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# *‘I shouldn’t be living there because I am a sponger’* : Negotiating everyday geographies by people with learning disabilities.

**Points of Interest:**

* This article looks at what inclusion policies aim to do and what happens in real life for people with learning disabilities.
* It looks at people’s everyday experiences of inclusion in their communities.
* The findings show how people enjoy inclusion some of the time but face harassment more widely.
* Peer-advocacy is one way that can help people to feel more connected.

**Keywords:** Intellectual Disabilities; Community Care; Inclusion; Exclusion; Independent Living; Belonging.

## Abstract

Learning disability policy has for some time been framed by the goal of *inclusion* which purports to enable people with learning disabilities to lead a ‘life like any other’ person. This paper examines the extent to which this is the case in England, by tracing the lived experiences of people with learning disabilities within their communities. It draws on two interlinked qualitative studies involving interviews that examined their local place-based experiences of inclusion and exclusion. The findings reveal ‘moments of inclusion’ and opportunities for social encounter from peer support, but these were situated amidst wider experiences of exclusion and harassment.

## Introduction

The aim of the paper is to examine one of the foremost goals framing contemporary disability policy – *inclusion* – as it relates to people with learning disabilities. This policy focus on inclusion is evident in learning disability policy in England, the US, and Canada (Power 2014). Indeed, it has gained greater international reach in the wake of being enshrined in the general principles of the UN Convention on the Rights of People with Disabilities (CRPD, Art. 3(c): ‘full and effective participation and inclusion in society’). The policy goal of inclusion is now largely entwined with the broader personalisation agenda, which is also being strongly advocated in many countries; known as self-directed care or self-determination in Canada and the US respectively (Power, Lord and DeFranco 2014).

Much research has sought to identify the barriers and facilitators to social inclusion for this constituency. In a review of the literature, Overmars-Marx et al. (2014) identify broad domains which shape inclusion, including individual characteristics, informal network, professional care, neighbourhood characteristics, and government policies. They conclude by arguing that the viewpoint of people with a learning disability and their experiences is often lacking. Our study fills this gap by adopting a geographical lens to critically assess people with learning disabilities’ own everyday place-based experiences in their efforts to cultivate inclusion.

By a geographical lens, we mean being cognizant of the active role that spaces and places play in dialectically shaping experiences. Our understanding of these terms derive from Massey's distinction; ‘whereas space is abstract [e.g. ‘public space’], place is concrete [e.g. a named park]’ (2005:184). Space only becomes a place when it is locally differentiated and endowed with a particular value and meaning. Similarly, we argue that real ‘place work’ is needed to implement contemporary welfare policy and to cultivate inclusion. By ‘place work’ we mean the real, on-the-ground, often complex work required by people with learning disabilities and others to create more inclusive lives in the community. This may involve for example, advocates working closely with communities to break down local barriers, arts projects to create inclusive spaces, or community allies to foster local ‘safe havens’ (Milner and Kelly 2009; Hall 2010; Power and Bartlett 2015). In our paper we identify peer-advocacy as one further avenue – where people come together in group settings (that are often facilitated by volunteers and paid advocates) to provide emotional, social or practical help to each other (Nind 2008). With austerity cuts to public services around the world (Sørensen 2018), a focus on community- and peer-led initiatives is becoming more timely, as local governments’ capacity to commission and provide social care has been curtailed.

To meet the aim of the paper, we draw on a programme of research in England involving two recent qualitative studies into the experiences of adults with learning experiences in cultivating inclusion around their home, neighbourhood and local town centre. The purpose is to offer an original contribution to inclusion debates, by shedding light on the personal everyday geographies of people living within a policy landscape framed by inclusion that typically fall below the radar.

Failing to recognise the role of place – a ‘place-denial’ – refers to occasions where policy goals – or the instruments designed to implement them – do not adequately appreciate the place-embeddedness of disabled people’s[[1]](#footnote-2) lives and their bodily ‘impairment’. While societal barriers of course shape people’s experiences of disablement (Oliver 1990), we recognise that all restriction of activity is not reduced to or caused solely by social barriers. Rather, we recognise Thomas’ (2007) relational model of disability that proposes that having a particular impairment implies some *effect*, and this effect is a necessary condition for experiencing disablement in certain places and circumstances. In the case of people with a learning disability these impairment effects might relate to language and comprehension skills in everyday social encounters, as shown by work by Hall (2000) and Williams (2013).

The intersecting nature of these three elements (the body[[2]](#footnote-3), social relations and place) is fundamental to the relational model of disability (Thomas 2007). The way in which impairment results in disablement differs according to changing circumstances (Reindal 2008). However, place is largely left implicit and muted within this conceptual framework. Its silent positioning is arguably borne out of an acceptance that the body has no choice *but* to occupy space, but little else. When examined more closely however, the location of people’s homes, the degree of neighbourhood segregation, the availability of local amenities all play a role in shaping inclusion for people with learning disabilities (Abbott and McConkey 2006). Moreover, they are key determinants of health; housing is in particular (British Medical Association 2016). At a micro-scale, social proximity in housing, local gossip networks and ingrained stoic cultures have also been shown to play a role in shaping how caring occurs in certain places (Burns, Parr and Philo 2003). In other words, understanding the place-based realities of disabled people’s lives can shed some original light on the way that social inclusion operates in practice. However, given the muteness of place, it is not surprising that Gleeson and Kearns (2001) found that when ‘community care’ was first advocated, policy makers, journalists and even academics envisaged an ‘imagined moral geography’ of communities *who are supposed to be able to care.* When placed in opposition to institutional care, they thought of community care as emancipatory, flexible, humane, and open. However, some geographical studies have since shown that the reality is often different, and indeed can be hostile to those deemed ‘out of place’ (see Needham 2014; Hall and McGarol 2012). Derogatory terms like ‘shirkers’ and ‘spongers’ have been used to stigmatise welfare recipients in some newpaper outlets (Garthwaite 2012), potentially creating more hostile communities in which people live.

We recognise from the wider literature that community is a heterogeneous and elusive concept (Crow and Allan 1994). For the purposes of this article, we draw on Willmott’s (1986) notion of ‘place community’, defined as sharing and finding connections across local, geographically soft boundaries, where people occupy, use, and travel through, rather than solely as a close-knit group of people. Thus ‘community’ does not just mean the locality or localities where people live, work, or socialise – that is more properly termed neighbourhood. Nor does it mean shared interests – that could be fulfilled by the ‘virtual community’ of the internet. It is recognised that ‘place communities’ envelope and shape multiple cross-cutting and at times contested groupings that shape the different things that community members may have in common. While social care policy, especially that relates to community care spaces such as day centres, is more focussed on communities of interest (based on cultivating groups based on shared characteristics and interests), such spaces nonetheless do bring together people who often share similar *spatial* backgrounds and a mutual sense of place with areas of the city; ultimately they also create specific encounters within a geographical setting. We therefore remain agnostic about the value of rigid distinctions between local ‘interest communities’ and ‘territorial communities’, as the different forms will overlap and intersect in particular circumstances.

In the literature review that follows, we explore the policy landscape in more detail, and draw on other relevant scholarship of people with learning disabilities’ experiences, before turning to our study.

## Literature and Policy Review: Cultivating Inclusion

Cultivating ‘inclusion’ stands as one of the cornerstones of learning disability policy alongside the other general principles of disability rights: participation, non-discrimination, equality and accessibility (UN CRPD 2006). In England, some time before the convention was adopted, this goal was articulated in the *Valuing People* (VP) (Department of Health 2001) strategy as part of four key principles, civil rights, independence, choice and inclusion. This principle became reinforced later as ‘including everyone’ in *Valuing People Now* (VPN) (Department of Health 2009). This policy goal of inclusion is predicated on a person with a learning disability being able to move towards ‘a life like any other’, which was a stated aspiration of the Parliamentary Joint Committee on Human Rights (2008). In order to achieve this aspiration in practice, VPN states:

*This means being able to participate in all the aspects of community – to work, learn, get about, meet people, be part of social networks and access goods and services – and to have the support to do so.* (2009, p.16)

This goal centres on a commitment that all people with learning disabilities are supported to *participate* and become empowered citizens. Underpinning this aspiration, according to Johnson and Walmsley (2010), is the idea that people with learning disabilities should be supported *through practice* to engage and participate in everyday life. By practice, Johnson and Walmsley mean encouraging people to learn through everyday experiences of going out in the community and navigating social encounters. Building on this idea, Kupai (2010) argues that inclusion in everyday life is underpinned by the degree to which people learn and create space for *shared* practices of loyalty, reciprocity, mutuality, and tolerance. Importantly, this is a two-way socio-spatial practice, as people must engage with and find ways of reciprocating with each other in a variety of everyday places (van de Ven et al. 2005). This conception of inclusion therefore reinforces how relevant an ‘imagined moral geography’ is in determining how ready a community is to reciprocate efforts to include people with learning disabilities.

Given the VPN policy above recognises that support is required to enable this to happen, the ‘place-denial’ does not appear within the context of the policy design. It recognises that real support in people’s everyday lives is necessary to make inclusion work. Rather, the real test of this policy goal is the extent to which it has fostered a culture of inclusivity and enabled people with learning disabilities to learn such skills in their everyday lives.

In terms of the implementation of these two policies, as early as 2006, one criticism levelled at the earlier VP policy, was that the real difficulties in providing supports to enable inclusion to be realised were made to appear of little significance and were likely to incur little further expenditure (Burton and Kagan 2006). The Parliamentary Joint Committee on Human Rights (2008) found that public authorities, including local authorities and Primary Care Trusts, were not fully committed to the implementation of the Government’s policy in VP and that limited resources were undermining attempts to implement the aims of that policy effectively.

This decline in real support became more pronounced with the subsequent VPN strategy. After only two years, its delivery no longer was led by a central programme team after the government decided it was to be cut (Mencap 2011). The national team was made up of the national directors for learning disability, along with national leads for areas such as health and housing. The news of the cut was met with many questions over whether the VPN agenda would lose momentum – a year before it was due to end. In terms of a more joined-up programme of inclusion, a lack of investment and central political support has become more extensive in the wake of the government’s austerity agenda, and is continuing apace with more extensive cutbacks with the Conservative government’s £12bn cut to welfare (BBC 2015). This has led to budget pressures for local authorities, whose total spending on adult social care has fallen by 33% (Duffy 2015). The implementation of inclusion policy has also been criticised for becoming exclusively concerned with work-participation as the sole avenue to being included (Hall and McGarrol 2012).

On the ground, examples of studies on how people with learning disability experience the city centre (McClimens et al. 2014) reveal how misleading it is to assume that communities are a resource of willing people welcoming each other; especially in low-income neighbourhoods where many individuals with learning disabilities and their families live (JRF 2005). While some studies (e.g., see Wielsel and Bigby 2014) have shown how people with learning disabilities can often ‘become known’ in local areas, this often fails to develop into fully fledged relationships of community participation. Moreover, VP has been found to indirectly result in *greater* levels of social exclusion and vulnerability, by not recognising the need to sustain adequate levels of support (Simpson and Price 2010). More damningly, the Equality and Human Rights Commission (2009) has reported that disabled people experience widespread ongoing low-level incidents of violence and as a result, they often must restructure their lives to minimise real and perceived risk. Gleeson and Kearns’ ‘imagined moral geography’ (2001) is therefore deeply relevant here, in that the notion of inclusion poses a misleading interpretive landscape of welcoming communities in policy framings.

Since the two learning disability national strategies prioritised inclusion, personalisation has become the dominant focus of social care policy. Despite originating from the physical disability movement demanding more control over managing personal assistants, it is now being seen as a broader mechanism which can facilitate greater community inclusion. With the 2007 *Putting People First* government concordat and subsequent *Care Act* 2014, personalisation has been endorsed as a way to move away from communal services towards self-managed supports in ‘real’ communities through personal budgets in an effort to remove barriers to participation.

With austerity cuts however, most local authorities now only fund packages of care to those in ‘substantial’ or ‘critical’ need (NHS England 2015). One of the most discernible place-effects of personalisation within this context has been the rapid decline of collectivist sites of care, such as day services and learning centres (Mencap 2012). Without this support, Roulstone and Morgan (2009) found that a great deal of former day centre-based time was beginning to be spent at home.

It is within this context that this paper aims to explore the everyday place-based experiences of inclusion by people with learning disabilities, highlighting the active role that place plays in shaping these experiences, and assessing whether the broader landscape of inclusion policy is making a difference in tackling local exclusionary practices in their lives.

## Methodology

The focus of this paper is derived from two intersecting qualitative research projects that both examined inclusion for adults with learning disabilities. In both studies, we used inductive grounded theory approaches (Strauss and Corbin 1990) to explore what life in the community looked like for them. Both studies received ethical approval from the research ethics and governance committee at University of Southampton. Consent was gained by means of an easy-read consent form and a meeting with each of the participants and their advocate to talk about what each study involved.

Study one took place in 2013 in Southampton. It involved six repeat focus group interviews (each 2 hours) and photo-elicitation with four adults with learning disabilities from working-class urban neighbourhoods. It examined what welcoming communities look like for them. Photo-elicitation (or ‘Photovoice’) is used to empower participants to reflexively explore their personal realities through taking photographs and describing them during interviews (Wang and Redwood-Jones 2001). In our case, it involved each participant using a disposable camera to record places in their community that they found welcoming and then using the photos as discussion points in the focus groups. The discussions focused upon why they had chosen each site photographed and their general experiences of inclusion and exclusion. Questions included ‘where do you meet your friends?’, ‘what places do you like to use and occupy during the week?’ ‘What places do you avoid?’. Although a small sample, it totalled 12 hours of interview data and offered a detailed rich account of their lives in and around their neighbourhood and city. We also interviewed four advocates to explore their broader knowledge of the local learning disability landscape, including the wider experiences of people they advocated for and of the local policy context. While their accounts are not referred to in this study, they were nonetheless important for us to gain a broader awareness of what was happening within this constituency. Further details of the methods employed are discussed in Power and Bartlett (2015).

Study two took place in 2015 in the same city. It examined how adults with learning disabilities experienced friendships and peer-support in the community. It involved interviews with 17 adults with learning disabilities. Two self-identified self-advocates with learning disabilities working as co-researchers on the project conducted the interviews with the help of social work interns. The questions included ‘how do you keep up with your friends?’, ‘do you go to any groups during the week to meet other people?’. The interviews were one-off and shorter that in study one but they were nonethless helpful in allowing us to explore more about the participants’ strategies for getting out of the house and meeting people. Further details of this study are available in Power, Bartlett and Hall (2016).

In both studies, analysis was conducted manually and involved using the general purpose tools on Microsoft Word, rather than dedicated qualitative data software. In study one, analysis involved viewing the content of photographs to identify key categories and sub-categories, and open and selective coding of visual and textual data. The aim was to identify and code the data pertaining to what a welcoming community means to adults with a learning disability, before grouping the codes into salient themes and sub-themes. This involved scrutinising the subject matter of images to assess the frequency of people, places, and objects; and focusing on the words of participants (rather than advocates) in the analysis of interview data. Halfway through the analytical process we invited participants to feedback on the themes we had identified. This helped with the validation of data by ensuring the appropriate coding of themes and sub-themes. Similarly, in study two, data were coded into themes and sub themes about peer support and friendship. The focus of the present paper is to draw out and discuss two cross-study themes and situate them within current debates about the wider policy context. These themes (outlined in Table 1) were identified from a subsequent analysis of both datasets and discussed with a local self-advocacy group of people with learning disabilities to ensure the themes appropriately reflected their experiences.

Insert table 1 around here.

## Cross-study findings

### Moments of inclusion amidst wider exclusion

Experiencing moments of inclusion amidst wider exclusion was a common theme crossing both datasets. Many participants spoke of times when they felt welcomed and part of the community. For example, analysis of the detailed accounts of participants’ everyday lives from study one, revealed how participants were able to ‘self-build’ associations with people within local ‘safe havens’. These included places such as allotments, Bingo Halls, marinas and football and gadget stores, which the participants found welcoming:

*A couple of shops up on London Road and East Street, and the shops I like to go into is like a lot of the technology shops, looking at all the gadgets, computers, all the electricals and the iPods… I sort of do a browse around and sometimes I meet up with my mates and that, sometimes we will go down to the Station [pub] with one of my mates.* (Mike, 40s)

The ability to occupy these places and meet with friends offers a more nuanced account of local moments of inclusion and serves to illustrate the importance of place in shaping these experiences. In study two, participants also spoke of the importance of having and making friends. It was clear that having designated learning disability meet-ups was well liked by the participants, particularly as an avenue to keep in touch with friends. Many of these groups were peer-led, a point expanded upon in the next section:

*I meet other friends through groups, such as Getting Out group or through the groups at Choices. So I meet up at the Hub once a month and meet up with the Getting Out group, and I also go to the Penguins Swimming group each week, so that’s a weekly group, and I attend a meeting called Busy People.* (Malcolm, 40s)

Another encouraging finding was the extent to which participants sought to create their own opportunities for social support and interaction. Such encounters were necessarily personalised, as people created them for themselves. For example, in study one, a participant spoke of inviting family around to his home and cooking for them.

*[That’s a big pan of the stove there! (looking at photo of his kitchen)] I know I think I was cooking for my family that day, I think my brother was coming round and he hadn’t eaten all day […] Yeah working all day I am starving you better get that pan on he said* (Alex, 40s)

While these accounts offer a positive insight into the lives of the participants, such moments were often set alongside a wider awareness of exclusion. An example of this is given below by Clare who was able to navigate a safe haven in her local British Legion club, which we learned she attended as a result of her late father being in the armed forces. While this was a place she liked going to, she was also aware of having to be cautious about speaking to people:

*Yes my dad was in the army, he was in the T.A. it used to be… going to a big hall on Poppy Day… was ever so good and I learnt such a lot… I belong to a Legion [club] at Romsey, mostly I just see my brother Mark on Wednesday night when I, after bingo, we play bingo and I only really meet him if Shane [friend of family] takes him from hospital. [Q. when you talked about the legion and the bingo do you feel included in those spaces?] Yes well some people do talk to me but if they don’t say hello I don’t talk to them either, sometimes I will say things and I get told off [Q. Who by?] Shane. Yes, he goes ‘you should only talk to them if they talk to you’, I say ‘yeah’ but I do not go up and have a conversation with someone who doesn’t want to hear nothing, so I said I will play it safe, if they say hello to me… then I will talk to them otherwise I don’t, my rule, get on with that. (Clare, 50s)*

The quote above reveals the links that Clare has made with this local place and its strong connection with the memories of her father. However, it also reveals a more complex picture. Firstly, having to rely on Shane shows the various inter-relationships which are necessary for her to attend this place and to meet her brother. Secondly, Clare’s account of having to learn not to talk to people unless spoken to reveals a more complex body-place-relational assemblage. Such an admission offers a more nuanced account of the place than simply a ‘place of inclusion’.

In some cases, more visceral experiences of harassment in the participants’ immediate local neighbourhoods were reported, as illustrated by the following three quotes by three different participants, the first being from Clare who recounted the experience above:

*I used to [go out to the local shops] but not now, some people have been bullying me and hitting me so I won’t go out, I had people banging on my door and that.* *[Q. And are they young people or older people?]* *Teenagers, they always used to do that…* *even now I will not go down the road myself. I want to but I can’t. [Q. So you can’t even go down to the local shops?]*  *No ...* *there* *was some idiot they had a sort of a gun and a pellet been throwing peas at me and that. They [police] come too late as usual and they goes oh what’s the problem and I told them and he goes oh you must have been in the wrong place at the wrong time, I goes I can’t be at the wrong place and the wrong time I said I only walked down the road to get some shopping on my own. (Clare, 50s)*

In this account from Clare, we learn about her experiences of bullying at her home and in her immediate neighbourhood down by the local shops. The police officer’s response about being ‘in the wrong place at the wrong time’ reinforces the coding of exclusion in these local places. Having this awareness of the coding of exclusion was also articulated by Mike in the following quote, where we hear about his experiences walking around different roads and estates in his area:

*I walk to the shops just up near my brother’s [house] and that, they are not so bad because they are on the main road so there is not so many people hanging around them, but the ones, the ones on the estate I try to avoid going to those shops because you have like loads of like youngsters hanging around outside them so you tend to avoid them and the ones near my brother and that are alright because he lives on the bottom of the estate and Bitterne Road East near the Thornhill Park road there is like a parade, a parade of shops so sometimes I take her [the dog] up there* (Mike, 40s)

Mike’s narrative about his local community reveals a complex awareness of inclusionary and exclusionary places which he navigates through when he visits his brother and as we later learn walks his brother’s dog.

A third quote below reinforces the localness of these exclusionary experiences, again often bound up in one’s immediate neighbourhood. Here, Billy recounts his general experiences of being bullied in his own estate:

*people picks on people who are disabled because they think they are bums…* *they said I shouldn’t be living there [council house] because I am a sponger*. *[Q. And has that gotten worse more recently?]* *Yeah. I got myself an allotment, they said you shouldn’t be [spending time on an allotment], you should be working I am sponging.* (Billy, 40s)

It is evident from each of these quotes above that the ways in which each participant’s experience is deeply-entwined with the places that they use and occupy, often on a regular basis: these are often immediate neighbourhoods and local shops where teenagers congregated, experiences of living in a council house amongst neighbours, and spending time at an allotment. Such accounts suggest the experience of moments of inclusion amidst wider exclusion.

As identified in the policy review, the implementation of inclusion policy is largely fixated on employment as an avenue to inclusion. Therefore we examined whether the participants were able to gain a sense of inclusion through employment. One participant talked about his positive experiences of previously working in Argos and Dixons but due to the economy he had been let go. He revealed the challenges of finding a new job:

*Like when [I was] at Tatchbury or Dixons or Argos you just feel part of the team you don’t feel like an odd number or that. [Q. And do you ever find that other members of staff have felt uncomfortable or that they have had to get to know you?] No I think they just mingle with you and that, providing you get on and do your job and they do there’s I think everybody is happy to mingle and that you just feel a part of the team and that. Well at the moment I am not working at all. It is pretty tough going and that because you are going around and sending off for applications and that, sometimes they never respond to you and others do respond, I have had three interviews but nothing has come of it at the moment… If we had more specialist people to help them [disabled people], I think it would be a lot better because I think there would be more acceptance (Mike, 40s)*

This personal account reveals the social benefits of having a job and ‘feeling part of a team’. However, the challenges of finding and keeping a job was clearly evident within the current context, with the feeling that more support was needed to help.

### Creating peer support opportunities to cope with declining state support

A second theme identified in both datasets was the opportunities that forms of peer-advocacy offered the participants to get by with the challenges of increasingly limited statutory support. Analysing data from both studies revealed how the context of austerity was shaping people’s entitlements for statutory support and as a result, opportunities for social encounter. Opportunities were perceived to be more limited and fragmented than they were before the cuts. For example, during the course of the second study, in 2015, the advocates (also interviewed separately) commented that three council-run day centres in the city were having funding withdrawn from the local authority. This provided some local evidence of how the cuts in social care were becoming more extensive when the second study was conducated, compared to 2013 when we conducted the first study.

The reduction in social care entitlements was also evident from the interviews with the adults with learning disabilities, in particular the degree to which people not deemed to be in critical need did not get services: *I don’t get [help], because I don’t, because I’m what they call medium, middle of the spectrum you don’t get help in the home.* (Jeffrey, 40s; study two). This was confirmed by the advocates who supported the interviews and provided additional background context.

As a result of the decline in support available, particularly for those deemed not to be in critical need, many of the participants reported experiencing loneliness, with one commenting below that the decline in support made this worse. This was a point raised more generally about the potential for peer-support to cultivate more encounters, illustrated here by Henry’s own account:

*I don’t have any friends. If I don’t go to [my local peer-support group], I get sort of lonely, sad and depressed […] I don’t like staying indoors, because when you count the tiles on the ceiling, one, two, three, after you’ve done that a few times it gets really boring life…* *I used to have people call on me, to check that I was doing alright, but not anymore.* (Henry, 60s; study two)

The quote above offers a potent example of the degree to which people with learning disabilities can be vulnerable to loneliness within the current context of declining (self-directed) social support. It also highlights the necessity for peer-support opportunities which Henry refers to as a way to overcome loneliness.

One participant in study two emphasised the importance of people having the opportunity to link up and this reinforced the importance of having peer-support groups. He said:

*people need self-advocacy groups, they’re important, link them together. Like people need communication; it’s very important, and link all the services. All the services like, in the UK or any, anything, people need linking together.* (Ray, 40s)

With assistance from advocacy workers (funded through the local Council), the participants had formed two groups, one called ‘busy people’ and the other ‘the hub’ to create more meaningful opportunities for peer support. The Hub met at a pub in the city centre and allowed the participants to buy a drink and meal at the bar before and/or after their meeting. Busy People met at a local neighbourhood community centre, which was used by the whole community, including parents with young children. When asked what these groups and their location meant to the participants, one referred to the way that the groups helped him to cope with difficult points in his life, and another referred to the opportunity for having a drink with friends.

*Everything, because if there wasn’t groups like that, at the Frog and Parrott [pub], helping me to tick on, especially when the lowest point of my life, I used to say I’d be looking for a dog and a cat and triangle and I’d be on the street.* (Henry, 60s)

*I meet new friends. It’s really nice, to meet with them and have a drink with them.* (Dianne, 50s)

Within the context of reduced public funding for social care, our study revealed the value of the peer-advocacy networks, as an avenue to getting by and feeling included within the networks.

## Discussion and Conclusion

The findings raise several critical points for discussion that should have relevance for scholars concerned with inclusion as a social policy goal. All which relate to the importance of recognising the place-based experiences of people with a learning disability. By offering a snapshot of experiences of some (not all) people with learning disabilities, as has been done in this paper, it is possible to discern firstly some positive examples of people sharing positive encounters with family members and friends within their communities. These examples reveal ‘moments of inclusion’ across different places in the home, neighbourhood and city centre, including cooking in their kitchen, visiting football and gadget stores in town, attending Bingo halls in British Legion clubs, and meeting in a peer-advocacy group at a pub. Cultivating such moments of inclusion reveal the agency of people with learning disabilities. While we cannot generalise from our two studies, such convivial encounters do nonetheless shed fresh light on the transformative potential of these practices and resonate elsewhere in the inclusion literature (see Wielsel and Bigby 2014; Williams et al. 2015) .

A second discussion point raised by these findings is that such moments were positioned within and alongside broader experiences of indifference, loneliness, and discrimination. Such experiences reveal a complex tapestry of places in which the participants negotiate, such as around the home, specific local shops and clubs, and particular streets and housing estates. Sometimes these experiences were very subtle and fleeting, as shown by Clare’s account of having to be cautious about not talking to people unless spoken to at the British Legion club on ‘Bingo night’. In these moments, the impairment effects of Clare’s learning disability were recognisable; they were triggering disruptions in the immediate social relations and were reinforced by her friend Shane reminding her not to talk to people or she would ‘get told off’. At other times, the experiences were of outright hostility and discrimination as illustrated by Billy and Clare being harassed on the street and within the home. The experiences of Billy being called a ‘sponger’ in his immediate neighbourhood reflects how macro-level hostilities found, for example, in sections of the tabloid media and more subtly in anti-welfare rhetoric (Garthwaite 2012), are being articulated around the homes and streets in which the research participants live. The challenges expressed by Mike with finding a new job is also relevant in understanding the more mundane everyday personal experience of being part of a group who consistently have low employment rates (6%; PHE 2016). This provides a further expression and reminder of their excluded status, and helps us to further understand Hall’s (2005) argument that obsessions with work-participation as an avenue to inclusion is not supportive of the needs and preferences of people with learning disabilities.

These accounts also resonate with other studies on exclusion, for example, on bullying of LGBT people with learning disabilities (Abbott 2015) and the Equality and Human Rights Commission (2009) which as mentioned found that ‘low level’ incidents of bullying are widespread and can lead to its victims changing their everyday practices. Understanding the impairment effects that shaped the participants’ everyday encounters also can help us to disentangle the spontaneous and over-lapping nature of the social and the spatial. Here places such as the ‘bingo hall’ and ‘down by the shops’ can be considered as part of a set of relations of ‘simultaneity’ (Massey 2005), with place both framing and shaping the social relations of exclusion.

The personal challenges of the participants identified in this paper are also exacerbated by the decline in support for those with mild or moderate learning disabilities. Jeffrey’s account of not getting support because he was ‘in the middle’ and Henry’s account of services not calling on him anymore, show how local authorities are being constrained in their ability to commission real place-based support for this constituency. This was most explicity seen in the second study when hearing that the local city council had withdrawn funding to a number of day centres, thus suggesting the cuts in social care had become more extensive than in 2013, when the first study took place. This has obvious implications for the inclusion of those deemed ‘too able’ to receive support, but unable to fully participate in mainstream community life (Hall and McGarroll 2012).

One avenue to inclusion we uncovered was the cultivation and use of peer-advocacy networks in mainstream community settings. These offered the participants’ opportunities to meet friends, socially engage, cope with stresses going on in their lives, and mingle. While these could be conventionally understood as interest-based rather than place-based communities, they do nonetheless allow disabled people from across the city to connect and participate in non-disabled specific places (e.g. in pubs, parks and coffee-shops). This last point is important, as the use and occupation of these places renders them familiar ‘safe havens’ in the community. This was a key goal by one of the advocacy groups to move away from learning disability specific places, as they felt mainstream community settings had more transformative potential for the participants, to ‘mingle’ with non-disabled people.

Despite these peer networks, the ‘good life’ of belonging in communities and learning the practices of engaging and reciprocating with non-disabled people is still something that remains only partially realised for the participants in our two studies. Gleeson and Kearns’ (2001) account of the deeply interpretative ‘imagined moral geographies’ offers a conceptual framework for understanding the degree to which the nuances and complexity of inclusion/exclusion across different places are being overlooked, as well as the importance of local peer-support to help people with a learning disability navigate this challenging terrain. The findings do not allow us to make the claim that policy makers supporting personalisation and inclusion do indeed ‘imagine’ community as more caring or not. They do however offer a timely reminder of how such policy is unfolding in local settings and in often very challenging contexts. The research thus offers an original and relevant snapshot of local experiences of people living with a learning disability within this policy terrain, and the active role that space and place can play in shaping both their impairment effects and the efforts to ameliorate and overcome them. One limitation of the research is that we did not ask what the word inclusion meant to the research participants, and if they could express any idea as to what being included meant. This conceptual engagement would be a fruitful avenue for further study.

As inclusion gains greater international policy reach across different nations with the UN CRPD, albeit often framed narrowly in national government policy as work participation, the question of whether (renewed) peer-advocacy strategies embedded *within* neighbourhoods and cities ought to be returned to the agenda. Putting in place peer-advocacy initiatives has the potential to engender or cultivate more social inclusion opportunities for people with learning disabilities. A focus on these types of initiatives also needs to recognise the delicate and complex work at the ‘street-level’ (Lipsky 1980) that goes on to cultivate more meaningful moments of encounter for people with learning disabilities. Also, more recognition of ‘inclusion work’ *with* people with learning disabilities (in conducting themselves as the kinds of subjects envisaged in the particular construct of inclusion in play here) would help in future policy debate. More broadly our research suggests that shedding light on the difficult realities of the peoples, places, and communities, who are supposed to become inclusive *of* people with learning disabilities (who rarely approximate the ideal envisaged in the policy rhetoric) offers a helpful way to critically engage with such debate. A more honest appraisal of impairment effects and a greater appreciation of the ‘messiness’ of inclusion work on the ground would go a long way to ensure better support is made available to people with learning disabilities in their individual management of their lives in and around their communities.

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## References

Abbott, D. 2015. “Love in a Cold Climate: changes in the fortunes of LGBT men and women with learning disabilities?” *British Journal of Learning Disabilities* 43(2):100-115.

Abbott, S. and R. McConkey. 2006. “The barriers to social inclusion as perceived by people with intellectual disabilities.” *Journal of Intellectual Disabilities* 10: 275-287.

*BBC,* 2015. “George Osborne: £12bn in welfare savings have been found”. http://www.bbc.co.uk/news/uk-33399650 Accessed 20 January 2018.

British Medical Association. 2016. *Health in all policies: health, austerity and welfare reform.* London: BMA.

Burns, N., C. Philo, H. Parr. 2003. “Rural madness: a geographical reading and critique of the rural mental health literature.” *Journal of Rural Studies* 19(3), 259-281.

Burton, M. and C. Kagan. 2006. “Decoding Valuing People.” *Disability & Society* 21(4): 299-313.

Crow, G. and G. Allen. 1994. *Community life: an introduction to local social relations*. New York: Harvester-Wheatsheaf.

Department of Health. 2001. *Valuing People.* London:HMSO.

Department of Health. 2009. *Valuing People Now.* London:HMSO.

Duffy, S. 2015. *A Fair Society?* Sheffield: Centre for Welfare Reform.

Equality and Human Rights Commission. 2009. *Disabled people’s experiences of targeted violence and hostility*. Manchester: EHRC.

PHE (Public Health England). 2016. *Learning Disabilities Observatory People with learning disabilities in England 2015*. London: PHE.

Garthwaite, K. 2012. “The language of shirkers and scroungers? Talking about illness, disability and Coalition welfare reform.” *Disability & Society* 26(3): 369-372.

Gleeson, B. and R.A. Kearns. 2001. “Remoralising landscapes of care.” *Environment and Planning D: Society and Space* 19: 61–80.

Hall, E. and S. McGarol. 2012 “Progressive localism for an ethics of care.” *Social and Cultural Geography* 14(6): 689-709.

Hall, E. 2010. “Spaces of social inclusion and belonging for people with intellectual disabilities.” *Journal of Intellectual Disability Research* 54: 48-57.

Hall, E. 2005. “The entangled geographies of social exclusion/inclusion for people with learning disabilities.” *Health & Place,* 11(2): 107-115.

Hall, E. 2000. “Blood, brain and bones: taking the body seriously in the geography of health and impairment.” *Area* 32(1): 21-29.

Johnson, K. and J. Walmsley. 2010. *People with Intellectual Disabilities. Towards a Good Life?* Bristol: Policy Press.

JRF (Joseph Rowntree Foundation). 2005. *UK poverty falls overall, but rates increase among disabled*. London: JRF.

Kupai, P. 2010. *Bulding Inclusive and Just Societies: The Role of Deliberative Theory*. ASLI Working Paper 16, Asian Law Institute.

Lipsky, M. 1980. *Street-level Bureaucracy*. New York: Russell Sage Foundation.

Massey, D. 2005. *For Space*. London: Sage.

McClimens, A., N. Partridge, and E. Sexton. 2014. “How do people with learning disability experience the city centre? A Sheffield case study.” *Health & Place* 28: 14–21.

Mencap. 2012. *Stuck at home: the impact of day service cuts on people with a learning disability*, London: Mencap.

Milner, P. and B. Kelly. 2009. “Community participation and inclusion: people with disabilities defining their place.” *Disability & Society* 24: 47-62.

NHS England. (2015) *Adult social care – the service and its role in an integrated system*. London: NHSE.

Needham, C. 2014. “Personalization: From day centres to community hubs?” *Critical Social Policy* 34(1), 90–108.

Nind, M. 2008. *Conducting qualitative research with people with learning, communication and other disabilities: Methodological challenges*. Project Report. Southampton: National Centre for Research Methods.

Oliver, M. 1990. *Politics of Disablement*. Basingstoke: Macmillan.

Overmars-Marx, T., F. Thomése, M. Verdonschot, and H. Meininger. 2014. “Advancing social inclusion in the neighbourhood for people with an intellectual disability: an exploration of the literature.” *Disability & Society* 29(2), 255-274.

Parliamentary Joint Committee on Human Rights. 2008. *A Life Like Any Other? Human Rights of Adults with Learning Disabilities*. London: Stationary Office.

Power, A., R. Bartlett, and E. Hall. 2016. “Peer-Advocacy in a Personalised Landscape: The role of peer support in a context of individualised support and austerity.”  *Journal of Intellectual Disabilities*, 20(2), 183-193.

Power, A., and R. Bartlett. 2015. “Self-building safe havens in a post-service landscape: how adults with learning disabilities are reclaiming the welcoming communities agenda.” *Social and Cultural Geography,* Published online: 18 May 2015.

Power, A., J. Lord, and A. DeFranco. 2014. *Active Citizenship and Disability: Implementing the Personalisation of Support*. New York: Cambridge University Press.

Power, A. 2014. “Personalisation and austerity in the crosshairs: government perspectives on the remaking of adult social care.” *Journal of Social Policy* 43(4): 829-846.

Reindal, S.M. 2008 “A social relational model of disability: a theoretical framework for special needs education?” *European Journal of Special Needs Education* 23(2):135-146.

Roulstone, A. and H. Morgan. 2009. “Neo-Liberal Individualism or. Self-Directed Support: Are We All Speaking the Same Language on Modernising Social Care?” *Social Policy and Society* 8(3): 333-345.

Simpson, G. and S. Price. 2010. “From inclusion to exclusion: some unintended consequences of Valuing People.” *British Journal of Learning Disabilities* 38(3): 180-186.

Strauss, A. and J. Corbin. 1990. *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage.

Sørensen,‎ E., H. Foss Hansen,‎ M. Bøge Kristiansen (Eds.). 2018. *Public Management in Times of Austerity*. London: Routledge.

Thomas, C. 2007. *Sociologies of Disability and Illness*. London: Palgrave MacMillan.

van de Ven, L., M. Post, L. de Witte, and W. van den Heuvel. 2005. “It takes two to tango: the integration of people with disabilities into society.” *Disability & Society* 20(3), 311-329.

Wang, C. and Y. Redwood-Jones. 2001. “Photovoice ethics: perspectives from Flint Photovoice.” *Health Education Behavior* 28(5): 560-72.

Wiesel, I. and C. Bigby. 2014. “Being recognised and becoming known: encounters between people with and without intellectual disability in the public realm”. *Environment and Planning A,* 46, 1754–1769.

Williams, V., L. Ponting and K. Ford. 2015. “A platform for change?” *British Journal of Learning Disabilities* 43(2): 106-113.

Williams, V. 2013. *Learning disability policy and practice: Changing lives?* London: Palgrave Macmillan.

Willmott, P. 1986. *Social networks, informal care and public policy*. London: Policy Studies Institute.

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| **Study one** | **Study two** |
| Aim: to examine what welcoming communities look like for adults with learning disabilities. | Aim: to examine how adults with learning disabilities experienced friendships and peer-support in the community. |
| Methods: photo-elicitation and repeat interviews with 4 adults with learning disabilities (6 times over 12 months). | Methods: one-off interviews with 17 adults with learning disabilities. |
| Findings: (1) Uncovering safe havens - places where participants felt they were not going to be harassed or bullied. | Findings: (1) Experiences of how and where people make and meet friends; social networks created through peer advocacy |
| (2) Self-building practices- keeping self, safe and well | (2) Collective problem-solving during peer-advocacy groups |
| (3) The role of advocacy workers in helping people build safe havens | (3) Informal learning – offered by peer advocacy groups |

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| **Cross-study themes** |
| Moments of inclusion amidst wider exclusion |
| Creating peer support opportunities to cope with declining state support |

**Table 1: Individual and cross-study themes**.

1. We use the term ‘disabled people’ here as it is the term used in British disability studies to convey how people are disabled by society. We similarly recognise and respect the use of the people first term ‘people with disabilities’. [↑](#footnote-ref-2)
2. We understand the body as incorporatating the mind, rather than as a distinct entity. [↑](#footnote-ref-3)