Pre-print version: accepted manuscript 16 March 2018: Social Science & Medicine

Ageing with a learning disability: Care and support in the context of austerity

Andrew Power & Ruth Bartlett

Highlights

- Study examines informal care gaps in times of austerity.
- It focuses on middle to older age adults with learning disabilities.
- Findings suggest support from friends, neighbours and siblings is very uncertain.
- There are also retreating opportunities and spaces to meet friends and socialise.
- Study contributes idea of 'care desert' to geographies of care and disability.

Abstract

Recent work in geography has begun to look at the opportunities for care from siblings, friends and neighbours alongside parents and spouses. This paper examines the daily relationships that middle to older age adults with a learning disability have with remaining kin members, friends, and neighbours, within the context of declining formal day services. Adults with learning disabilities are likely to have different life course experiences and be living on low incomes and in poor housing than the rest of the population as they have had less opportunity to work and save money through their lives. We draw on two qualitative studies with adults with learning disabilities. Findings suggest that friend and kin networks are anything but certain, as opportunities to meet and socialise shrink, and connections with siblings do not necessarily lend themselves to support. The findings raise the possibility of a space of attenuated care to convey the increasingly limited fronts from which support can be derived.

Keywords

Welfare; community; disability; informal care; friendship; neighbours; UK; participatory methods.

Introduction

Friends and neighbours are considered an integral part of caring relationships and spaces and have become increasingly called upon to become involved in active citizenship roles (Amin et al, 2002). However, until recently they have been largely neglected in geographical studies of care (Bowlby, 2011). A focus on the potential care given by friends is timely as the support that many people receive (or hope to receive) from public services has been eroded significantly over the last 10 years. This decline has been largely driven by a politics of austerity, characterised by significant neoliberal reform of care provision, involving a programme of financial cutbacks (Clarke, 2012). This has been seen across Europe, the US, Canada, Sweden and the UK (Taylor-Gooby, Leruth and Chung, 2017).

To illustrate this change, in the UK for example, most of government cuts have fallen on social assistance benefits (20% cut), most of which is for disabled people and people in poverty, and social care (33% cut) (Duffy 2014). Numbers of day centres for adults with a learning disability have reduced, with Mencap (2012) reporting that over half their sample (57%) of people with a learning disability who are known to social services no longer receive any day service provision whatsoever. Home care has also been negatively impacted with higher eligibility criteria (NHS England, 2015).

Given statutory care is on the decline, the theme of informal support beyond parental ties is arguably becoming more pertinent. This paper aims to contribute to what can be regarded as an extension to the fields of geographies of disability and caring by examining the lives of people ageing with a learning disability, and in particular, their experiences of care and support in the context of austerity.

A focus on the experiences of people ageing with a learning disability is timely. According to Emerson and Hatton (2008), the number of people with learning disabilities aged over 60, in

England, is predicted to increase by over a third between 2001 and 2021. Evidence suggests that older people are one of the fastest growing groups of the learning-disabled population (Emerson and Hatton 2011). However, this is likely to be an underestimate of the actual numbers both now and in the future as many older people with learning disabilities are either not known to services or indeed do not use learning disability services in adult life.

To date there has been a lack of empirical work about the nature of informal relationships this group has or how they intersect with the care that is provided by formal welfare systems. As explored in the literature review, the focus largely remains with parent caregivers. Adults with a learning disability are potentially more at risk of being cut adrift from austerity than the rest of the population who may need support during their lifetime. This is for several interconnected reasons. First, this group have had less opportunity to work and save money through their lives (British Institute of Learning Disability, 2012). As a result, they are more likely to be living on low incomes and unlikely to be able to afford private care or home-help, which is what other more privileged older people may do to make up for any shortfall in publicly-funded services. Second, adults with a learning disability are more likely to live in poor housing in the most deprived neighbourhoods than other people. For example, a recent study in Scotland by the Scottish Commission for Learning Disability found that the majority (6922 people) live in the 40% most deprived areas of Scotland (SCLD, 2015, cited in Murray 2017, 131). This raises an important question regarding the level of neighbourliness available (Blunt and Dowling 2006) and opportunities for engaging in local activities. Third, adults with a learning disability are less likely to be married or have children; one study found that only 4.6% of their study sample had ever married (Beber and Biswas, 2009). Given that spouses and children are often the ‘mainstay’ of support in later life, anyone who is without a spouse and/or childless is at risk of isolation as they grow older (Deindl and Brandt, 2017: 1543).

These factors, we suggest, compound to facilitate a potential care gap for this group and form the analytical focus of this paper. Given this context, we examine empirical data collected from adults with a learning disability aged between their mid-40s and 70s focusing on their experiences of support from kin, neighbours and friends.

For the purposes of our paper, we draw on the relational model of disability (Thomas 2007; Hall and Wilton 2017), which argues that people's experiences of disablement are not solely caused by societal barriers, but also by their experiences of 'impairment' and its 'effects' (e.g. pain, exhaustion and disorientation). As further expanded upon in Power and Bartlett (2018a), impairment effects are dialectically related to space and the social/structural barriers that occur within such space. The spaces of people's homes, neighbourhoods, and city centres play pivotal roles in both framing and shaping the experiences of disability. Space is understood here as a sphere of 'dynamic simultaneity' (Massey 2005: 55); at all times shaping the 'ongoing production' of social relations. The lived spaces that people occupy, use and shape in their everyday lives, and the tactics used to make friends and experience care, are important elements in understanding people's geographies of care.

In the literature review that follows, we explore the theme of friendship and how it relates to care and older people with a learning disability, drawing on other relevant scholarship in geographies of disability and care, before turning to our study.

Literature Review

Friendship and care

Bowlby's (2011) paper on the neglected spaces of friendship, co-presence and care creates the opportunity for a debate about the patterns and practices of people's connections with their siblings, neighbours and friends. This paper provides a natural starting point in our review of literature for considering the idea of care for people ageing with a learning disability within the context of austerity, as it seeks to explore the potential for these people outside the traditional parent or spousal relationship to provide care. Bowlby's paper marks a welcome addition to informal/personal care scholarship, as for much of its history since the mid-1980s, a central area of concern has been the dyadic relationship between caregiver and care recipient (typically the parent or spouse) (see Milligan and Power 2009 for a review). This is a point we return to below.

A close friend is defined by Rawlins (1993) as 'somebody to talk to, to depend on and rely on for help, support, and caring, and to have fun and enjoy doing things with' (p. 271). Bowlby (2011) puts this potential for care under the spotlight. She identifies small acts of emotional and practical care and support that can be exchanged between friends, neighbours, and community allies, such as lifts to the doctor, pet care, assistance with small DIY tasks, dropping off the shopping, as well as sharing convivial encounters with those in need (Bowlby, 2011). Taking this theme of the benefits of friendship further, Tillman-Healy (2003) identifies both 'emotional resources' and 'identity resources' that can derive from friendship. The former refers to affective ties forged through common interests, a sense of alliance and close affiliation. The latter refers to the ways that friendships can help shape conceptions of self and other. He points out that we are prone to befriend those who are like ourselves; our friendships are more likely to reinforce and reproduce social differences than to challenge or transcend them.

The accounts of friendship offered by Bowlby and Tillman-Healy provide a broad snapshot of how friendships are typically constructed across diverse socio-economic communities. Bowlby draws on Allen (1996) whose empirical findings showed that in the mid-twentieth century working-class men typically kept meetings with friends to venues such as the pub or working men's club. Allen argues that these differences in friendship practices were related to resources. Not only were the homes of working-class men small, but restricting friendship encounters to the pub ensured that differences in household wealth and resources were not made evident. This work is still significant as it raises useful questions about the meaning of different spaces of friendship, within a context of wealth inequalities and a rhetoric of social equality.

Work that is more recent has sought to examine the impacts of austerity on social relations. Here, the social climate is considered a key factor for the forging of friendships. For example, Boyle (2016), drawing on the example of austerity in Ireland, argues that the proclivity of scarcity can render people more vulnerable to mistrust, suspicion, insecurity, estrangement, alterity, and even fratricidal conflict. He argues that people are therein more likely to sabotage their more ethical dispositions towards making friends or creating bonds of solidarity, reciprocity, inter-subjectivity, mutuality and cooperation. In effect, people's ethic of care can become more 'attenuated' in the wake of increased precarity. This prompts the question of how much societal and economic influences potentially curtail the development of friendships.

While the points of extension offered from this work are welcomed, notably the potential of care from non-kin members, there are implicit assumptions in this work that need to be identified. The first is that everyone has friends. The second is that everyone has access to space, in which to make and be present with said friends. For older people with a learning disability, this may not be the case for reasons we have already outlined (e.g. not working, living on a low income); a point we return to when discussing our study.

Friendship, care and learning disability

The potential for care from siblings, friends, neighbours and other non-kin members is a useful lens for exploring the nature of care for people with learning disabilities within the context of austerity. Since Hall and Kearns' (2001) call for the greater inclusion of learning disability in health geography debates, there has been growing interest in the geographies of disability for this group. Recent work by Hall (2012), Power and Bartlett (2018a), Wiesel and Bigby (2014), and Wilton and Fudge-Schorman (2017) have examined the social lifespaces that they occupy and shape. This corpus of work exists alongside disability studies scholars like Goodley (2001) who has helped animate debate about the complex nature of disablement and impairment in people's everyday experiences.

A focus on parental care has been typically used within the learning disability literature given most people with learning disabilities live at home and are supported by their parents (see Emerson and Hatton, 2008; McCallion and Nickle, 2008). Geographers have traced the everyday practices of care by parents involved in these settings (Daley et al 2014; Power 2008). This work more generally reveals the significant input that parents provide in care and support, and the central role they play in the lives of children and young adults in particular.

Much scholarship has sought to challenge the dyadic focus on the (singular) family caregiver within this work, arguing for a recognition of the degree of inter-dependency in informal caregiving that is woven into the fabric of everyday lives (Bowlby et al. 2010; Phillips 2007). Similarly, Goodley (2001) uses the term 'distributed competence' to illustrate how peoples' care practices are typically shared activities. To advance health geography debates, this paper thus seeks to draw on the experiences of an older cohort at (either side of) a transition point in their lives, where dependency on a parent carer is brought into question. Our focus is on those who have passed a point in their lives where they can rely heavily on their parents for care.

Indeed, by virtue of their life-stages, it is likely that people in this cohort either had parents that had passed away or who would have caring duties themselves for an ageing parent.

Work on friendship networks of people with learning disabilities has been conducted by Forrester-Jones (2006) on the social networks of people with learning disability living in the community 12 years after resettlement from long-stay hospitals. They found that a quarter of people's networks were other people with learning disabilities. The main providers of both emotional and practical support were support staff (43%), although these relationships were less likely to be described as reciprocal. On this point, Pockney (2006) revealed that paid support staff were very aware of maintaining the boundary between professional and friend. This boundary arguably reinforces the assumption that the nature of friendship with disabled people is founded on dependency not interdependency. This is a point that Castrodale (2015) strongly counters in his autoethnographic account of friendship between a disabled and nondisabled person. He points out that disabled people are not the sole benefactors from friendship with nondisabled people.

Nonetheless, as outlined in the introduction, various factors compound to complicate the potential for older adults with a learning disability to make and be with friends (financial, housing, marital and child status). With austerity cut-backs to services also to contend with, Hall and McGarrol (2012) found that a lack of support from day centres and the ability to 'get away' for adults with learning disabilities can create a sense of isolation within these communities.

This review of literature serves to illustrate some of the complex and uncharted terrain that people living with a learning disability must occupy. The experiences of this group of people tend to be overlooked in the geographies of care literature. Yet the circumstances of middle- to older age adults living with a learning disability at a time of reduced public services, offers a potentially instructive case to understand further the patterns of and potential for care from non-parental kin members, friends and neighbours.

Methods

The remainder of this paper reflects on a programme of research undertaken between 2013 and 2015, involving two qualitative research projects. Both projects involved a local advocacy centre for adults with learning disabilities in a city on the south coast of England. In 2013 and 2015, we received funding respectively from a Faculty interdisciplinary research fund and a British Society of Gerontology Averil Osborn award to undertake qualitative research with this constituency. The aims of the work were to explore what spaces in the community were most and least welcoming to adults with learning disabilities, and to understand peoples' subjective experiences of friendships and peer-support in the wake of declining service availability.

Ethical approval for this programme of work was granted by the University of Southampton. All participants gave informed consent to take part with the use of easy read participant information sheets and consent forms. The local advocacy service assisted with finding potential participants for the study, and we worked closely with this organisation throughout the research to ensure it was conducted as inclusively as possible, as described below.

The first study (Power and Bartlett, 2018b) was more exploratory in nature and used repeat interviews and photo-elicitation with participants using disposable cameras to record places that were important to them (advocated by Crang, 2005). As one leading visual researcher highlights, photographs 'can inspire people to represent and then articulate embodied and material experiences that they do not usually recall in verbal interviewing' (Pink, 2007: 28). We thought this was an important opportunity to provide, given that participants had a learning disability. The second study (Power, Bartlett and Hall, 2016) built on these findings, to examine in more depth how people kept in touch with friends, and what role peer-advocacy played in their lives. As non-disabled academics, we acknowledge the power-knowledge relations of research with people with learning disabilities. We thus sought to ensure we conducted the research as inclusively as possible *with* rather than *on* the participants with learning disabilities (Nind, 2014). This involved including the participants in research design meetings, analysis workshops, and co-organising and co-presenting the research at exhibition events. Our motivation for using inclusive research approaches was to help enhance the quality of life of the participants through directly involving them in core research activities. This further enhanced the quality of research, as participants had been involved as research partners, as opposed to research 'subjects'.

Over the two projects, semi-structured interviews were conducted with 21 adults with learning disabilities (12 men and 9 women, with further characteristics summarised in table 1 overleaf). Four participants (indicated with * in table) were purposively sampled to be interviewed four times over the course of the year, while the remainder of the interviews were once-off. The purpose was to gain more in-depth biographical insights to add to the more general accounts from the wider sample. A purposive sample was also used for the larger cohort to capture the views of people aged 45 to 70+ living with a learning disability in the study region.

The cohort had a wide range of learning difficulties and lived in a range of different settings, including those still resident in the family home, Shared Lives (a supported living arrangement), and on their own in social housing. All but one of the participants were White British, with one being British-Pakistani (Rasheen), reflecting the challenges that the disability service had in reaching out to non-white British communities. Significantly, given the discussion earlier about the particular circumstances of older adults with a learning disability, all participants were single, and all except one was childless; the one participant who had a child had her child taken away by social services when she was younger.

Table 1.

Summary of characteristics of participants.

Number	Pseudonym (indicating gender)	Age range	Living situation
1*	Mike	Mid-40s	own place
2*	Barry	Early-60s	own place
3*	Aidan	Mid-40s	supported living
4*	Catherine	70+	own place
5	Monica	Early-60s	supported living
6	Matt	Early-50s	own place
7	Eric	Early-60s	supported living
8	Geoff	Late-40s	shared lives
9	Deirdre	Late-40s	own place
10	Henry	Early-60s	own place
11	Kate	Mid-40s	supported living
12	Naomi	70+	supported living
13	Alice	Mid-60s	supported living
14	Julie	Early-60s	supported living
15	Andy	Mid-50s	with parents
16	Caroline	Late-50s	own place
17	Rasheen	Late-40s	with parents
18	Harry	Mid-50s	own place
19	Alan	Early-50s	with/caring for parent
20	Patrick	Late-40s	with parent
21	Megan	Late-40s	supported living
*** interviewed 4 times over year**			

Interviews were recorded and transcribed verbatim. In each case, a professional advocate acted as a mediator to help with gaining consent and facilitating the conversation. In practice, this meant helping those with speech impairments to articulate and vocalise their points and ensuring the researchers understood what was being said. In some cases, it meant filling in some background context where relevant. Every advocate was very skilful and respectful in ensuring they did not take over the process. In addition to the interviews with adults with learning disabilities, we conducted separate interviews with five professional advocates, two-day service workers, and two local authority leads to gain a broader insight into the context in which the participants lived and sought care and support. However, findings from these data are not reported here, as our focus is the lived experiences of people with a learning disability.

The remit and timescale of the projects allowed the interviews to be relatively unstructured, which facilitated the cross-referencing of over-lapping themes that related to the participants' experiences of their own lifespaces, as well as the climate of austerity and change in the social care sector. Analysis was carried out through a two-phase approach. First, as each project was unfolding, we conducted concurrent analysis of the data. We drew preliminary key themes manually from transcripts in Word, and then presented these themes to the local advocacy group from whom we had drawn participants. Second, we conducted a period of secondary analysis drawing out over-arching themes which crosscut both projects, and which were driven by the focus on the friend and kin networks underpinning their lives in the community.

In terms of methodological limitations, we recognise that the study setting is quite specific – that is, one service in a particular city in the UK. As a result, the sample is not as diverse in terms of age, gender or ethnicity as we would have liked. The findings are therefore not necessarily applicable to other areas or research populations. In addition, the broader context of austerity in the UK was a significant mediating factor shaping the research. For example, at the time of the second study in 2015, the local authority had withdrawn the provision of day centres, something that was discussed at the self-advocacy group from whom the participant took part in. Nonetheless, this research provides a useful window into the particularities of daily care relationships for middle to older age adults with a learning disability. Our intention was always to highlight the complexities of care for this cohort, rather than seek to present a representative case of this constituency.

Findings

Kinship

Our research revealed a complex and intricate picture of kin relations that had evolved given the points in the participants' life-course in middle and older age. This involved both positive and negative accounts of family life. In most cases, these accounts focused on relations with siblings, typically living elsewhere, although for some, living with an ageing parent was still evident.

In terms of positive accounts, one participant Adam talked fondly of cooking for his brother at home in his kitchen. He said:

Q. That's a big pan of the stove there? [looking at a picture of his kitchen he had taken]

A. 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. – Adam, mid-40s

Another participant Mike had a large family with four brothers and two sisters, and he recounted many positive stories of them 'checking in' with him, sharing texts about football scores, and of him calling by the house of one of his brothers to walk his dog around the estate.

R. Mike do you have any brothers or sisters? M. Four brothers and two sisters. R. Goodness me. M. Two, I speak to, I see one brother almost every day because I walk his dog and the other two of my brothers I only speak to on the phone a lot but they do come and see us as often as possible… I see my sisters every week, I see my eldest sister who comes in and helps every week and my youngest sister I go and see her after swimming every week so generally *we keep quite close, just my second eldest brother except for funerals or things like that you don't ever see him so don't really hear much from him.* – Mike, mid-40s

These positive accounts of convivial sibling relations and episodes of care were far from universal. Contrasting accounts were evident of siblings taking advantage of the participants in both small and more significant ways. In one case, a participant fell out over an issue with money and belongings. In the following exchange, an advocate is helping the participant recall an incident with his brother.

Advocate. How about Mark, what happened with your stereo with Mark when you were moving?

R. Is Mark your brother?

A. I think did he sell…? (beginning to recall story)

Advocate. And you had a great big stereo and he had that tiny little one didn't he and what happened, what did Mark think was a good idea?

A. Sell it didn't he (looking disappointed) – Adam, mid-40s

While the above discussion reveals an example of a small-scale family transgression, another participant shared an even more troubling story about the falling out with her sister over how she had treated herself and her late brother.

I don't talk to my sister, well I haven't seen her for ages and I don't want to, well I will tell you why, my brother Tom before he passed away we went to his house, he was in a place, there were lady carers looking after him day and night and every time I went to see him [with her], she [my sister] wanted him to go to the hole in the wall [ATM] and get money from his money card and when he died she took a lot of things off Tom and they asked me well *apparently he left a letter where he got some money, writing letters to me and I never did get that letter so I don't know, I can't do nothing about it because I haven't got the letter […] when my sister went into his room and took his things I didn't like it and I haven't seen her since. – Catherine, late-60s*

This story shows how family relations can change and erode over time, especially when money is involved. Interestingly, another story was revealed of an estranged father who did not come to visit one participant very often but when he did, he often took the participant to the ATM to take her Disability Living Allowance.

Other participants shared stories of how they have managed the transition in their lives, as their parents either became frail or had died. For example, one participant stated that he had become a full-time caregiver for his elderly mother. Another talked about being at a stage where his parents and brother were now deceased, and the loneliness that came with that. He said:

All my family is gone and I have only got a few sisters left, my brother died last year and I don't see the rest of the family at all and it gets lonely, I mean if you have got a basic family behind you it is a big help and when you have got no family behind you and you are stuck in that flat on your own and you're stuck seeing four walls… [showing photograph of his old neighbourhood] – Billy, mid 60s

Inherent in Billy's narrative is a strong sense of bereavement over the loss of his core family members and a strong sense of the loss of the wider ties with the local community that came with being part of a bigger family.

Some participants shared vivid recollections of the point in their life when they learned of the need to plan for life after their parents, and the first introduction to services.

What happened to me was when my folks passed away, on that day my doctor says do you know anyone or anything? And he quietly went away, and I thought oh you know why ask these questions. Next thing, the lady, a couple of days later, called Helen, she rushed in and with eight other people, into my home, to talk to me about how things are and what's happening. A little bit surprised, because I only had the one chair, to see them sitting on the floor on my cushions, it was embarrassing. – Henry, late 50s

This data excerpt highlights the spatial aspects of care; in the above case, the participant felt he did not have enough space to host people in his home, and as a result had a self-perception of inadequacy. Later in the interview, we learned that the same participant was referred to an advocacy service and was encouraged to attend a local speaking up group.

if there wasn't groups like that 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, late 50s

Friendship

An equally complex picture emerged around the building and sustaining of friendships by the participants given the presence of disability and weakening welfare. Many positive accounts were expressed, where participants talked about a wide group of friends with a learning disability and an array of learning disability specific places that were important to friendship.

R: How do you keep in touch with your friends?

M: some of them I will go and visit, some I go out on social, I meet other friends through groups, such as Getting Out group or through the groups at Choices. I also keep in touch with friends through emails and on the phone and on Facebook and Twitter.

R: Do you have any groups that you meet up with, e.g. swimming or social groups?

M: Yes. 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 [disabled person's] Swimming group each week, so that's a weekly group, and I attend a meeting called Busy People. – Mike, mid-40s

As alluded to here, the presence of local learning disability-specific groups was important, where the participant welcomed the potential to 'keep yourself busy' in organised collective spaces. In the additional example below, Rasheen reveals how self-advocacy can help to link people with learning disabilities together, especially at a time when access to other services is becoming more limited.

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 on, in the UK or any, anything, people need linking together when they do something. They done really good. People need advocacy keep going, you know, they're very good speaking up. – Rasheen, late-40s

As well as the convivial encounters between friends from local groups expressed in the above quotes, we also learned from one participant of the existence of very significant acts of care from a close old friend of the family. In Catherine's case, she talked about the close bond that grew with an old friend of her now-deceased parents, and the significant level of support she receives from him:

Yes, well Gavin is mum and dads friend I knew him years and years but now Gavin lives with me and he looks after me. Without Gavin my friend I wouldn't be able to get out of the house, because I am disabled and I can't read or write and one day at ASDA [supermarket] I got on the wrong bus and I got lost. So now I don't get lost, Gavin takes me shopping, he takes me to *my meetings, he brought me here today to meet Charlene and my meetings, without him I wouldn't be able to get on.* – Catherine, late-60s

Other participants expressed much less positive accounts of their friendship networks. Some revealed a feeling of deep loneliness from not having any close friends, as articulated by Henry:

R. How do you keep in touch with your friends?

H. I haven't got any! – Henry, late 50s

This reaction reveals how normative the idea of having friends is, as assumed in our question. The same participant, as with some others, revealed a very lonely lifespace, where he stated: '*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'.* Similar to other participants though, Henry tried to participate in '*things to keep yourself busy… or if you don't you get sort of lonely, sad and depressed*.' In Henry's case, he takes part in a local self-advocacy meeting once a month. When asked about how self-advocacy benefits him, he stated: *'In many ways. One for social, it's wonderful, and so to be able to go to a group of people, to learn, to socialise, it is a wonderful thing.'*

Having a learning disability meant some (not all) participants were eligible for a limited level of domiciliary support. We explored the potential of developing a friendship with support workers. This proved to be very limited given the high turnover and structured shifts of staff within care agencies, and the professional boundaries that are maintained. As Billy explains, this can be a frustrating experience, as there were previous times when friendships did grow, but these were abruptly cut short by an unannounced change in the care worker that turned up at his door.

You get a support worker coming into your house and you get a good friendship with them and [service provider] changes it. You go for three months, I was sat indoors one day and a woman turned up see, and I thought who is that then, oh she said I am your new support worker, the other one has been shifted, so you have to start all over again. It is wrong and I had a person for two years and they took her off me because we got too friendly, I mean it is wrong when you get a friendship, not a friendship when you work with a person, it is wrong when they go and change it – Billy, mid-60s

With shrinking levels of care being offered, some also revealed the feeling of being 'cut adrift':

I used to have people call on me, to check that I was doing alright, but not anymore. – Henry, late 50s

Neighbourhood allyship

Participants were asked about their connections or otherwise with neighbours. These proved to be an additional realm that was equally shaped by the intersections of age, disability, gender, and poverty. Given the socially disadvantaged neighbourhoods that many of the cohort lived in, the scope for supportive neighbourhood relations was varied. On the one hand, some participants shared positive accounts of their neighbours, and gave examples of meeting up with them for social outings. For example, this is how Mike spoke about a photograph he had taken during a recent visit to the local football stadium:

M. I go there with my neighbour, both my neighbours go so I get a lift most weeks, if one is not going the other one is going and then I get a lift both there and back so it is quite handy.

The same participant later revealed that one of these neighbours had been a close friend to his oldest brother and he had known him through that connection. This demonstrates once again that prior family connections can help people to link into wider community networks. Other participants expressed similarly positive encounters.

On the other hand, many participants revealed a more cautious attitude towards their immediate neighbourhood. Indeed, when talking about what spaces people visited to meet friends, some talked about going ‘into town’ to pubs in the city centre outside of their local neighbourhood, because they felt greater feelings of anonymity, and less opportunities to be bothered by neighbours. This cautiousness of the local neighbourhood stemmed from a broader awareness of the hostility and exclusion that some participants reported. Throughout the interviews, some expressed vivid accounts of bullying and harassment by neighbours, as shown in the example below.

C: we got indoors and they [local teenagers] started again, banging the doors and throwing things and I get very, very frightened and nervous but it has been going on for years when I was a little girl I used to get beaten up…

R. When that was happening Catherine what would you and Gavin do?

C. Well I would just get very annoyed… and he would go ‘well they won’t get into your house because we have got [bolts]’ but what happened was the door is now not shutting properly because they kicked it all the time, it has been painted twice you wouldn’t think so, we have got all egg marks down the wall. Well without Gavin I would just be indoors I wouldn’t go out on the road by myself it frightens me, what happened is I went out to Brocken Road, was some idiot they had a sort of a gun and a pellet, been throwing peas at me and that. - Catherine, late 60s

This quote reveals a long history of abuse that the participant had faced within her immediate neighbourhood. Another participant also referred to being called a ‘scrounger’ by a neighbour, and that he did not belong there. One final example below reveals another participant’s view of a broader cross-cutting sense of exclusion and an unwelcoming place within working-class neighbourhood life for all people regarded as different:

R. And you mentioned that your community, your neighbourhood is quite unwelcoming?

B. They don’t want disabled people there I mean my friends, my friend next door to me he is blind and he is gay, not gay I don’t know what is the word but they don’t like him, the bloke across the road said to me oh people like that should be put to death they shouldn’t be alive and that’s how people are. My friend uses a wheelchair and he wanted to put a bay over there so one of the neighbours across the road said oh he should be put down, he shouldn’t be alive in a wheelchair, all people like that shouldn’t be in the community, that’s the way life is you know, I might be thinking wrong what I am saying but it is the truth. – Billy, mid- 60s

Such vivid accounts reveal the neighbourhood can also be a space where care is absent.

Discussion & Conclusion

This research shows how people who are ageing with a learning disability deal with and respond to changes in family and non-kin relations and welfare provision. A key theme identified from the analysis is of attenuated care – or a ‘care desert’ – in which the spaces for care are weak or weakening, and at risk of diminishing completely. Our analysis suggests that such spaces are being constricted on four fronts. First, the retreating welfare state. While we must be careful not to assert that our participants’ experiences all solely rested on austerity, some important signals of weakening ties did nonetheless exist. Signs of austerity were evident in both datasets, but perhaps most clearly articulated in Henry’s account of services not calling anymore, and Billy’s account of the threatened nature of care at home. More widely, hearing that the local city council had withdrawn funding to many day centres in 2015, suggested the cuts in social care were becoming more extensive than in 2013, when the first study took place.

Second, an absence of kin; participants were all childless and the majority had lost their parents. Again, we must be careful not to assume that these same participants all had caring parents when alive. Even so, it is significant that the stalwarts of family care (i.e. adult children and parents) are absent for people with a learning disability. There was some evidence of strong ties and valuable relations with siblings, certainly in terms of small acts of care and sociability. However, this was anything but certain. Not everyone has a sibling, and some data pointed to the possibility of financial abuse from siblings (as well as an estranged parent). Beyond the immediate family, there was no evidence of links with extended family (e.g. cousins, aunts, uncles) which suggests a particularly impoverished kin-network. Hence, this data opens up a space for considering the geographies of attenuating care that sits at odds with the geographies of personal care, which assumes the existence of family members willing to take responsibility implicit in care.

Third, the support offered by neighbours and within neighbourhoods was hugely variable, ranging from close ties and practical assistance (e.g. lifts to football matches) to abuse and bullying. The myriad of people’s experiences in their locales highlights the time-space dimensions of care – that is, at certain times and in certain spaces, care encounters will change (Bowlby, 2012). For example, it is argued that people shrink away from a collective sense of community when narrations of crisis are more prevalent (Boyle, 2016). Others have suggested that people with a disability are seen as not ‘fitting-in’ when their spatial requirements are at odds with others (Garland-Thompson, 2011). Recall for example how Billy’s neighbour, who used a wheelchair was subject to abuse, when he wanted to make adaptions to his home. Neighbourhoods clearly affect people’s experiences of care.

Fourth, limited opportunities and spaces for friendships to flourish; while there was still evidence of friends being made with other people with learning disabilities, the state withdrawal of disability specific centres meant that opportunities for meeting these friends were also shrinking. Some either felt embarrassed to host people within their home or too threatened by the immediate neighbourhood to leave their home on their own. We found that friend and neighbourhood allies are often based on former family-based ties, as illustrated by the examples of Catherine's old family-friend Gavin and Mike's close neighbour who was an old friend of his brother. In these cases, the friendships had lasted. By contrast, Barry's account of losing connections with local people after his father and brother had died revealed how such wider networks can dissipate.

Collectively, these fronts mean key sources of care and support for adults with a learning disability (i.e. the state, kin, neighbours, friends) are at best tenuous, and at worst, disappearing completely if they were ever existent at all. The idea of a geography of attenuated care, akin to a 'care desert', therefore seems relevant for some adults with a learning disability in their 50s and 60s, as they are ageing with a lifelong disability. Individuals are likely to be facing profound changes in their life (such as death of a parent), as well as new emotional experiences (such as loneliness). Our research reveals personal accounts of people whose places to entertain, hang out, and share convivial encounters are limited.

The idea of a 'care desert' borrows from the term 'food desert', which describes urban areas where residents do not have access to an affordable and healthy diet (see Cummins and MacIntyre, 2002). While the idea of a 'care desert' is compelling, the data also points to the agency and creativity of individuals to deal with changing levels of formal and informal support. We therefore hold a certain scepticism of the idea of a 'care desert', and instead suggest that ageing with a learning disability is not an entirely bleak experience. Some examples persist of the local spaces where care can take place, as evidenced by Adam's experience of cooking for his brother at home, Billy calling to his brother's home to walk the dog, and Henry's engagement with a local self-advocacy group. Rather than complete, fixed and unchanging, a 'care desert' could be characterised as an 'assemblage of disparate hybridised and inherently precarious arrangements that exist side by side with residual arrangements from previous [care] settlements' (DeVerteuil, 2015: 6). With this in mind, the concept does offer a helpful contrary starting point than Bowlby's (2011) call for more work on friend, kin or neighbourhood allyship, challenging at the outset any implicit assumptions about having these types of connections in the first place. It allows us to ask more open questions beyond the experiences of the participants cited here; about whether *or not* people do have friends, neighbours or kin to rely on, or indeed if these relationships can be negative, as shown by bullying neighbours and siblings. It also can reveal how the opportunities to make such connections can diminish depending on the compounding effects of disability, age, poverty and gender. Finally, it challenges us to think about what, if anything is filling the gap in declining statutory services.

Acknowledgements British Society of Gerontology Averil Osborn Award and University of Southampton Faculty Interdisciplinary award.

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