ORIGINAL ARTICLE



Researching belonging with people with learning disabilities: Self-building active community lives in the context of personalisation

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Accessible Summary

- We wanted to understand more about how people with learning disabilities are building active community lives to help belonging.
- We spoke to 39 people from 29 different support organisations, 7 local authority representatives and 43 people with learning disabilities.
- They said belonging was about having the time to connect with other people
 in "everyday" places, being part of a supportive network and having the right
 choice and information.
- Belonging is like a cake. It needs the right ingredients. These ingredients include the right combination of people, places and times.
- Because of cuts to funding, many people with learning disabilities lack the right support, choice and information to access their communities. This is not belonging.

Abstract

Background: This journal article draws on findings from a research project that examined how people with learning disabilities and their allies were seeking to build a sense of belonging. We wanted to focus on the concept of "belonging" in the context of personalisation and reduced government social care funding. Specifically, we sought to understand how people with learning disabilities and their supporters were coming together to "self-build" networks of support including friendship clubs and self-advocacy groups to enable a greater sense of belonging in their local communities.

Methods: Qualitative interviews were conducted with seven local authority representatives across four case study areas in the UK, as well as 39 staff across 29 organisations providing a range of day and evening support and activities. We also talked to 43 people with learning disabilities across the four areas about their experiences.

Findings: Our findings demonstrate how belonging involves a complex configuration of actors, places, times, relationships and institutional roles (much like the ingredients in a cake). The ways in which belonging intersects with agency and choice was also identified as an important and novel finding of our study.

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Conclusion: While belonging is often presented to people as a desirable and realisable outcome of social inclusion policies, cuts in funding and a lack of appropriate support frustrate people's desires to meaningfully belong with other people in their local community. This demonstrates the importance of supporting social environments that meet people's needs for social connectedness and belonging.

KEYWORDS

inclusion, support, belonging, community, personalisation

ACCESSIBLE VERSION

This journal article comes out of a research project. This project wanted to find out how people with learning disabilities and their allies are "self-building" their daily lives when responsibility for daytime social care and support is handed to them (Figure 1).

For this article, we wanted to find out about how people with learning disabilities are building support and groups of friends (e.g. friendship clubs or "getting out" groups) in ways that promote belonging (Figure 2).

This article was written by some members of the research project advisory group based in Scotland, with a team of researchers at the Universities of Dundee and Southampton (Figure 3). To make this article more accessible we have decided to use photographs. pictures and artwork that we have made (as well as text)—in order to explain our findings. Some of these are not like the easy-read style but we felt this was a better way of representing what we found, and as a way of telling our story.

Using different research methods (Figure 4), we spoke to 39 people from 29 different support organisations, 7 local authority representatives and 43 adults with learning disabilities.

We looked at their experiences of belonging and not belonging. We grouped what people said into "themes"—these are our research findings. To make sense of the data we met together to talk about what belonging means to us. We also made collages (Figure 5)—using pictures, card and other craft materials to explore what it felt like to belong and not belong.

Belonging is like a cake—it needs the right ingredients. These ingredients include the right combination of people, places and times (Figure 6).

For the participants in our study, belonging was about, being able to spend time with friends as well as family, being an active part of the community, feeling welcome in everyday places and having the time to connect with other people and places (Figure 7).

Local friendship and self-advocacy groups offer an important source of belonging. These groups provide support and opportunities to make and meet friends, often with other people with learning disabilities. These are seen as a positive and supportive network to be part of (Figure 8).

They also provide opportunities for people to "give something back" to their community (Figure 9)—for example through volunteering, supporting others or campaigning.

Belonging is not always about belonging to a specific group. People can also find belonging in "everyday" spaces (including favourite shops, local sports centres and at church) (Figure 10).

But other "everyday" places can feel less welcoming. For example, some participants said that they often feel unwelcome on public buses—bus drivers can be rude or impatient and other people using the bus are not always friendly or nice (Figure 11).

With fewer day centres available, people can feel isolated if they do not have opportunities to connect with others (Figure 12).

For those without family or the ability to meet up independently with friends, weekends and evenings are often spent stuck at homethis is "not belonging" (Figure 13).

Cutbacks make it difficult for people to have meaningful choice about where to go and who to spend time with (Figure 14).

It can be difficult for people who are more isolated or "stuck at home" to have this choice and information. This can make people



FIGURE 1 Project logo - the idea for the logo came from the research project advisory groups in Scotland and England, and was designed by a disability arts organisation based in Brighton

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FIGURE 2 The buttons in these pictures were used by the research group to explore, discuss and illustrate feelings associated with belonging and not belonging





FIGURE 3 Some of the research group – including one of the academic researchers and members of the advisory group based in Scotland

feel like they are not part of their community and that they do not belong (Figure 15).

2 INTRODUCTION

Social care provision is becoming more personalised for people with learning disabilities in the UK. This has involved a shift in emphasis towards personalised care, community-based support and meaningful inclusion or "belonging" (Power & Bartlett, 2018). Increasingly, people in need of social care are being asked to take more responsibility for organising care, support and activities. For example, the move from institutional funding to personal budgets in adult social services is offering some people with learning disabilities the chance



FIGURE 4 The different types of research methods used for the study [source: photosymbols.com]

to gain more independence, arrange support and take control of their life. However, there has been a long-term reduction in social care budgets and a tightening of eligibility criteria affecting the provision and sustainability of new initiatives. Malli et al. (2018) show through their synthesis of relevant research literature that people with learning disabilities have been disproportionately affected by cuts in local

FIGURE 5 Photograph of the research group during a participatory data analysis session

authority services in the UK over the past decade and are at greater risk of social isolation. Day centres, adult education centres and other services are closing or have limited availability. While personalisation has sought to increase opportunities for people with learning disabilities to live and belong in their communities through accessing community-based services and amenities, cuts in funding and a lack of appropriate support frustrate people's desire to meaningfully feel a part of their local communities (Hall, 2010; Power, 2013). Understanding how individuals and groups can be facilitated to cocreate their own networks of support and learn to live and belong in the community within this policy landscape is, therefore, one of the key challenges for commissioners, organisations and families.

Within the current context, there is evidence that in some areas of the UK people with learning disabilities are "self-building" their own networks of support, in their efforts to lead active lives in the community (Power & Bartlett, 2018; ADASS, 2017). With the input of families, friends, advocates and more bespoke, grassroots and empowering forms of support provision, individuals are seeking to build supportive networks to facilitate greater belonging as well as navigate the changing landscape of social care. Activities include taking part in and co-constructing local networks of support including friendship and self-advocacy groups. These initiatives develop people's friendships and confidence to engage in their communities, thus working towards achieving greater senses of belonging—a concept we explore in more detail in the next section. We use the term



FIGURE 6 The buttons in this picture were used to represent the different 'ingredients' needed to make belonging happen

"self-building lives" to indicate this engagement in local networks which are co-created from the assortment of local resources and relationships available. We also explore how these activities have evolved in the context of changing social care policy and provision, that has seen a long-term reduction in social care budgets and a tightening of eligibility criteria affecting the provision and sustainability of new initiatives (Pearson & Ridley, 2016). Thus while these initiatives are proving more important in the wake of declining care services, the wider changes to social care are undermining the foundations that underpin them.

In this article, we examine the circumstances by which people create a sense of belonging within this context and the role that local initiatives and networks play. We first explore what belonging means to people and then examine the types of initiatives that facilitate such an experience, including self-advocacy, friendship and meet up groups. This article was written by members of the one of the research project advisory groups and academic researchers at the Universities of [omitted for review].

3 | THE CONCEPT OF "BELONGING"

Belonging is a concept that is widely used in everyday talk—perhaps reflecting the fundamental importance of belonging to people's lives

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FIGURE 7 Collage made by a member of the research group – to illustrate feelings of belonging

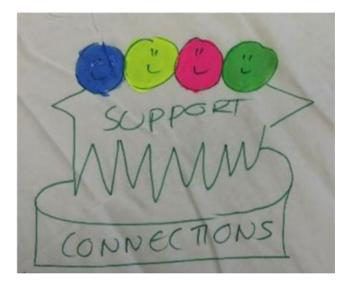


FIGURE 8 Image drawn by a member of the advisory group during an arts-based activity to illustrate the importance of being supported to make and meet friends

and "its power [...] to make communities and collectives, to bring together and to separate in the most intimate, loving or violent ways (Wright, 2015, p.391). Indeed, if asked to think about what it means



FIGURE 9 Photograph taken by the research group to depict 'helping hands' and the importance of volunteering and 'giving something back'

to "belong" somewhere, most of us are able to recall significant emotional encounters that we associate with a feeling of belonging or not belonging, and the impact that this had on us. Despite its common usage in everyday language, "belonging" remains a rather nebulous concept, often difficult to define or pin down. Indeed, the literature on belonging engages with this concept in diverse and varied ways (e.g. as a form of place attachment, psychological identity or spatial politics (Wright, 2015), while often assuming that its meaning is self-evident.

The concept of belonging has perhaps received its fullest theoretical development in geography, and geographers have long used belonging as way of understanding issues of spatial ex/inclusion, power, difference and inequality (Morrison et al., 2020). In the geographic literature, belonging is defined as an emotional or embodied attachment to place, of feeling secure, accepted or "at home" in familiar surroundings (Antonsich, 2010; Hall, 2010; Yuval-Davis, 2011). While belonging is often used to describe the emotional experience of feeling attached to a specific locality or place, others argue that belonging is also about the social, economic and political processes which "construct, claim, justify or resist forms of sociospatial inclusion/exclusion" (Antonsich, 2010, pp.4-5) or a "politics of belonging" (Wright, 2015,p.393). To this end, the concept of belonging has been used in the disability studies literature as a way of critiquing social policies which tend to focus on a rather narrow conception of inclusion, one that principally involves securing paid employment or independent living. For example, the number of people with learning disabilities in paid employment continues to be very low at around 6% of adults known to their local authority (NAO, 2017). Similarly, people with learning disabilities often depend on others for their care and support and have limited financial means to participate in community life (Power, 2008). As Hall (2005) observes, this leaves many people with learning disabilities in an impossible position, typified by everyday experiences of social exclusion on the

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FIGURE 10 Photograph of Gary (one of the research participants) outside his favourite shop. During Gary's interview one of the researchers asked him where his favourite place was, and he replied "the hiking shop" because he likes the clothes and "the staff are friendly and nice"



FIGURE 11 Photograph taken by a member of the research group of their local bus route - to illustrate feelings associated with independent travel

one hand, and limited opportunities to meet the demands of social inclusion (narrowly defined) on the other. Disability scholars, people with learning disabilities, their families and allies are, therefore,

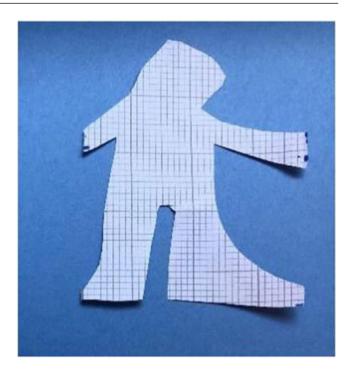


FIGURE 12 Part of a collage created by a member of the research group to depict feelings of isolation, loneliness and 'not belonging'

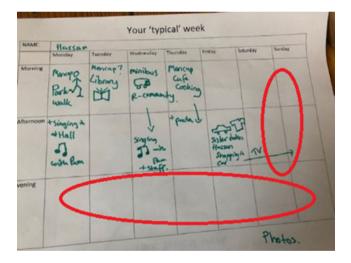


FIGURE 13 This is a timetable that one of the research participants completed to explore what they did in a 'typical week'. We have highlighted some of the blank spots where this individual had not much going on i.e. most evenings and weekends. This was a common story for many of the people who took part in our study

increasingly turning to the concept of belonging as a way of describing the experiences and aspirations of people with learning disabilities and to challenge the narrowness of the goal of inclusion. In this way, belonging has been used to add nuance to what it means to feel "in" or "out" of place (Morrison et al., 2020. For the purposes of this paper, belonging is defined as "meaningful engagement and reciprocal relationships within local neighbourhoods or networks



FIGURE 14 Part of a collage created by a member of the research group to illustrate the impact of cuts to funding and services



FIGURE 15 Image selected by a member of the research group to represent the feeling of being isolated or 'stuck at home'

between people with and without disabilities" (Power, 2013, p.69). It therefore moves beyond normative or ableist ideals associated with social inclusion policies (e.g. having a paid job, living on your own or being independent) drawing attention to the many different ways in which people with learning disabilities people can feel accepted, welcome or "in place." Given our larger research project's aim was to examine how people were "self-building" networks to create active community lives, our analysis of the belonging literature for this paper was informed by an implicit acceptance that belonging was an inherent practice. Such a practice involves for example participation in networks of support and voluntary initiatives, rather than being a passive experience. In the literature, this is illustrated with examples of people with learning disabilities engaging in community-based activities, such as art-based projects, gardening, environmental projects and community farming activities (e.g. Hall, 2005, 2010; Hall, 2013; Hall & Wilton, 2017; Parr, 2008; Kaley et al., 2019).

Through taking part in these types of activities, people with learning disabilities gain greater opportunities for "convivial encounters" (Wiesel & Bigby, 2016; Bigby & Wiesel, 2019), where strangers experience temporary shared identification with each other. For people with learning disabilities, encounters with strangers are an important aspect of belonging and can create opportunities to achieve more meaningful levels of engagement, categorised as "everyday recognition" and "becoming known" within their communities (Bigby & Anderson, 2021). There has also been greater engagement with how these encounters can be facilitated, through for example the presence of a dog, and participation within social enterprises, community groups, classes and volunteering (Bould et al., 2018; see also Bredewold, 2020). This work helps to demonstrate how belonging is not merely about being placed within an environment we generally think of as inclusive but also taking part in practices that help people to "fit in within a specified place or environment" (Power, 2013, p.69). To build upon these studies, we focus on the circumstances by which people can work towards a sense of belonging and how they can be supported to navigate the complex interplay of environmental and relational factors. Here, the wider social care context is relevant in shaping the practices that people with learning disabilities and their supporters can engage in.

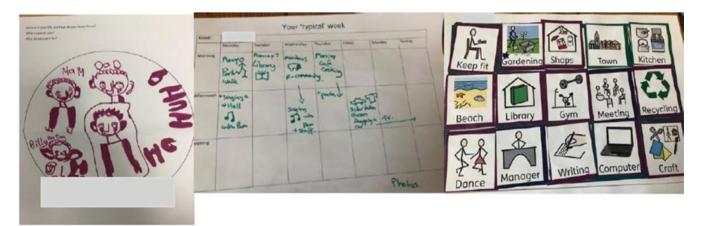


FIGURE 16 Examples of interview facilitation materials

In the UK, this context has evolved in a way that has shaped how people can achieve and build upon their encounters with others. Social care policy has created a personalised yet increasingly spatially and temporally fragmented, complex and dispersed support landscape, with expanded private and voluntary sector provision alongside increasingly constrained local authority services. This has impacted 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.

In response to this context, community-based friendship clubs and self-advocacy groups and local voluntary initiatives (where they exist), have become more increasingly important for people with learning disabilities, although high demand can mean that opportunities are limited. This is reflected in the extensive literature on the role that self-advocacy groups play in social inclusion (e.g. Gilmartin & Slevin, 2010; Anderson & Bigby, 2015; Tilley et al., 2020). In the absence of coordinated support services, responsibility for working towards belonging has largely been placed on individuals and families, and the community sector, comprising local charities, micro-enterprises and peer support groups. Beyond the immediate supportive relationships found within private spaces such as the home or other sites of "care" (e.g. within the day centre), the process of creating belonging therefore involves building capacity to bridge connections with local community members and allies in ways that may widen a person's support networks (Hall, 2010). We thus situate the focus of our enquiry within the context of individuals creating senses of belonging through their own local friendship and self-advocacy groups, as well as volunteering opportunities. We next turn to outline the study which underpins our paper.

4 | THE STUDY

The research was funded by the ESRC and conducted by researchers at the Universities of Dundee and Southampton. Both universities gave ethics approval for the research. The research was determined through working closely with the Southampton Platform for Inclusive Research and Ideas Together (SPIRIT), and our national stakeholder partners Think Local Act Personal (TLAP) and the Scottish Commission for Learning Disability (SCLD). SPIRIT formed our initial advisory group in England, which expanded to include a range of disabled people's organisations in Scotland. The research team collaborated with the advisory group partners throughout the project to formulate the research methods, to frame questions, and hone the methods, and discuss research findings and communication strategies. With this engagement, the aim was to find out about how people with learning disabilities are experiencing and responding to the changes in social care, the learning that was involved, and how support organisations are adapting to the changes. In this article, pseudonyms are used instead of participants real names to ensure anonymity.

5 | METHODS

As mentioned, the first phase of the research involved scoping community-based day support provision in four case study areas in the UK—two in England and two in Scotland (one urban and one rural in each). We interviewed 7 local authority commissioners in social care/learning disability and worked with the local advisory groups to map activities and networks in the case study areas. From this, we interviewed 39 staff and volunteers from 29 organisations providing support and activities to fill the gap in community-based support (as formal social care and support was withdrawn) and we spent time at meetings and events of eight of them. Many of these were microenterprises and charities, some user-led organisations and some day centres in transition; they included voluntary work and training initiatives, community living support networks, self-advocacy and friendship groups.

The second phase of the study involved people with learning disabilities more directly. We worked with gatekeepers in communityfocused support organisations in each area to recruit 43 people with learning disabilities to tell us about their experiences of self-building their daily lives. Participants were 24 men, 19 women, aged 18-70, two Asian British otherwise White British. We recognised that these would not be representative of the wider group of people with learning disabilities, many of whom would not be directing lives in the community and whom it is more difficult to reach, particularly people with more severe and profound disabilities. We began with focus groups so that participants could support each other and use others' experiences to prompt recall and reflection of their own. Each group met twice so that we could generate a picture of their lives collaboratively and iteratively. As such, the research process was itself inherently relational. Each focus group facilitator had spent time with the participants in their communities, chatting and observing, and this informed the mix of talk and activities they deployed in the focus groups. Activities included discussing photographs they took of their daily lives and creating a circle of people in their lives, a timetable of their typical week and a collage of images of activities in which they participated. The design and use of these materials were informed by our advisory group members. We followed up with individual interviews to understand in more detail the contexts, decision-making, learning and agency involved for each person selfbuilding their daily life (Figure 16).

5.1 | Data analysis

5.1.1 | Phase 1: Developing a coding framework

Participant interviews were transcribed verbatim, and the university researchers on the project analysed the dataset in NVivo using an iterative, deductive and inductive process. Initially, individual researchers focused on exploring different topic areas of interest which were relevant to the overarching research aim and objectives (e.g. the landscape of care, the sustainability of voluntarism, the role

of the state and support initiatives for self-building, the lived experiences of people with learning disabilities, or on the informal, community and lifelong learning evident). Next, a priori and emerging codes from this process were identified and examined together and a coding framework was developed. The analytic process allowed the researchers to identify the places people go and things they do, the roles they take up, the learning they engage in, and the issues that arise in self-building daily lives.

Phase 2: Participatory thematic analysis 5.1.2

As an inclusive research group, the authors of this article analysed some of the research data in more detail to find out what research participants said about their experiences of belonging and not belonging. The data analysis process involved regular meetings between one of the academic researchers and members of the project advisory group, based in Scotland, over a period of 12 months in which relationships, familiar ground, and common assumptions could be built (Nind & Seale, 2009). First, we collated all of the codes we felt were relevant to our research interest of "belonging". This included codes such as—"feeling comfortable or welcome," "sense of connection to a place," "sense of connection to a group," "sense of connection with individuals" as well as codes like "feelings of exclusion" and "stigma(tised)." Next, we examined the coded data segments in extensive detail in order to immerse ourselves in the data, and what people were telling us. This was followed by a thematic analysis of the data. Our methods of data analysis were creative and varied and included "hands on" analysis of the text-based and visual data, and involved cutting up and colour coding relevant sections of participants data—in order to construct our final set of themes. Ideas and evolving concepts were also enabled to emerge through an iterative process of informal discussion and conversations—as well more directed activities such as visual mapping on flipchart paper and creative arts-based activities using photography, collages and other craft materials (Aldridge, 2006; Fox & Macpherson, 2015; Garland-Thomson, 2002).

FINDINGS

6.1 Welcome and accepted in everyday places, at all times of day

For the participants in our study, belonging was about feeling welcome and accepted in everyday places, including favourite shops, local sports centres and at church (Figure 10).

Researcher: And where would you say your favourite place is?

Gary: [name of clothes shop].

Researcher: So is this where you spend a lot of your time?

Gary: Yeah.

Gary: I like the clothes and the staff are friendly and nice. (Gary, participant with a learning disability, qualitative interview).

Researcher: And why is that?

So I like, I like to just spend time in the chapel in prayer. I just relax, just being relaxed in the chapel (Linda, participant with a learning disability, qualitative interview)

Some of the people who took part in this study had individual care and support plans and used a personalised budget to access various services and community-based activities. This was often seen as a welcome development, because it helped people to feel more confident about spending time in their communities in ways that promote belonging.

> You can do anything like going to the restaurant or anything, go there, you can go to a garden centre somewhere, or anywhere like that, if you like, it's going to anywhere in the restaurants when you fancy, it's in town or in [name] or anywhere you like, but build confidence as an end point, and also speak to anybody if you want to. (Penny, participant with a learning disability, qualitative interview)

But being able to access so-called "everyday places" does not always mean that people with learning disabilities feel like they are welcome or "belong" there. For example, some participants said that they often feel unwelcome on public buses—bus drivers can be rude or impatient and other people using the bus are not always friendly or nice (Figure 11).

> And then they [the bus driver] start complaining at you. And they say, "Would you mind hurrying up please, you're holding up the other customers, passengers." [...] And if you do something wrong, like if you put your bus pass on the wrong place, on the machine, they go [tuts and sighs] (Billy, participant with a learning disability, focus group)

Activities such as volunteering and campaigning can help people to feel more welcome in everyday places. This is because they provide people with opportunities to give something back (Figure 9), learn valued skills and have a more visible presence in their community.

> I think a sense of belonging, a purpose, you know. It's back to that old adage, the five dimensions of inclusion. It's just that sense of belonging and purpose, and being able to give back. So, for the likes of [NAME] particularly, he's been able to give back. He's been able to give back to our organisation, to our board, some real benefit to



us, and people historically haven't been given that opportunity (Ellie, advocacy organisation, qualitative interview).

Participation in voluntary roles was common and generally valued by participants. Several participants volunteered at least one day a week. Jobs included sorting clothes in a charity shop, working at a food bank, cleaning a church, helping out at a community centre, fixing up bikes, gardening, working in a bookshop, serving in a café (within a Learning Disability service site), and doing administration tasks for the local authority.

Volunteering therefore provided people with important opportunities to engage with members of the community on a regular basis, for example, by talking to customers or engaging in fundraising activities on behalf of the organisation. These activities were meaningful for the people involved and helped them to gain confidence spending time with new people in other community settings.

Before [...] I don't like mixing in with new people the same age [...] I can mix in with people at the day centre [...] at the end of last year, mixing in with people like normal people, I've had always--, had disabled people around me and since I've got this [volunteering opportunity] mixing outside of [day centre] mixing in with different people my age and see what they do. It's got me the confidence a bit to try it myself, before I wouldn't have done (Nick, participant with a learning disability, qualitative interview).

Some of the participants in our study had busy and active social lives—and were able to spend time with friends, family or their partner during their "free" time in the evenings and weekends. However, not everyone likes to spend time in their communities in the evening because of fears around safety.

In the evening with football if I'm walking back through the park I sort of keep my distance from groups, if anything does happen to me, they're in like the distance, a short distance between me and them, with a group of friends (Daniel, participant with a learning disability, qualitative interview)

Some people in relationships only saw their partner once or twice a week, in some cases always accompanied by a family member or support worker. Other participants did get to do things like go to the pub with friends, but only during the weekdays when they had paid support.

Researcher: And what about friends, have you got any friends that you like to spend time with?

Beatrix: Not really, just at the [day centre].

Researcher: And you go to the pub on a Monday afternoon?

Beatrix: Yeah.

Researcher: And who is that with?

Beatrix: People from the centre (Beatrix, participant with a learning disability, focus group)

For those without relationships or family, or the ability to meet with friends independently, weekends and evenings were often spent alone, stuck at home (Figure 13). This left some participants feeling very isolated and like they were not a part of their community.

Researcher: So it doesn't leave many people to do things with in the evening?

Sarah: Because I don't have my friends in [town] so I don't see anyone, I'm always bored in [town] by myself.

(Sarah, participant with a learning disability, focus group)

6.2 | Being part of a supportive network

For the people with learning disabilities who took part in our study, belonging was about having opportunities to make new friends and engage in social activities. However, some participants spoke of needing to build up their skills and confidence to meet and spend time with new people. Some people lacked practical skills to keep in contact with the people they were friendly with, including competence in independent travel and in using an online social network like Facebook. Local friendship and self-advocacy groups were often a lifeline for people, because they provided them with opportunities to make and meet friends.

Cause it's a group. I'm meeting with groups of people and we're all doing the same thing. Like if you wanted to go, a night out, or a day out, then we're all doing the same thing. And that's why I like doing it (Yvonne, participant with a learning disability, qualitative interview)

Being part of a supportive network of people was also identified by participants as important for peer support. Peer support meant that people were able to learn from each other and solve problems. Participants who had accessed opportunities for peer support had formed sustainable networks of support and were less likely to experience feelings of isolation.

It's good when you're with your peers, so that's what it is, because they know what you're talking about, we all understand each other [...] And also they've got similar experiences I guess, so it's something that you can share (Elaine, participant with a learning disability, qualitative interview)

We found that those people who demonstrated the greatest capacity to lead active lives in the community had done so through peer support found in a self-advocacy group, a steering group, or a friendship group. In our research, we encountered multiple types of

these groups, including neighbourhood networks, friendship clubs and speaking up groups, where people typically met in community settings such as the pub or a community centre. The focus was on building confidence, peer support and mentoring as well as having fun and engaging with people with and without learning disabilities. These groups were facilitated by staff, volunteers and more experienced self-advocates.

The following participant reflects on the lifeline that participation in his friendship club offers him particularly in response to the harsh social care system in which it is situated.

I think it's getting a bit ridiculous in some places about how to get information and where you get information from, and if I didn't work here and we didn't do [friendship club] it would be a million times harder to do anything anyway and we'd all be still scrabbling. I think the austerity and stuff has got worse, not better. I think all that stuff about the universal credit and people's rights and all that stuff, I think it's all got worse. And I'd like to see more people getting together but I know the [self-advocacy] groups helped that because lots more people have got confident in speaking up and getting involved (Kev, participant with a learning disability, focus group).

Participants talked about becoming less shy, more outgoing, more communicative and generally more confident through taking part in group activities in community settings such as nightclubs or theatre trips.

On Saturday we do our own thing, and the Friendship MeetUps' members meet up on their own on Saturday nights. We go to the local bar about once a month. Last Saturday there was about six, seven of us... we arranged it. (David, participant with a learning disability, qualitative interview)

Participants reported that they had attended with support workers or family members initially, but because of these experiences had learned over time how to make things happen, arranging to go for a coffee together or a night out.

With fewer day centres available, people can feel isolated if they do not have these opportunities to connect with others (Figure 12).

If they weren't at a day centre so they were at home and [...] where do they go and, you know, because we know, we know ourselves that when we have looked at people not coming in [to a day centre] [...] they're not going to have 35 hours of support adult care in the community. Some people you know, can go out in the evenings, to go clubbing, to do whatever they want to, you know, have the same opportunities as the rest of us. But for other people with higher support needs kind of thing, it is like,

well, where do they go? (Angela, Disability Day Service Provider, qualitative interview)

One person reported that everyone in his housing block had their own support budget and support worker, so they never did anything as a group. New build accommodation designed without communal spaces also limited socialising opportunities.

For belonging to happen, participants were often reliant on one group or network, and some people worried about the sustainability of this support.

Without [name of organisation] there would be this black hole in my life [...] if it ever closed down I would feel lost (Jake, participant with a learning disability, qualitative interview)

6.3 | Having the right choice and information

In order to lead active lives in the community, people need to know what is going on in their community and the support that is available to them. However, participants' awareness and capacity to find out about the support available and how to access it was hugely variable. Because we were speaking to people who were already engaged in organisations and activities, many participants had learned how to make contact, to keep in touch, and to arrange joint activities. They used skills in texting, using Facebook or WhatsApp, and local travel skills.

The social media side of it is becoming more and more important as well, that's been really [growing], we're finding a lot of our members are actually supporting each other through things like the Facebook page and through Twitter and so on. (Greg, Disability Rights Organisation, qualitative interview)

Some people who took part in our research used smart phones and computers to search for information, network with friends and find out what others were doing. Use of these technologies varied, however. Some people did not have access to them or the skills or capacity to use them.

Alexander: I'm not comfortable or confident enough to use all the aspects of it [speaking about Facebook] Is everyone on Facebook comfortable in using all aspects of it? Does anyone? Jay: Not really, do you?

Leonard: No, I don't do Facebook anyway [...] I might do a text on it, and YouTube and phone calls. That's all I use my phone for. I don't understand the rest of it. There's so many symbols on it isn't there? I just really use YouTube and I do texting now.

(Alexander, Jay and Leonard, participants with a learning disability, focus group)

Being part of a learning disability self-advocacy group or friendship network was the most helpful way of keeping up-to-date, enabling members to share information and experiences with each other. Organisations like these were also able to signpost other organisations and opportunities in the local area. Being part of a local friendship or self-advocacy group also helped people to have a more active role in choosing what to do with their time and to have more control over their daily schedule.

Participants' ability to build an active life in their communities came from gaining the confidence to make their voices heard. For example, our study found that self-advocacy was key to forming the ability to speak out, take part in discussions about important issues and make decisions about their services and support. For example, one participant spoke of how her local self-advocacy group gave her the confidence to tackle issues arising in her house.

I'd go to [the agency], speak to one of the staff in charge. I'd just go across. I'd speak to the manager. (Amy, participant with a learning disability, focus group)

Self-advocacy organisations also provided people with learning disabilities with opportunities to support each other, self-organise, solve problems or raise issues of concern. Some participants were able to take on new roles as mentors, organisers and trainers as part of their involvement in a self-advocacy or friendship group—this helped them to develop the skills and confidence to speak up, influence decisions and raise awareness of local opportunities and common issues.

You have people around you, wherever you are that you can talk to. [Your Voice] was originally set up for people to come together and be allowed a voice. But now you guys [self-advocates] do that, but also decide for yourselves what you're going to do, throughout the year, so you decide what you'll do each meeting (Brendan, self-advocacy organisation, focus group)

It is more difficult for people who are not part of a self-advocacy group or friendship network to have this voice, choice and information. This is because these individuals are already quite isolated or "stuck at home" (Figure 15) and may be solely reliant on their support worker or care manager for information. This can make people feel like they are not part of their community and that they do not belong.

My support workers, they would ask me what I wanted to do that day, but I didn't know and they never gave me much choice [...] we would go to the café and they would talk to each other and not talk to me and I felt like a spare wheel [...] so one day I just got up and walked out of the

café (Lauren, participant with a learning disability, qualitative interview)

7 | DISCUSSION

For the participants in our study, belonging was about being able to spend time with friends as well as family, being an active part of the community, feeling welcome in everyday places and having the time to connect with other people and places. Belonging, then, is about both supportive and accessible contexts and the actions and experiences of people. These findings broadly fit with other research on the experiences of people with learning disabilities living in the community (e.g. Mooney et al., 2019) and the wider literature on belonging (e.g. Antonsich, 2004; Hall, 2010; Wright, 2015). We would also agree with Power (2013) however, that feelings of belonging for the people in this study were about more than feeling attached to places where people can feel safe and accepted. Belonging was also about being recognised, understood and valued (Power, 2013-see also Bigby, 2014; Wood & Waite, 2011). For example, voluntary roles were highly valued by participants because they provided people with opportunities to have a more active role and visible presence in their community.

It is important to acknowledge however, that being physically present in a public or community setting does not necessarily mean that a person belongs there. Rather belonging involves a complex configuration of actors, places, times, relationships and institutional roles (Power, 2013) much like the ingredients in a cake (see Figure 6). For example, if a person with a learning disability is only supported to spend time with friends at the pub on weekdays (as was the experience of Beatrix, in our study)—this time spent "out in the community" is not belonging, because that individual is not being afforded opportunities to socialise in the evenings in the same way as their nondisabled peers. Such restrictions can, in turn, close down possibilities for building new connections in the community in ways that enable people with learning disabilities to be seen and understood differently by others. Explicit focus on the importance of time for shaping people's belonging experiences have rarely been explored in the literature—and is useful to consider in the context of people with learning disabilities who have campaigned for their right to lead full and active social lives at all times of the day (e.g. The Stay Up Late campaign).

Belonging is not just about being in the right place at the right time and with the right people. It is also about being able to actively choose who you spend time with, when and where. Antonsich (2004) asks an important question in his seminal paper—who grants belonging? This highlights how belonging is about politics and power as well as feelings and attachments. Often, there is one actor who grants belonging and another who merely receives it. For example, social inclusion policies—which are typically about placing people in the "right" sorts of settings, signify an inherently passive role for marginalised groups, such as people with learning disabilities. As a

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challenge to this, we suggest that self-building lives is about people with learning disabilities having meaningful information, choice and control about what to do with their day. For example, our study found that peer-led networks such as friendship clubs and local advocacy groups provide important forms of collectivised (peer) support, where people can begin to have a more active role in building their own networks, as well as work, leisure and social opportunities (see also work by Gilmartin & Slevin, 2010; Chapman et al, 2012). This demonstrates how people with learning disabilities are coming together to grant *themselves* belonging and is evidence of a shift in control in the design and development of services from the state to individuals and communities. The ways in which the experience of belonging intersects with agency and choice was, therefore, an important and novel finding of our study.

Belonging, we argue, is often presented to people as a desirable and realisable outcome of social inclusion policies (e.g. Care Act 2014; The Keys to Life Implementation Framework and Priorities 2019–2021). But as our study shows, 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. Indeed, the reality is a complex set of contexts, where belonging can be experienced as fleeting or fragile. Austerity policies have made it difficult for people to have a meaningful choice about where to go and who to spend time with in ways that promote belonging. In the UK, for example, there has been a dramatic reduction in community services and infrastructure, such as libraries, leisure centres and further education programmes, as well as rapid closure of day centres across the UK (Mencap, 2012). As our study shows, this makes it increasingly difficult for people with learning disabilities to meaningfully participate in their communities and illustrates the structural fragility of belonging. By drawing on examples of "unfriendly" social encounters, we have also sought to emphasise the interpersonal fragility of belonging, and its impact on the lives of people with learning disabilities seeking to create welcoming spaces in their communities. This demonstrates the importance of supporting social environments that enable people to build social connectedness. To make this happen, policymakers and commissioners need to recognise the value of organisations that facilitate self-advocacy in their local areas, foster connections with them and support them financially. This will help to ensure that people with learning disabilities have access to peer support and self-advocacy opportunities and that these opportunities reach people with learning disabilities in the most vulnerable and isolated situations—where building networks can be a lifeline.

8 | CONCLUSION

In this study, we wanted to find out how people with learning disabilities and their support networks are "self-building" a sense of belonging through leading more active and meaningful lives in the community. As a research group, we were interested in the concept of belonging as a way of exploring the experiences of people with learning disabilities engaged in activities that they co-created.

Getting together to talk about our findings and how they resonated with our own experiences of belonging and not belonging (and the community groups and networks that have helped) was a helpful and interesting process-and enabled us to make better sense of the data and what participants were telling us. For the participants in our study, belonging was about being able to spend time with friends, as well as family, being in and taking an active role in the community, feeling welcome and having the time to connect with other people and places. Local friendship and self-advocacy groups, as well as volunteering opportunities offer an important source of belonging in and of themselves for people with learning disabilities. They can also enable people to build confidence in their wider community. This is because they provide people with opportunities to make and meet friends, feel welcome in the community and offer people with meaningful choice and information about what is going on in their local area. Policymakers and other people in government often talk about belonging as an important thing to have or to aim for. But as our study shows, if people do not access to these informal support networks, belonging is a very hard goal to achieve.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are openly available in UK Data Service (ReShare) reference number [854243].

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REFERENCES

- ADASS (2017). Association of Directors of Adult Services Budget Survey 2017. Available at:https://www.adass.org.uk/media/5994/adass-budget-survey-report-2017.pdf Accessed 31st May 2018.
- Aldridge, J. (2006). Picture this: the use of participatory photographic research methods with people with learning disabilities. *Disability* & *Society*, 22(1), 1–17. https://doi.org/10.1080/09687590601056006
- Anderson, S., & Bigby, C. (2015). Self-advocacy as a means to positive identities for people with intellectual disability: 'we just help them, be them really. *Journal for Applied Research in Intellectual Disabilities*, 30(1), 109–120.
- Antonsich, M.(2010). Searching for belonging: An analytical framework. *Geography Compass*, 4, 644–659.
- Bigby, C. (2014). Being recognised and becoming known: encounters between people with and without intellectual disability in the public realm. *Environment and Planning A*, 46(7), 1754–1769. https://doi.org/10.1068/a46251
- Bigby, C., & Wiesel, I. (2019). Using the concept of encounter to further the social inclusion of people with intellectual disabilities: What has been learned? Research and Practice in Intellectual and Developmental Disabilities, 6(1), 39–51.
- Bigby, C., & Anderson, S. (2021). Creating opportunities for convivial encounters for people with intellectual disabilities: "It looks like an accident". *Journal of Intellectual & Developmental Disability*, 46(1), 45–57. https://doi.org/10.3109/13668250.2020.1812178
- Bould, E., Bigby, C., Bennett, C., & Howell, J. (2018). 'More people talk to you when you have a dog' dogs as catalysts for social inclusion of people with intellectual disabilities. *Journal of Intellectual Disability Research*, 62(10), 833–841.

- Bredewold, F. (2020). Struggling with sameness and strangeness: (Non)-encounters between people with and without intellectual disabilities in two Dutch neighbourhoods. *Journal of Intellectual and Developmental Disability*, 46(1), 15–25.
- Chapman, M., Bannister, S., Davies, J., Fleming, S., Graham, C., Mcmaster, A., Seddon, A., Wheldon, A., & Whittell, B. (2012). Speaking up about advocacy: findings from a partnership research project. *British Journal of Learning Disabilities*, 40, 71–80. https://doi.org/10.1111/j.1468-3156.2011.00688.x
- Fox, A., & Macpherson, H. (2015). *Inclusive Arts Practice and Research: A Critical Manifesto*. Routledge.
- Garland-Thomson, R. (2002). The Politics of Staring: Visual Rhetorics of Disability in Popular Photography. In S. Snyder, L. Brueggemann, J. Brenda, & R. Garland-Thomson (Eds.), *Disability Studies: Enabling the Humanities*. Modern Language Association of America.
- Gilmartin, A., & Slevin, E. (2010). Being a member of a self-advocacy group: experiences of intellectually disabled people. *British Journal of Learning Disabilities*, 38, 152–159. https://doi.org/10.1111/j.1468-3156.2009.00564.x
- Hall, E. (2005). The entangled geographies of social exclusion/inclusion for people with learning disabilities. *Health & Place*, 11(2), 107–115.
- Hall, E. (2010). Spaces of social inclusion and belonging for people with intellectual disability. *Journal of Intellectual Disability Research*, 54(1), 48–57.
- Hall, E. (2013). Making and gifting belonging: creative arts and people with learning disabilities. Environment and Planning A, 45(2), 244-262.
- Hall, E., & Wilton, R.(2017). Towards a relational geography of disability. *Progress in Human Geography*, 41(6), 727–744. https://doi.org/10.1177/0309132516659705
- Kaley, A., Hatton, C., & Milligan, C. (2019). Spaces of care farming: Therapeutic or ameliorating? Social Science and Medicine, 227, 10-20.
- Malli, M., Sams, L., Forrester-Jones, R., Murphy, G., & Henwood, M. (2018). Austerity and the lives of people with learning disabilities. A thematic synthesis of current literature. *Disability & Society*, 33(9), 1412–1435. https://doi.org/10.1080/09687599.2018.1497950
- Mencap (2012). Stuck at Home: The Impact of Day Service Cuts on People with a Learning Disability. London: Mencap.
- Mooney, F., Rafique, N., & Tilly, L. (2019). Getting involved in the community—What stops us? Findings from an inclusive research project. *British Journal of Learn Disabilities*, 2019(47), 241–246.
- Morrison, C. E., Woodbury, E., Johnston, L., & Longhurst, R. (2020). Disabled people's embodied and emotional geographies of (not)belonging in Aotearoa New Zealand. *Health and Place*, 62, https://doi.org/10.1016/j.healthplace.2020.102283
- NAO (2017). Local Support for People with a Learning Disability. Department of Health.

- Nind, M., & Seale, J. (2009). Concepts of access for people with learning difficulties: Towards a shared understanding. *Disability & Society*, 24(3), 273–287. https://doi.org/10.1080/09687590902789446
- Parr, H. (2008). Therapeutic Natures? Urban Gardening, Citizenship and Social Inclusion. In: *Mental Health and Social Space*, H. Parr (Ed.), London. https://doi.org/10.1002/9780470712924.ch4
- Pearson, C., & Ridley, J. (2016). Is personalization the right plan at the wrong time?: Re-thinking cash-for-care in an age of austerity. *Social Policy and Administration*, 51(7), 1042–1059.
- Power, A. (2008). Caring for independent lives: Geographies of caring for young adults with intellectual disabilities. *Social Science and Medicine*, 67, 834–843. https://doi.org/10.1016/j.socscimed.2008.05.023
- Power, A. (2013). Making space for belonging: critical reflections on the implementation of personalised adult social care under the veil of meaningful inclusion. *Social Science & Medicine*, 88, 68–75. https://doi.org/10.1016/j.socscimed.2013.04.008
- Power, A., & Bartlett, R. (2018). Self-building safe havens in a post-service landscape: how adults with learning disabilities are reclaiming the welcoming communities agenda. Social & Cultural Geography, 19(3), 336–356. https://doi.org/10.1080/14649365.2015.1031686
- Tilley, E., Strnadová, I., Danker, J., Walmsley, J., & Loblinzk, J. (2020). The impact of self-advocacy organizations on the subjective well-being of people with intellectual disabilities: A systematic review of the literature. Journal of Applied Research in Intellectual Disabilities, 33(6), 1151–1165.
- Wiesel, I., & Bigby, C. (2016). Mainstream, inclusionary, and convivial places: locating encounters between people with and without intellectual disabilities. *Geographical Review*, 106(2), 201–214.
- Wood, N., & Waite, L. (2011). Emotion, Space and Society editorial: Scales of belonging. Emotion, Space and Society, 4(4), 201–202. https://doi. org/10.1016/j.emospa.2011.06.005
- Wright, S. (2015). More-than-human, emergent belongings: A weak theory approach. *Progress in Human Geography*, 39(4), 391–411.
- Yuval-Davis, N. (2011). The Politics of Belonging: Intersectional Contestations. SAGE.

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