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How do people with learning disability experience the city centre? A Sheffield case study

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ABSTRACT

The use of city centre spaces by people with learning disability is not much debated in the literature. Here we include the thoughts and opinions of groups of people with learning disability as we undertook some guided walks through Sheffield city centre.

We found that few of the participants had independent access to the city centre. Many cited concerns over personal safety and the most, on few occasions when they did visit, did so with family and/or paid staff for pre-planned purposes, usually linked to shopping. The need for appropriate support figured prominently. There is also a need to re-assess what we mean by social inclusion for this cohort.

1. Introduction

Beck (1998:119) claims that 'the city represents the laboratory of civilisation'. If so then the city centre might provide a useful locale in which to explore ideas central to the ambitions of learning disability policy makers and users of services. For, to spend time negotiating the city centre invites us to consider to what extent inclusion, belonging, participation and the exercise of choice can be realised within that milieu.

Dines and Cattell (2006:1) then point to the absence of knowledge around 'the extent to which spaces are shared and may influence social integration, or about the benefits or disadvantages, especially to a sense of well-being, derived from the use of different kinds of public spaces'. And, as noted by Bates and Davis (2004:199), if inclusion is to be effective there has to be a realignment of thinking from the mind-set that constructs the mass of people with learning disability as passive recipients of services to a perspective from which 'service users are recognised as citizens'.

The notion of citizenship offers a useful lens by which to examine the relationship between the individual and the state as the subaltern identity positions occupied by various social groupings are made apparent in this alignment (Bucholtz and Hall, 2004; Oliver, 1996). Morris (2005:16) was aware of this when she notes that 'participation both requires and gives expression to self-determination, and like self-determination is an integral part of being a citizen'.

With this in mind we set about to design a study that would answer the question: how do people with learning disability[1] experience the city centre? In attempting to answer this question we also hope to prompt some elements of discursive exchange between the contributing disciplines to that hybrid area of enquiry characterised by interest from social geography and disability studies.

We were also keen to discover from the accounts narrated by our participants whether their experiences of the city centre were in any way dialectical, defined by a two-way process of being and belonging, or whether their experiences were characterised as passive as defined by a consumerist agenda ( ). This, we reasoned, might give us clues as to what extent the social relations they experience in the city centre are constructed, limited and influenced by that place. But now, we will discuss some background to the main policy initiatives that have shaped the lives of people living with learning disability in contemporary UK society.

2. Policy background

The social exclusion of this population is well documented. In Valuing People (DH, 2001) it is noted that people with learning

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[1] We are aware that the terminology remains contested but that argument can be had another day and in another place.

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disability '….are amongst the most socially excluded and vulnerable people in Britain today' (DH, 2001:14). This situation has some history.

Since the NHS and Community Care Act (DHSS, 1990) accelerated the move towards community care there has been debate on the impact of the legislation on one of the main social groupings affected, namely people with learning disability (Myers et al., 1998). After this 'dissolution of institutions' (Mansell and Ericcson (1994)) much of that debate was focused on quality of life (Rapley and Ridgway, 1998), cost effectiveness (Beecham et al., 1997) and on issues around choice and control (Stalker and Harris, 1998). In these areas commentators found a discrepancy between the policy rhetoric and the lived reality. And while Beecham et al. (1997:39) were able to report in their study that they had found 'community care costs were generally lower than the cost of long-term hospital care from which people had moved' and Stalker and Harris (1998:65) could point out that 'people living in community settings generally have more freedom of choice than those in hospitals', caveats remained. Stalker and Harris, 1998:66 also indicated that 'Compared to the general population, opportunities for people with learning disabilities to exercise choice are still restricted.

The underpinning philosophy behind the NHS and Community Care Act (1990) owed much to the work of Wolfensberger (1972, 1983) and O'Brien (1987) who both promoted the rights of the individual living within services. However, what is important to grasp is that the fulcrum of the legislation rested on the artificial division that was constructed between health authorities (HAs) and local authorities (LAs). The Las' function was to assess the needs of local populations and then to buy care from the newly formed NHS Trusts. This consumerist agenda not only introduced the purchaser/provider split and internal markets but also cast the individual with learning disability in the role of customer. This role was to become even more apparent in the next major legislative effort when Valuing People (DH, 2001) aligned rights, independence, choice and inclusion as the four cornerstones of learning disability policy.

Contemporary social policy (DH, 2001; DH, 2009) advances and legitimises the earlier notions of 'normalisation', as popularised by Nirje (1969) and Wolfensberger (1972, 1983). This is premised on a social model of disability which sees the organisation of society, at street level and at an ideological level, as the main barrier to the inclusion of people with a variety of disabilities into the mainstream (Swain et al., 2003; Thomas, 2004). This has led some commentators to consider the actual meaning and relevance of these terms when applied to the target audience (Hall, 2005; Cummins and Lau, 2003). From these Hall (2005:108) suggests that there is too narrow a focus on socio-economics. He says that in practice inclusion within and exclusion without mainstream society are more narrowly conceived, namely as employment and independent living.

And while arguments over the effectiveness of community care as a model were largely over, doubts remained about how best to empower people to take advantages of the policy promises. People were indeed living in their local communities but how could they then become part of those communities? Morris (2004:428) said 'independent living is also associated with the words 'choice' and 'control' and concerns both the environment in which someone lives and the assistance needed in order to go about daily life'. But the physical movement of a population from one location to another also requires an accompanying mental shift in attitude.

Ootes (2013:12) develop this argument with reference to the experiences of Dutch mental health services. Leaving aside the obvious differences between Dutch mental health and UK learning disability policy agendas there remain parallels. In both settings a period of deinstitutionalisation was followed by a subsequent promotion of community-based care where both sets of service users found that genuine integration was often more rhetoric than reality. We take up the idea of the 'citizen' later in our discussion with reference to the claim that Ootes (2013:12) make when they say 'Our goal is to develop a new spatial metaphor and a new notion of citizenship—a notion, which may be useful to professionals in long-term mental healthcare as well as elsewhere'.

3. What we already know

There is no single body of work that adequately summarises what is known about the way people with learning disability experience the city centre. What we do know of this topic must be gleaned from those liminal spaces between disciplines. To contextualise our project we considered the contributions to the body of knowledge from several sources. In doing this we hoped to be able to discern some focus on how the individual with learning disability is conceptualised whether as a citizen, consumer, commuter or in some other permutation of identity positions.

Park et al. (1998:222) in their review noted that 'Like virtually all social scientists, geographers have paid less attention to intellectual disability'. We have not restricted our reading to geography but even if this was true then it is less in evidence now. However, of those who have considered learning disability in relation to accessing city centres the angle of the approach is sometimes oblique.

In her study Aitchison (2003:960) documented the preferences of fifteen young disabled people for social activities. Going into town came seventh behind typical housebound activities like watching TV, listening to music and using a PC. But crucially going into town was the first outdoor activity cited as a preference. Fange et al. (2002:323) interviewed 33 Swedish teenagers with functional limitations about their use of leisure time. This cohort showed similar preferences to our participants when they listed their favourite facilities as including music shops, department stores and cafes.

Such consumerist motivations for town centre visits are, however, influenced by considerations of how the individual manages. Gleeson (1999, 2001) and Hall (2005, 2010a, 2010b) were both very aware that moving around the city centre means more than just knowing your way. Both were aware too that exclusion operates to disadvantage people by denying them social opportunities and life chances. Hence architectural and structural inequality exists in planning and design. As Freund (2001:694) says 'The social organisation of space is not merely a place in which social interaction occurs, it *structures* such interaction'. This point is echoed by Bucholtz and Hall (2004:303) who notes the reaction of some participants in his study who 'make the decision to exclude themselves from discriminatory and intimidating mainstream social spaces'.

This more conceptual analysis is then given an empirical slant by Abbott and McConkey (2006:282) who looked at the personal consequences of inclusion and exclusion. They note that 'Participants appreciated that their own lack of skills created difficulties for them which further reduced their confidence and motivation'. A participant is then quoted as saying "Not being able to use the bus or train or taxi on my own. Not being able to go to [town] on my own to go shopping" .

This introduces the idea that before people with learning disability can experience the city centre they first have to secure access. Mathers (2008:517) undertook a multi-site study that used a photo-elicitation toolkit to enable participants to express their feelings about the urban sites they visited. The toolkit was used 'to facilitate the exchange of ideas and experiences between designers and PWLD, with the intention that it will thereby help ensure landscapes of genuine accessibility'. The issue of accessibility was