

'The shops were only made for people who could walk': impairment, barriers and autonomy in the mobility of disabled adults

James Bonehill+, Nadia von Benzon* and Jon Shaw#

+ North Star Consultancy

* Lancaster Environment Centre, Lancaster University. Corresponding author:

n.r.vonbenzon@lancaster.ac.uk

School of Geography, Earth and Environmental Sciences, University of Plymouth

Abstract

Based on research carried out with a group of adults with Cerebral Palsy in Birmingham, UK, we consider the complex inter-relationship between the accessibility of the urban environment to those with impaired gross motor skills, and the ability of these people to lead full and independent lives. Drawing on and developing Cresswell's (2010) holistic framework of mobility as both 'brute fact' and meaning-making, we demonstrate the reality of differentiated mobility. For those with bodies that function outside the presumed operating parameters of the model subjects of urban design, urban mobility may be possible, but is often uncomfortable and even dangerous, with significant associated effects for impaired people's autonomy. Our study details social and structural, or design, barriers to impaired people's mobility, demonstrating the inter-connection between individuals' behaviour and urban design in a manner that questions a clear distinction between the two. We suggest that further investment in universal design and public education for urban accessibility are issues of social justice.

Key words

Differentiated mobility, urban design, Cerebral Palsy, wheelchair users, mobile methods, video elicitation

Introduction

According to the Department for Work and Pensions (DWP) (2017), 13.3 million (or one in five) people in the UK are disabled. Whilst different definitions of 'disability' exist, the social model of disability, the preferred definition of disability amongst activists and scholars, sees disability as a social injustice resulting from society's inability to meet the needs of people with impairments (Oliver, 2004). Under English and Welsh law¹ rights enshrined in the Equality Act 2010 mean that disabled people should be treated as full members of the community, with the right to access public and private spaces on the same terms as non-disabled people, the right to engage in social and leisure activities, to work and to personal relationships and family life. Despite such rights, there remains widespread evidence of systematic environmental and social exclusion of disabled people in the UK, referred to by Goodley and Runswick-Cole (2011: 602) as a 'dominant culture of disablism'. Periodically, high-profile news stories or media outputs highlight specific examples of social injustice – in 2016 there was public outrage when British Paralympian Anne Wafula-Strike was forced to urinate in her wheelchair whilst on a train without an accessible toilet – but statistics report a broader picture in which disabled people are far more likely than non-disabled people to be unemployed, live in poverty, be victims of crime, and suffer from mental illness (e.g. Equality and Human Rights Commission (EHRC), 2016). The EHRC (2017) is clear that disabled people experience this social exclusion as a result of unequal power relations, referred to within the social science literature as the experience of stigma and marginalisation (see Goffman, 1973).

The EHRC identify mobility as a particular area of disadvantage, demonstrating that disabled people do not experience widespread autonomous mobility in the same way as non-disabled people (Pooley et al., 2005); this social experience is referred to by Massey (2008) as *differentiated mobility*, recognised as both a cause and result of social exclusion, with the potential for significant detriment to lived experience and ultimately quality of life. Indeed, Cresswell (2006: 1) argues that mobility is 'central to what it is to be human' and Yarwood (2013) considers it a key tenet of the experience of citizenship (see also Spinney et al., 2015). Following this logic, it is no great step to argue that those who experience disadvantaged or curtailed mobility are experiencing a curtailed humanhood, or impaired citizenship rights (Gaete-Reyes, 2015). The idea of disabled people as not fully human, either viewed this way through the lens of social perception, or materially dehumanised through the effects of living in society with an impairment, is not a new framework for understanding. Goodley et al. (2016), for example, refer to the Dishuman Child, and similarly we might position a person who is not mobile as dehumanised or 'dishuman' (Cresswell, 2010; Oliver, 1996), a state alternatively

¹ In the UK there are three different legal jurisdictions: England and Wales, Northern Ireland and Scotland.

referred to by Goffman as 'spoiled identity' (Goffman, 1973). Under this lens, urban mobility moves far beyond an urban planning issue to become one of social justice.

In this paper, we examine the mobility experiences of a group of wheelchair-using adults with Cerebral Palsy² in Birmingham, to investigate issues of impairment and barriers to individual autonomy in an urban environment. The data developed with our participants calls into question the distinction between the physical, built and structured experience – that which is objective – and the meanings, or the lived experience, of mobility. This non-dualistic or hybrid experience is explored here as a subjective reflection of the interplay between participants' impairments and the environment in which they are mobile. We argue that the material environment that mediates participants' mobility experience cannot be separated from social stigma and marginalisation, in that the environment is both a product of, and a catalyst for, this stigma and marginalisation.

Disability signifiers

The social model of disability referred to above has been widely accepted in Western academia as the appropriate tool for exploring disability from a structural perspective. In presenting disability as a failure of society, it becomes a social problem, one of government (both centrally and locally), policy-makers, public services, business and communities. Because it does not call on individuals – and particularly not impaired individuals – to make changes, to try harder, or to be better, the social model of disability becomes a crucial analytical tool in addressing the social stigma and marginalisation of disabled people (Gabel and Peters, 2004).

This said, the social model has not been without opposition. Feminist disability scholars in particular have critiqued the model for its lack of personalisation and its avoidance of the lived experience of impairment, including intensely individualised pathology such as pain that might detrimentally affect an impaired person even in a society with no physical or social barriers to inclusion (Thomas, 2004). Another criticism of the social model is that whilst its universalism – its rather blanket or binary grouping of disabled people without attention to specific impairment – is a useful tool for generating a voice in activism (Oliver and Barnes, 2010), it does not properly reflect the individuality or identity of people with impairments and the associated potential for highly differentiated life experiences

² Cerebral Palsy is a neurodevelopmental condition that affects 1 in every 400 babies born in the UK every year (NHS Choices, 2017) due to issues with brain development or brain injury during pregnancy or soon after birth. The condition affects muscle control and movement although people experience different manifestations of Cerebral Palsy. These may be accompanied by secondary disturbances including those related to sensation, communication, cognition, behaviour, and seizure.

(Shakespeare and Watson, 2001). Publicly this argument might be seen played out in the calls for 'people centred' or 'people first' language around disability. Particularly in the USA, movements spearheaded by disabled people and their families, as individuals or collectivised groups, have called for the public use of terms such as 'person with a disability' rather than a disabled person, or 'person using a wheelchair' rather than 'wheelchair user'. The argument here is that whatever impairment a person might experience, they remain first and foremost, a person³.

A perceived need for differentiation may also reflect intersectional experiences relating to race, gender and class that impact on experience of disability (Gaete-Reyes, 2015; Dean et al., 2017; Dowse et al., 2016; Fine and Asch, 2018). Intersectional theory explores the way that different (typically 'spoiled' – Goffman, 1973) identity markers may present differently in different social and spatial contexts, interacting with one another to produce particularly intense experiences of marginalisation that differ from other people with a single marginalised characteristic. Experiences of disability will, however, not only be mediated by an individual's 'other' identity markers, but by the sorts of impairments individuals experience. This phenomenon was clearly articulated by the disability academic and activist Prof Tom Shakespeare (2009), who found his experience as a disabled adult altered drastically when in addition to his achondroplasia⁴, a related spinal condition impaired his ability to walk and required him to become a wheelchair user. Shakespeare's new impairment altered his lived experience as a disabled man, bringing into sharp relief the lack of homogeneity of the experience of disablement.

A range of research has addressed the ways in which disabled people's aids – the technology that seeks to compensate for their disability – shape both impaired people's own sense of self, and their interactions with the people and places around them. Much of this work has explored the detrimental impact of aids as signifiers of difference (e.g. Keith, 1996; Watson and Woods, 2005; Cahill and Eggleston, 1994; Papadimitriou, 2008). For example, Nancy Worth's research uncovered young, blind, participants choosing to leave their cane at home, relying instead on friends to support their mobility, due to a desire to avoid being easily and publicly identified as visually impaired (Worth, 2013). Young wheelchair-using participants in Michelle Pyer and Faith Tucker's (2017) research also discussed experiencing stigma when travelling in public which they associated with the use of the chair. As Cahill and Eggleton (1994) argue, wheelchair users often experience 'nonperson'

³ It is interesting to note that in the UK the Department for Work and Pensions guidelines on disability and language (<https://www.gov.uk/government/publications/inclusive-communication/inclusive-language-words-to-use-and-avoid-when-writing-about-disability>) endorse social model 'compliant' language – e.g. 'disabled person' rather than 'person with a disability'.

⁴ A bone growth condition that is the most commonly occurring type of disproportionately short stature (Great Ormond Street Hospital for Children NHS Foundation Trust, undated).

treatment in public, rendering them invisible to passers-by (see also Unsworth et al., 2017). By contrast, more limited work has suggested that some aids are beneficial. Research shows the significant role that assistance dogs can play in supporting the social interaction of blind, and other disabled, adults and young people, due to public normalisation of interaction with dogs (Lane et al., 1998).

The language and the material objects we use to denote and delineate disability matter. Both feminist and disability scholars have worked hard to demonstrate the interplay between the perception of 'other', the resultant and the perpetuating discourse, and the way in which discourse and understanding can result in stigmatisation and marginalisation (Green et al., 2005). Goffman's (1973) concept of stigmatisation has been widely accepted as a useful lens for understanding the lived experience of some of the least powerful in society. The concept of stigmatisation clearly implies painful social experiences, but work by disability scholars and geographers such as Worth (2013), Pyer and Tucker (2017), von Benzon (2016) and Imrie (1998) has demonstrated that this social ill manifests additionally as material barriers to disabled people's mobility.

Mobility, rights to the city and full citizenship

Material barriers to access of the built environment are interwoven with the fabric of the urban and suburban environment. Spaces which have been crafted and formed by human hands which had the potential to be widely accessible, in a way that the unbuilt, or less-built, countryside did not, failed to address this opportunity. Internationally, and historically, towns and cities industrialised, grew and (quite literally) cemented themselves into the landscape across periods when most disabled people died in infancy and those that survived were cared for at home or in institutions (Wolpert, 1980; Hall, 2004). The city, therefore, was designed around the productive body (Imrie, 2000); the disabled body was not part of the architectural logic of either organic or systematically planned urban development (Imrie, 1996; 2000). Kitchin (1998: 343) goes as far as to argue that 'spaces are currently organized to keep disabled people "in their place" and "written" to convey to disabled people that they are "out of place".' It is clear that urban cities offer complex and manifold barriers to access for disabled people (Gaete-Reyes, 2015; Imrie, 2014). For Titchkosky (2011), inaccessible spaces become sites of exclusion distinguishing between those who are 'in' and those who are 'out'.

In addition to stigma, apathy, inattention and budget constraints, accessibility of urban design and development is also limited by the near-impossibility of true universal design. Universal design, as an urban planning principle, seeks to do as it says on the tin – to create environments that are

accessible to all (Steinfeld and Maisel, 2012) – although due to the varied and contradictory needs of people living with and without impairments and illness, people of different ages and statures, and people living with other bodily, psychological and emotional differences, the concept is always destined to be complex. For example, for a blind adult, an audible alarm from a pedestrian crossing might be considered a crucial signal that facilitates safe interaction with roadways; for a deaf person wearing a hearing aid, or a person who experiences heightened sensory perception, this crossing signal may present a disorientating intrusion to their safe navigation. Similarly, one person's 'sufficient' lighting is another person's 'glaring' lighting; one person's much-needed bench is another person's barrier to access. Still, the difficulty of achieving maximum accessibility is not a good reason to sideline this goal, and certainly not an excuse to avoid attempting to broaden the accessibility of urban spaces. This is particularly the case if you identify urban mobility as a social justice issue.

Hine (2016) recognises mobility as crucial for accessing the social, cultural and political systems within society that are vital for social inclusion. Mobility is a requirement for accessing employment, leisure and social opportunities, as well as for dealing with the 'housekeeping' of daily life – visiting banks, post offices and supermarkets. The more independent mobility a person has, it might be argued, the more fully they can enjoy their rights to citizenship (e.g. Yarwood, 2013), with independence particularly key to markers of personhood such as employability and the ability to develop and sustain inter-personal relationships. At the same time, mobility is more than just the 'brute fact' of movement through space; it is experienced in a manner that is embodied, affective and emotional, and this experience is subject to understanding via representation (Cresswell, 2006). In other words, movement is felt by a person, and other humans understand this person's experiences through the crude and differentially limited ways in which s/he is able to communicate the experience. To further complicate this issue, Shaw and Docherty (2014) argue that 'brute fact' is, itself, more than just brute fact, in that the very act of the movement is a product of socio-political, economic and environmental processes. For example, our drives to work (the brute facts) are largely dull, sometimes tiresome and, on occasions, hazardous (our embodied, emotional and affective experiences which we are communicating using, what we hope, is written language in a manner appropriate to the audience). But the fact that we are in the position (of needing) to drive to work itself arises from a broad range of factors including my employment status, UK infrastructure, the cost of fuel to the consumer, technological innovation... and so on.

If we return to consider the implications for disabled people's movement in urban environments of this complex positioning of what it is to be mobile, then we can see this tripartite interconnection of movement as 'brute fact' as a person moves through space independently or with assistance from aids or other people, movement as individualised experience that can be only imperfectly

communicated to others, and movement as a product of a culmination of a myriad socio-economic and political processes that have led to the point at which the person is moving and experiencing movement. Barriers to movement can happen at any of these three loci, with the potential for ramifications that reverberate into all aspects of the individual's life and to disrupt their broader lived experience, for example by presenting a barrier to accessing employment, recreation and other vital services. In so doing, barriers to mobility present barriers to independence and therefore to the development of inter-personal relationships and family life. Indeed, as we now go on to demonstrate, drawing on fieldwork with adults with Cerebral Palsy, issues of localised mobility are not simply questions of motion and movement, but a concern for the rights of disabled people to lead full lives. As such, the issue of urban mobility is an issue of social justice and human rights.

Fieldwork

The primary research was carried out by one of us (James) in Harborne, located three miles southwest of Birmingham city centre in the West Midlands, UK. The area might be considered representative of a 'typical' British high street providing a range of independent retailers, restaurants and bars. Cerebral Palsy Midlands managed the recruitment of participants to the study (Table 1) and became the research facilitator and participant gatekeeper⁵. The organisation provides a day care service for people with Cerebral Palsy, actively supporting and empowering them to ensure that they are able to get out in the local community and experience an improved quality of life (Cerebral Palsy Midlands, Undated).

The research took place over five months. An initial meeting between James and the gatekeeper at Cerebral Palsy Midlands provided an opportunity for an introduction to some of the participants and a reconnaissance of the local high street. A month later James returned to undertake the initial research stage. This involved short trips to the Harborne High Street with participants and their carers. These were made either with individual participants or in small groups, lasting about 30-40 minutes each and following a route predetermined by the organisational gatekeeper and the carers, in discussion with participants. During the trips, participants wore GoPro video cameras attached to their person using either a head or chest harness according to their preference. Our deployment of such recording devices follows the extensive use of video to explore embodied experiences in geographical research (see Bell et al., 2015; Blazek and Hranova, 2012; Garrett and Hawkins, 2014; Kindon, 2003; Simpson, 2017). James accompanied participants and carers on all trips, observing

⁵ Full ethical clearance was obtained in advance of the project's commencement.

their 'normal' practices which included going in to some of the shops, and recording his own observations in a field diary. Following this, the GoPro videos were watched and particularly interesting moments were recorded. These moments were edited and organised thematically in a short video to share with individual participants as a discussion catalyst (von Benzon, 2017), and an interview guide was produced for each participant based on the content of the videos.

Participant	Impairment and Differentiated Experience
David	This participant is independently mobile with the aid of a walking stick.
Isobel	This participant experiences Quadriplegic Cerebral Palsy affecting all four limbs. She is a wheelchair user who requires assistance with communication, mobility, eating and personal care. She has complex needs and is dependent on others for help.
Alan	This participant experiences both physical and cognitive impairment as a result of Cerebral Palsy including hearing loss. He uses a wheelchair to facilitate mobility outside the home which he is able to self-propel. The wheelchair is not needed indoors.
Ben	A participant with both physical and cognitive impairment who experiences communication difficulties. He often uses a walker but preferred to use a wheelchair for research participation.
Thomas	This participant has both Down Syndrome and Cerebral Palsy. The primary impairment is cognitive and relating to communication difficulties.
Julie	This participant has Quadriplegic Cerebral Palsy and uses a wheelchair to aid her mobility. She experiences communication and swallowing difficulties.
Ralph	This participant uses a wheelchair to aid mobility but has independent access to the local community. He has some cognitive impairment that limits his judgement capacity and may put him at risk.
Gareth	This participant is able to use a walker but is prone to falling, so chose to use a wheelchair for participation in this research. He experiences communication and swallowing difficulties, and epilepsy.

Table 1. Participants in the study. Pseudonyms have been used to protect the respondents' anonymity.

The following month James returned to Harborne to interview the participants. These interviews took place at Cerebral Palsy Midlands and were conducted in the presence of a member of staff who

could take responsibility for the participants' comfort and personal needs, and support communication where required. Interviews lasted up to 40 minutes. During the interviews, participants were shown parts of their video footage and encouraged to reflect on their mobility experiences as they watched. Transcripts of these interviews were later returned via the gatekeeper to participants, who were given the opportunity to comment on and edit the text. All of the transcripts were approved and then coded using NVivo.

As a final research activity, James returned to Harborne High Street five months after the research had begun. He carried out an accessibility audit of businesses on Harborne High Street using a predetermined set of categories established from information derived from three urban design accessibility guidelines concerning the entrance of buildings: that at least one entrance, ideally the main entrance, is built flush to the external level and is wide enough for unrestricted passage (City of London, 2015); automatic doors are preferable (Wolverhampton City Council, 2009); and ramps should be provided wherever stairs obstruct free passage (United Nations Enable, 2003). Three outcomes for businesses were determined: very accessible, moderately accessible and not very accessible (Table 2).

Very accessible	Step-free access with wide, automatic doors. One entrance that is able to be used by everybody.
Moderately accessible	Step-free access with wide, manual doors. May have separate ramps or a separate accessible entrance and may use bells for people to ring for assistance at the entrance.
Not very accessible	Stepped entrance with narrow, manual doors. No alternative entrance is offered.

Table 2. Accessibility descriptors for businesses on Harborne High Street.

Movement, experience and representation

Stigma and marginalisation

For the participants, movement around the High Street was an experience of encounters. By and large, these encounters were negative experiences for participants, who were frequently stared at by those they moved past in the street. There was, of course, the possibility that passers-by took to staring at the participants because they were wearing a Go-Pro camera (even in the context where

'casual filming' has become both possible and widely practised in public), but watching back the video footage with those affected confirmed to James that it was an all-too-common experience:

JB: Does that happen a lot where people look at you?

Isobel: Mhmm [nods head]

JB: So what I want to look at is just the people by the bus stop. So if you notice, a couple of them take a bit of a... they look at you and then they look down.

Julie: Mhmm

JB: Does it happen a lot where people might look at you a lot whilst you're in the street?

Julie: Mhmm

The two examples above come from participants with quadriplegic Cerebral Palsy who use wheelchairs. Although the participants did not have sufficient verbal or non-verbal communication to provide a full answer to the questions posed, both the researcher and carers present were clear that the participants were agreeing with the suggestions.

Ralph was able to articulate this experience clearly and in some detail:

Ralph: Sometimes when I'm in Harborne, sometimes I get people who honestly... they just look.... And they turn away.

JB: Do you think that is because you're in a wheelchair...?

Ralph: Because I'm in this [gesticulates at the wheelchair]. If I was walking, nothing. But because I'm in this most of the time, they think it's strange.

These findings reflect research by Wiesel et al. (2013) from Melbourne, Australia, who found encounters between people with intellectual disability and the public reinforcing exclusion and a sense of 'othering'. Similarly, Pyer and Tucker (2017) demonstrated the experience of stigmatisation felt by teenagers in wheelchairs on public transport (see also Gibson et al., 2007). Indeed, for the participants in this research there was a sense by some that it was the presence of the wheelchair, more than any other aspect of their disability, that led to a hostile or unwanted gaze from the public (see also Zitzelsberger, 2005 who argues that wheelchair using simultaneously makes disabled

people visible and invisible in public places). This was clearly articulated by David who is normally able to get around using a walking stick, but on some occasions uses a wheelchair:

JB: So when you've been out and about in a wheelchair then, do you find it quite different, your experience of an environment in a wheelchair than when you're walking?

David: Sometimes they look at you more or less.

JB: ... Okay, so you are thinking that when you're in a wheelchair that people look at you more?

David: Yeah.

Brown and Boardman (2011) and Parette and Scherer (2004) suggest that it is the power of assistive technology devices, such as wheelchairs, to communicate the vulnerability of a person, that has positioned these technologies as key indicators of difference within society. The notion that these technologies are 'undesirable clinical equipment' (Sapey et al., 2005: 493) is as clear in the responses of these adult participants as with the young people in Worth (2013) and Pyer and Tucker's (2017) research. The stares the participants experience serve not only to make them feel out of place, but often have deeper affective impact on their experience of mobility. For Julie, the result of being stared at whilst she is out and about leads to fear. When watching back some GoPro footage of an example of people looking at them when passing a bus stop, Julie commented:

Julie: [participant goes through their communication book and points out an emotion relating to fear]

JB: Do you feel scared when people look at you?

Julie: Mhmm

Julie was then asked why she felt scared.

Julie: [goes through their communication book]

Carer: Relax... Body relax? You feel tension?

Julie: Mhmm

JB: You feel tension when people look at you?

Julie: Yeah.

During this exchange there was a visible tensioning of Julie's limbs, in particular her arms and wrists, a clear demonstration of the emotional effect of being a subject to so many strangers' gazes. Other

emotions expressed from other participants included feelings of sadness and annoyance (Isobel) and being upset and uncomfortable (Gareth).

Discomfort and inaccessibility

For the participants, the emotive and affective experience of mobility was interwoven with the Brute Fact of the practicalities of getting around. The lack of empathy from the public that led to stares, and their feelings of extreme discomfort also led to unthinking actions that presented physical barriers to their access to the high street. This was summed up by Alan: 'When people see people in wheelchairs, they don't care a bit'. A specific example referred to by participants was the habit of local people to park their cars on the pavement. Just outside the Cerebral Palsy Midlands centre, the road is full of vehicles parked on the pavement, which causes a barrier for participants, particularly those in wheelchairs. The experience of navigating this barrier was caught clearly on Isobel's GoPro footage (Figure 1).

This issue was discussed in some detail with Alan:

Alan: When the car is like that you can't ever get a wheelchair on the pavement. You have to go around the car and shoot around the side of the car. All the cars are parked on the pavement.

JB: Do you think people don't think of other people then? So the driver of the car. Do you think they are not thinking...

Alan: Yeah, because they are not thinking.

On some occasions the barriers presented by the cars cannot be circumnavigated, and participants find their paths barred and they are unable to travel to their intended destination. Ralph in particular reflected on an experience of not being able to go into Harborne because of vehicles parked on the pavement:

Ralph: I went out once to the gate here... I couldn't get out... because one of the, I don't know who it was... Parked the car too far over by that much [he indicates a measurement using his fingers]

JB: Oh my goodness, okay.

Ralph: And you can see how wide the chair is.

JB: So how does it make you feel when stuff like that happens?

Ralph: It makes me angry.



Figure 1. Sequence of events during which Isobel was forced to cross the road in order to circumnavigate a car that was parked in such a way as to block the pavement: a) Isobel notices the car parked on the pavement ahead (circled); b) she makes the decision to cross the road as the gap is too narrow to pass through; c) crossing the road; d) using the pavement on the other side of the road, which is clearer.

The participants were particularly angry that the parking of cars on the pavement seemed not only to reflect an ignorance of the harm they might cause, but was a wilful disregard for the needs of those in wheelchairs. This was evidenced by the fact that cars continued to park on the pavements close to the centre, despite a number of signs on the road outside Cerebral Palsy Midlands to 'alert' drivers to the fact that disabled people would be using the roadway (Figure 2).



Figure 2. Footage taken from Isobel’s GoPro shows the ‘Disabled People’ road sign with cars still parking on the pavement.

Parked cars, however, were not the only material barrier interrupting participants’ experience of movement within Harborne. Participants commented on several aspects of the streets themselves that cause them difficulty. Those in wheelchairs highlighted that the comfort of their ‘ride’ was crucial to their affective experience of being out in Harborne (see also Bromley et al.’s 2007 research in Swansea). A particular determinant of comfort was the evenness of the pavement surface (Figure 3). Uneven surfaces caused participants significant discomfort in their wheelchairs and this was clearly visible on the camera footage where the footage ‘jumps’ up and down: ‘you can see it. You’ve got it! The camera is jumping around because the surface there is not level’ (Ralph).

JB: Can you see that the camera is jumping because of how uneven the pavement is? Is that uncomfortable?

Ben: [inaudible]

Carer: Does that make you feel good or bad?

Ben: Bad.

JB: Bad? Does it make you feel frustrated?

Ben: Yeah.



Figure 3. An uneven and broken section of the pavement on Harborne High Street that caused participants discomfort and led to undue exertion and exhaustion (JB).

Danger and dependence

Whilst uncomfortable for all participants, the uneven surfaces appeared to pose a danger particularly for participants who manually propelled and manoeuvred their own wheelchairs.

Ralph: It's horrible because when you're going around Harborne it's just bumpy, isn't it?

JB: Yeah.

Ralph: And they ought to make it one flat... You watch how it comes to the end of the dip. I'm pushing myself, I'm knackered... Pushing hard round that puts me out of breath.

Ralph: It's uneven, it's uneven.

JB: Is it tiring for you?

Ralph: Yes.

Sometimes this unevenness creates a barrier to independent mobility, forcing a participant to be reliant on others for help. Alan commented that when he gets tired, which happens more frequently on uneven surfaces, his carers need to push the chair. Participants thus expressed a need for the pavement surfaces in Harborne to be made smoother which, in turn, would improve their experience of mobility whilst out and about by making their journey more comfortable. Rebecca, a participant in Gaete-Reyes's (2015) research, described having to leave the pavement in order to travel on the road, when the pavement surface was of particularly bad quality.

In addition to pavement surfaces, it was clear from the video footage and from the interview with participants that dropped kerbs also presented a particular challenge. During the research, participants encountered situations where they got stuck and had to wait for a carer to help them up onto the pavement, for example:

JB: So you're just about to cross this road here [indicates to screen]. It's quite a jump to get down.

Alan: Yeah.

JB: And then you need to get back on to the pavement. And then you get stuck.

Alan: Yeah.

JB: And then I think, if I remember rightly, that [carer] had to help you get up. Is that a problem?

Participant: No no. For the people that are waiting because the chair is light you see.

JB: Yeah, but is it annoying to get stuck?

Participant: Yeah.

For many of the participants, it was difficult to see where the dropped curbs were. The GoPro caught a situation in which Alan was approaching the wrong part of the kerb to cross the road and was called back and oriented towards the dropped kerb by his carer (Figure 4).



Figure 4. Sequence of events in which Alan experiences difficulty identifying the dropped kerb: a) Alan approaches the crossing; b) he attempts to cross the road to the left of the dropped kerb (circled), but the carer calls out, “Alan, it’s over here, the lower flooring”; c) the carer says, “see where that lady is crossing? You can’t go down there, mate”; d) Alan moves towards the dropped kerb to cross the road safely.

It became apparent that the easiest way to negotiate the dropped kerbs was to take the wheelchairs down backwards. Within Ben’s interview, his carer, who was present in the room, explained the reason for this:

JB: Why were you taken off backwards? Is that easier to do?

Carer: Mhmm, for the kerb. If it’s a big higher it is better to bring back because if you’re going forward maybe he will tip forward but you can...

JB: Support it?

Carer: Yeah.

Both Ben and his carer acknowledged that this method of travelling over the dropped kerb was potentially dangerous, but that it was necessary sometimes where the kerbs were very steep. Additionally, Ralph experienced two scenarios during the research where the dropped kerbs nearly caused him to fall out of his wheelchair.

JB: You roll back and you almost fall out. So that could've been really dangerous.

Ralph: It can be.

JB: Because there's a really busy road behind you. Can you imagine if you had gone back?

Ralph: If I had gone backwards... I could've got hit, couldn't I?

This sequence of events was captured by Julie's GoPro as Julie was accompanying Ralph during the research trip (Figure 5).



Figure 5. Sequence showing Ralph nearly falling out of his chair when negotiating the dropped kerb (JB): a) Ralph is crossing the road and approaching the dropped kerb; b) he encounters difficulty with the dropped kerb and the back wheels of his wheelchair get stuck, causing the wheelchair to roll backwards, elevating the front wheels; c) the carer 'rescues' Ralph, pushing him onto the pavement.

In this situation luckily the carer was there to catch the participant and prevent him falling backwards into the road. The scene demonstrates that the participant would otherwise have been capable of travelling independently in this space, but the slope of the kerb rendered him suddenly and unexpectedly dependent on someone else for their mobility and safety. The failure here was not that the access needs of wheelchair users had been completely overlooked, but one of design and testing; the dropped kerb was not level enough to be useful for the purpose for which it had been designed.

Similar design faults were experienced at pedestrian crossings, which many participants found impossible to operate independently. David suggested the crossing panels were too high for people in wheelchairs to reach. Meanwhile, Isobel and Ben both commented that the button required to be pushed to operate the crossing was too small. Figure 6 illustrates the difficulty of pressing the button for someone who struggles with motor skills, or does not have full range of movement in his or her hands. In most cases, the participants relied on the accompanying carers to operate the pedestrian crossing, but in the interviews, they expressed the frustration that this caused for them. Participants were clear that they do not want to be dependent on others whilst out in Harborne and would far prefer to carry out such actions, that may seem small, meaningless and everyday to onlookers, by themselves.



Figure 6. Isobel experiencing difficulties trying to press the operation button at the pedestrian crossing (JB).

On the High Street itself, participants described the frustration of having to negotiate narrow spaces on the pavement created by street features such as bus stops and lamp posts. A particular concern was the placement of sandwich board advertisements that blocked the pavement (Figure 7).



Figure 7. Footage from Ralph's GoPro showing the placing of a sandwich board that has created a narrow passage on the pavement (JB).

Exclusion as feeling and fact

Once participants made it out of the Cerebral Palsy Midlands centre, navigated the parked cars on the neighbouring roadways and negotiated dropped kerbs, inaccessible pedestrian crossings and blocked pavements, their mobility experience was then impacted by their differentiated ability to use the high street shops. All of the wheelchair-using participants commented on the lack of accessible shops in Harborne - 'half of the shops in Harborne you can't get in' (Alan). Exclusionary design features were typically doorways that were unable to accommodate the size of the participant's wheelchair and a lack of level or ramped access. This 'brute fact' of exclusion from high street shops due to lack of safe access was experienced affectively by the participants.

JB: How does that make you feel?

Ralph: That makes me feel... that makes me angry.

JB: How do you feel that you can't go into those shops because of the steps?

Julie: [Participant points at an emotion in their communication book]

JB: Disappointed, yeah?

JB: Does it make you sad that you might not be able to access something?

Isobel: Yeah, yeah.

JB: So you'd like to go and eat in the restaurant on the other side of the road but you can't because you can't get in?

Ben: Mhmm... [points at their hair]

JB: A haircut?

Carer: Is it a barber's shop?

JB: Yeah? So you can't go and get your haircut?

Ben: Mhmm.

JB: Ah okay, and does that annoy you?

Ben: Mhmm.

David and Thomas, neither of whom were using wheelchairs during the research, claimed not to experience any problem associated with access on the high street, although, having said this, James did note that David fell on some steps at the entrance to a pub. In some cases, access was technically possible, but participants were still made to feel out of place due to the fact that segregated entrances were used with a separate 'wheelchair friendly' entrance. When watching footage near one store, Ralph commented:

Ralph: That's got two entrances.

JB: Yep.

Ralph: One for wheelchairs and one for people... Sometimes that makes me angry because most shops should have one entrance for everybody.

JB: Yeah. Do you feel excluded then, if you have to go a different way?

Ralph: Yes, yes.

Ralph's concerns demonstrate that it is not only the *fact* of access that matters to wheelchair users but the *social context* of this access. Access that happened on separate terms to that of non-wheelchair users was deemed second rate access. Whilst the outcome – the ability to get into the shop to purchase goods or access services – might have been the same, the value associated with this activity was eroded through the perceived segregation of disabled customers. Participants were left feeling that they were not welcome in these spaces: 'the shop is made for people without their own disability. That's what the shop is there for' (Alan). Similarly, Ralph stated: 'Some people think that the shops were only made for people who could walk... and they didn't think about wheelchair users'. As such, the relative ease of access provided by a dedicated, but separate, entrance did little to address a lived experience of stigma and marginalisation through the requirement to do something differently.

The participants' reflections on and reactions to the level of (in)accessibility of Harborne High Street and its shops echoes Imrie's (2001) characterisation of the urban environment as an architectural apartheid due to the way in which urban design processes prioritise the 'normal' body and ignore the needs of people with differing access requirements (Swain et al., 2014). This experience is not unique to wheelchair users or disabled people with significantly impaired motor functions. The Will Pike documentary *Yes I can, If...* (Don't Panic London, 2016), explored the experience of Paralympians accessing the high street and found similar concerns. Whether Paralympian (Pike, 2016), teenager (Pyer and Tucker, 2017), female wheelchair user (Gaete-Reyes, 2015) or Harborne resident, physical barriers to access impede the movement of those in wheelchairs or who use walking aids, and render them dependent on others for assistance and support with daily activities. Whilst dependence will be a necessary experience for some disabled adults regardless of urban design, this research demonstrated that careless urban design, and careless use of urban spaces, renders some adults unnecessarily dependent.

Imrie's notion of urban apartheid is reinforced by the results of our business accessibility survey in Harborne. Of the 110 businesses surveyed, only 13% might be considered 'very accessible', 33% 'moderately accessible' and 54% 'not very accessible' (Figure 8), although we note that Harborne High Street appears to be less accessible than is the norm in the UK. DisabledGo (2014), an organisation that provides accessibility information for disabled people, found in a study of over 30,000 shops and restaurants on British high streets that 20% were not able to provide step-free access.



Figure 8. Colour-coded map of accessibility of the businesses on Harborne High Street. Base map source: Digimaps, 2017.

In conclusion

In this paper, we have examined the mobility experience of some adults with Cerebral Palsy in Harborne, West Midlands, within the broader research context of disability and mobilities geography. We presented the experience of disabled research participants, following their journeys from the Cerebral Palsy Midlands centre where they meet, along Harborne High Street. We reflected both on the material reality of their journey – the discomfort, the complete barriers to access and the danger – and the experiential reality of stigma, fear, humiliation and marginalisation. The stories of the challenges to access were illustrated with material from interviews with participants, and through stills from the videos shot by participants’ GoPro recorders.

Pulling our findings together, we return to our tripartite framework of movement as brute fact, as a process imbued with experienced meaning capable of representation, and as a product of the culmination of myriad socio-economic and political processes (Cresswell, 2006; Shaw and Docherty, 2014). Our research reveals the participants’ everyday movement, constituting trips that would be taken for granted by most able-bodied individuals, as uncomfortable, hazardous and, at times, impossible. The material environment, and the fear experienced as a result of social reaction to the

participants' impairment, particularly wheelchair use, rendered independent travel impossible for most of the participants. Importantly, it was not the participants' physical or cognitive inability to navigate the environment, but design failures and social stigmatisation that rendered participants disabled in their local community. Whilst the participants in this research described their experience in terms of 'spoiled' leisure (mirroring Goffman's 1973 notion of disability as 'spoiled identity'), the barriers they faced would also have limited their ability to independently access work or basic services. The need to travel with an able-bodied companion may be infantilising and prevents the development of normal inter-personal interaction between friends or with acquaintances. Thus our data clearly depicts Massey's (2008) notion of differentiated mobility.

The second arm of the triad considers movement as activity imbued with meaning, an experience that can be represented, albeit only imperfectly. The impairment experienced by some of the participants makes this communication additionally difficult, as might the continual weight of explaining one's experiences from the position of a marginalised member of a community. Our methods sought to address the challenges of representation by providing for the researcher to be present in the moment (the go-along) and to reflect on these experiences afterwards with participants and a Cerebral Palsy Midlands staff member using a video prompt. The GoPro's captured image that was useful in understanding and illustrating the participants' experiences, adding rich data and underpinning illuminating discussions, but James's presence on visits and his own experiences provided both complementary and conflicting data (the latter most evident when he witnessed a participant stumbling and was subsequently able to question a participant's own assertion that he did not face material barriers to access). Thus we see an interesting complication to the practice of representing mobility – was the stumble simply not part of the individuals' experience? Did it hold no significance to them? Had they forgotten this experience? Or was it simply not part of the narrative they were seeking to contribute to this research?

The final part of the triad, movement as a culmination of socio-economic and political processes, is both implicit and explicit within the narratives explored in this paper. Our discussion reflected on the way that stigmatisation and marginalisation led to some of the emotional discomfort and fear felt by participants as a result of stares. We also discussed how emotional discomfort resulted from physical exclusion of bodies from spaces – whether the pavement or shops, or everyday activities such as pushing the button at a pedestrian crossing. In many instances the marginalisation wasn't total, or outright, but experienced in more mundane ways such as discomfort on an uneven pavement or perceived denigration through the use of an alternative shop door. In large part this is a result of social attitudes and social ignorance: the cars parked in a manner that blocks the pavement, the small size of the button the pedestrian crossing, or the wider socio-economic and political processes

that led to a lack of inclusion of disabled people or their representatives (such as Cerebral Palsy Midlands) in urban planning consultations.

Indeed, a number of participants suggested directly to us that many of the barriers to access they faced had a common cause in a lack of empathy and awareness. There was a clear desire that societal attitudes towards disabled people need to take more account of the situations in which people with Cerebral Palsy and other impairments find themselves, perhaps through public awareness training and education. Such initiatives would seek to improve understanding of disability and thereby reduce the associated stigma (see Lewis, 2002 and Scope, 2014). Ralph suggested that to understand and develop empathy for the experience of being a wheelchair user, some first-hand knowledge of the barriers faced is important:

Ralph: Someone's staring because I'm in the chair. What would they... what would they do if they were in a chair themselves?... People's attitudes have got to change.

JB: Yeah... How do you think we could change people's attitudes?

Ralph: The only thing I can think of is, put them into a wheelchair for a whole day.

JB: See from your perspective?

Ralph: [nods]

This method is also recommended by Adcock and Remus (2006) as a means of supporting students' understanding of the impact of different sorts of impairments. The authors suggest activities such as getting students to sit in wheelchairs and to use blindfolds in order to learn what '**being and doing there** feels like' (Brown and Spinney, 2010: 150). Certainly in this project watching the GoPro footage from the participants' point of view was eye-opening as a way of appreciating the mobility experiences of participants (see also Simpson, 2011). However, there is also an important discourse in disability studies that claims that true understanding of the experience of impairment is impossible for non-disabled researchers, and that what is fundamental to valuable disability research is participatory research with disabled participants, ideally alongside disabled researchers (Stone and Priestley, 1996).

For the majority of participants, social attitudes towards their impairments – whether displayed through actions like staring, thoughtless parking and placement of sandwich boards - impacted on their experience of mobility in Harborne. For Isobel and Julie, it was not the physical barriers that posed the greatest threat to the experience of mobility in the local area, but the experience of being singled out and stared out – the fear of encounters with other people as a disabled adult (see

Cardona, 2013; Papatirou and Windle, 2012). This negative experience of mobility challenges individuals' comfort in public space, and presents a challenge to independence where participants do not feel able to go out in public without a carer or friend due to fear. Painter and Philo (1995:115) argue that this experience of stigma challenges participants' citizenship, questioning whether people can be considered as equal citizens if they: 'cannot be present in public spaces without feeling uncomfortable, victimized and basically 'out of place''. In the final analysis, issues of localised mobility are not simply questions of motion and movement, but of social justice. They are crucial to attaining the Equality Act's requirement that disabled people should be treated as full members of the community, with the right to access public and private spaces on the same terms as non-disabled people.

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