* Health Foundation.
- Victor, C.R.** (2010) 'Where now for social care in England?', *BMJ*, p. 340. Available at: <https://doi.org/10.1136/bmj.c2017>
- Williams, V., Marriott, A. and Townsley, R.** (2008) *Shaping our future: a scoping and consultation exercise to establish research priorities in learning disabilities for the next ten years*. London: National Co-ordinating Centre for NHS Service Delivery and Organisation.
- Willis, D.** (2020) 'Whorlton Hall, Winterbourne View and Ely Hospital: learning from failures of care', *Learning Disability Practice*, 23(6). Available at: <https://doi.org/10.7748/ldp.2020.e2049>

TO CITE THIS ARTICLE:

Leishman, E., Abbott, D., Quilgars, D., Cooper, B., Pollin, A., Hodgkins, S.L., Scarrott, P., Clark, S. and Beech, L. 2024. The Role of Adult Social Care in Supporting People with Learning Disabilities Who Rent Their Own Homes in England. *Journal of Long-Term Care*, (2024), pp. 403–413. DOI: <https://doi.org/10.31389/jltc.309>

Submitted: 12 February 2024 **Accepted:** 30 August 2024 **Published:** 21 October 2024

COPYRIGHT:

© 2024 The Author(s). This is an open-access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs 3.0 Unported International License (CC BY-NC-ND 3.0), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited. See <http://creativecommons.org/licenses/by-nc-nd/3.0/>.

Journal of Long-Term Care is a peer-reviewed open access journal published by LSE Press.