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**'The shops were only made for people who could walk': impairment, barriers and autonomy in the mobility of adults with Cerebral Palsy in urban England**

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## **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 for those with impaired gross motor skills, and the ability of these people to lead full and independent lives. Drawing on a framework that considers mobility as movement, meaning-making and political, 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, 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 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 draw upon the notions of emotional work and a commoning approach to mobility in suggesting that further investment in urban accessibility is squarely an issue of social justice.

## **Key words**

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

## Introduction

According to the UK's 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 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 law<sup>1</sup>, rights enshrined in the Equality Act 2010 mean that disabled people should be treated as full members of the community, with the rights to access public and private spaces, social and leisure activities, work and personal relationships on the same terms as non-disabled people. 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'. The Equality and Human Rights Commission (EHRC) (2017) is clear that disabled people experience this social exclusion as a result of unequal power relations – the social *politics* of who can do things, who can't and in what conditions (Cresswell, 2010) – referred to within social science literature as the experience of stigma and marginalisation (see Goffman, 1973).

The EHRC identify mobility as a particular area of disadvantage: disabled people do not experience widespread autonomous mobility in the same way as non-disabled people (Goggin, 2016; 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 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 impaired citizenship rights (Gaete-Reyes, 2015) and therefore a curtailed humanhood (Oliver, 1996).

The idea of disabled people as experiencing impaired humanhood, either through the lens of social perception (Goffman's, 1973, 'spoiled identity'), or as materially dehumanised through living in society with an impairment, is not a new framework for understanding (Goodley et al., 2016). Under this lens, urban mobility is squarely an issue of social justice, presenting fundamental challenges to urban planning and ideas of universal design (see Martens 2017). In our paper we examine the mobility experiences of a group of wheelchair-using adults with Cerebral Palsy<sup>2</sup> in Birmingham, UK, 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,

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

<sup>2</sup> 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.

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 as a subjective reflection of the interplay between participants' impairments, the environment in which they are mobile and the physical and emotional work (Hochschild, 1979) that wheelchair users must do to access it. We argue that the material environment that mediates participants' mobility experience cannot be separated from social stigma, marginalisation and the politics of power in that the environment is both a product of, and a catalyst for, this inequality.

### **Disability, mobility and rights to the city**

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), policymakers, 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 stigmatisation and marginalisation of disabled people (Gabel and Peters, 2004). At the same time, it 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 (Thomas, 2004). Further, 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 (Shakespeare and Watson, 2001). A perceived need for differentiation may also reflect intersectional experiences relating to race, gender and class that impact on the lived 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.

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 people and places. 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, Worth's (2013) 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. Young wheelchair-using participants in Pyer and Tucker's (2017) research also discussed experiencing stigma when travelling in public which they associated with the use of their chairs. As Cahill and Eggleton (1994)

argue, wheelchair users often experience 'non-person' 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, 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 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.

Material barriers to access the built environment are interwoven with the fabric of the urban and suburban environment. 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, displays a particular mobility 'constellation' (Cresswell, 2010) 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, 1998; 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".'

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 because of 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 (see Imrie and Luck, 2014). 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. Still, the difficulty of achieving maximum accessibility is not a good reason to side-line this goal, and certainly not an excuse to avoid attempting to broaden the accessibility of urban spaces. Where the initial design of an environment has not been made with the needs of disabled users in mind, or where design has not been focused on meeting the needs of those with a specific

sort of impairment, accessibility information sharing, through evaluation, auditing and mapping, can be a useful tool for increasing the ease of use of an environment for disabled people (Aarhaug and Elvebakk, 2015; Watchorn et al, 2018). Matthews et al. (2003), for example, tested MAGUS, a GIS system designed to capture the experiences of wheelchair users in the built environment to create a model of accessibility that could be presented as interactive local area accessibility maps to wheelchair users online. We adopt the approach of producing a static map based on an amalgamation of auditing guidelines in our own research, below.

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, 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. Yet mobility is more than just observable 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). Movement is felt by a person, and other humans understand this person's experiences through the crude and differentially limited ways in which they are able to communicate them. It is also impossible to escape the politics of mobility. Cresswell (2010: 21) explains:

By politics I mean social relations that involve the production and distribution of power. By a politics of mobility I mean the ways in which mobilities are both productive of such social relations and produced by them. Social relations are of course complicated and diverse. They include relations between classes, genders, ethnicities, nationalities, and religious groups as well as a host of other forms of group identity.

We obviously include people with disabilities among these group identities, and in this context it is useful to note Nikolaeva et al's reference (2019) to a 'kinetic elite' and a 'kinetic underclass' when distinguishing between the lived experiences of those who are mobile at will, and those with restricted mobility. This terminology of disabled people in motion as an underclass chimes clearly with Oliver's (1996) discourse of disability as an experience of curtailed humanhood, and while clearly a social justice issue, measuring, recording and disseminating such experiences, as a catalyst for change, presents a challenge.

Evidently, too, the politics of mobility are both productive of and produced by the *policies* of mobility (see Shaw and Docherty, 2014; Martens, 2017). Every journey – and the mode(s) by which we make it – is a product of socio-political, economic and environmental processes. For example, while our drive to work may be largely dull, sometimes tiresome and, on occasions, hazardous, the fact that we are in the position of needing to drive to work in the first place arises from a broad range of factors including our employment status, UK infrastructure, the cost of fuel, technological innovation and so

on. The various elements of mobility, in other words, 'are always circumscribed by existing governance structures, histories, power relations, and embodied experiences' (Nikolaeva et al., 2019: 349).

In considering the implications for disabled people's movement in urban environments, then, we can see: the interconnection of movement as a person moves through space independently or with assistance from aids or other people; movement as individualised experience capable of representation 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 impede at any of these loci, with the potential for ramifications to reverberate across all aspects of an individual's life and disrupt his or her broader lived experience. In so doing, barriers to mobility present barriers to independence, and indeed, for our respondents, issues of localised mobility are not simply questions of motion and movement but are fundamental to the rights of disabled people to lead full lives as socially included citizens.

## **Fieldwork**

The primary research was carried out by one of us (James) in Harborne, located three miles southwest of Birmingham city centre. The area might be considered representative of a 'typical' British high street providing a range of independent retailers, restaurants and bars. Cerebral Palsy Midlands (CPM) managed the recruitment of participants (Table 1) and became the research facilitator and participant gatekeeper<sup>3</sup>. 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 (CPM, Undated).

The research took place over five months. An initial meeting between James and the gatekeeper at CPM 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 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 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 Parent, 2016 for a discussion on the use of wheelchair-based video recording in mobile interviews). James accompanied participants and carers on all trips, observing their 'normal' practices which included going into some of the shops, and recording his own observations in a field diary. Following this, the

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<sup>3</sup> Full ethical clearance was obtained in advance of the project's commencement.



GoPro videos were watched and particularly interesting moments were identified. 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.

<b>Participant</b>	<b>Impairment and Differentiated Experience</b>
David	David is independently mobile with the aid of a walking stick.
Isobel	Isobel 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.
Alan	Alan 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 (not needed indoors).
Ben	Ben experiences both physical and cognitive impairment who experiences communication difficulties. He often uses a walker but preferred to use a wheelchair for research participation.
Thomas	Thomas has both Down Syndrome and Cerebral Palsy. Their primary impairment is cognitive, relating to communication difficulties.
Julie	Julie has Quadriplegic Cerebral Palsy and uses a wheelchair to aid her mobility. She experiences communication and swallowing difficulties.
Ralph	Ralph uses a wheelchair and independently accesses the local community. He has some cognitive impairment that limits his judgement capacity.
Gareth	Gareth is able to use a walker but is prone to falling, so chose to use a wheelchair for research participation. He experiences communication and swallowing difficulties, and epilepsy.

**Table 1.** Participants in the study<sup>4</sup>.

The following month, James returned to CPM in Harborne to interview the participants. These interviews were conducted in the presence of a carer who took responsibility for the participants' comfort and personal needs, supporting communication where required. Interviews lasted up to 40 minutes. During the interviews, participants were shown parts of their videos 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 by the participants and then coded using NVivo.

As a complementary research activity, James carried out an accessibility audit of businesses on Harborne High Street using a predetermined set of categories informed by three sets of guidelines derived from the principles of Universal Design. These are: a) that at least one entrance, ideally the

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<sup>4</sup> Pseudonyms have been used.

main entrance, is built flush to the external level and is wide enough for unrestricted passage (City of London, 2015); b) automatic doors are preferable (Wolverhampton City Council, 2009); and c) ramps should be provided wherever stairs obstruct free passage (United Nations Enable, 2003). Three outcomes for businesses were thus determined (Table 2). Related social context elements were addressed during the trips and subsequent interviews with participants.

Very accessible	Step-free access with wide, automatic doors. One entrance, accessible to all.
Moderately accessible	Step-free access with wide, manual doors. May have separate ramps or separate accessible entrance and may use bells to ring for assistance.
Not very accessible	Stepped entrance with narrow, manual doors. No alternative entrance offered.

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

## Experience, representation and the politics of mobility

### *Encountering strangers from a wheelchair*

For the participants, movement around the High Street was an experience of encounters. By and large, these encounters were negative, with participants 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 widely practised in public), but watching back the video footage with the participants confirmed that it was an all-too-common experience:

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

Isobel: Mhmm [nods head]

James: 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

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

Julie: Mhmm

These two examples come from participants with quadriplegic Cerebral Palsy who use wheelchairs. Although the respondents were not able to provide expansive answers, both the researcher and carers present were clear that the participants were agreeing with the suggestions. At the same time, Ralph was able to articulate the 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.

James: 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.

Such findings reflect research by Wiesel et al. (2013) in Melbourne, Australia, who found encounters between people with intellectual disability and the public reinforcing a sense of living a spoiled identity (Goffman, 1973). Similarly, Pyer and Tucker (2017) demonstrated this experience of stigmatisation felt by teenagers in wheelchairs on public transport in the UK (see also Gibson et al., 2007). Indeed, some of their participants felt it was the presence of their 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:

James: 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.

James: ... 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 the power of wheelchairs and other assistive devices to communicate the vulnerability of the user 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 clear in the responses of our participants as with the young people in Worth's (2013) and Pyer and Tucker's (2017) research. The stares that participants experience serve not only to make them feel stigmatised, but often have a deeper affective impact on their experience of mobility. For Julie, being stared at leads to fear; as illustrated in this extract from her interview:

Julie: [participant uses her communication book to point out an emotion relating to fear]

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

Julie: Mhmm

Julie was then asked why she felt scared.

Julie: [uses her communication book]

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

Julie: Mhmm

James: You feel tension when people look at you?

Julie: Yeah.

During this exchange Julie visibly tensed her arms and wrists, a clear demonstration of the emotional effect of discussing this experience. Other participants expressed feelings of sadness and

annoyance (Isobel) and upset and discomfort (Gareth). These reactions bring to mind Oliver's (2006, cited in Cresswell, 2010: 21) argument that an ideology of walking has arisen that 'gives the fact of walking a set of meanings associated with being human... Not being able to walk thus falls short of being fully human.' Accessing places without the ability to walk, therefore, presents not only an additional physical effort to the individual, described below, but an emotional work (Hochschild, 1979), discussed in more detail later in this paper.

### *Experiencing physical barriers to access*

For the participants, the emotional work and the affective experience of mobility was interwoven with the awkward practicalities of getting around. The lack of empathy from the public that led to stares, and the participants' experience of stigmatisation also led to careless acts that resulted in physical barriers to the participants' access to the high street (see Imrie, 2001 and Swain et al., 2014, discussed in more detail later in the paper). A specific example referred to by participants was the habit of local people parking their cars on pavements. Just outside CPM's centre, the road is full of vehicles parked on the pavement, which blocks wheelchair access. The experience of navigating this blockage was caught clearly on Isobel's 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.

James: 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. Ralph, in particular, discusses being trapped at CPM due to careless parking:

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]

James: Oh my goodness, okay.

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

James: 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 to circumnavigate a car that was blocking the pavement: a) Isobel notices the car parked on the pavement ahead (circled); b) she turns 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 angry that the parking of cars on the pavement reflected 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 CPM to ‘alert’ drivers that disabled people use the pavement (Figure 2).



**Figure 2.** Isobel’s footage shows the ‘Disabled People’ road sign with cars still parking on the pavement.

The footage provides us with some insight into the reality of differentiated mobility (Massey, 2008) for our participants who are here shown to experience a denial of access to basic urban infrastructure, not in this case through the failure of urban design, but through the lack of care taken by a general public who do not consider the access needs of wheelchair users. This lack of regard provides an example of the dehumanisation of disabled people (Oliver, 1996; Goodley et al., 2016), as participants experience curtailment of their rights to the use of public space.

### *Danger and dependence*

Parked cars, however, were not the only material barrier interrupting participants' experience of movement within Harborne. Other barriers resulting from lack of attention to the needs of wheelchair users included the placement of sandwich board advertisements that blocked the pavement (Figure 3). Participants also commented on several aspects of the streets themselves that cause them difficulty. Commonly described was the frustration of having to negotiate narrow spaces created by street features such as bus stops and lamp posts, and those in wheelchairs highlighted the discomfort of their 'ride' due to the unevenness of the pavement surface (see also Bromley et al., 2007). This is clearly visible on Ralph's camera footage where it 'jumps': '*you can see it. You've got it! The camera is jumping around because the surface there is not level*' (Figure 4). Ben had a similar experience:

James: 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.

James: Bad? Does it make you feel frustrated?

Ben: Yeah.





**Figure 3.** Footage from Ralph's GoPro showing the placing of a sandwich board that has created a narrow passage on the pavement.



**Figure 4.** An uneven and broken section of the pavement on Harborne High Street.

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?

James: 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.

James: 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 both the video footage and the interviews 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:

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

Alan: Yeah.

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

Alan: Yeah.

James: And then...[carer] had to help you get up. Is that a problem?

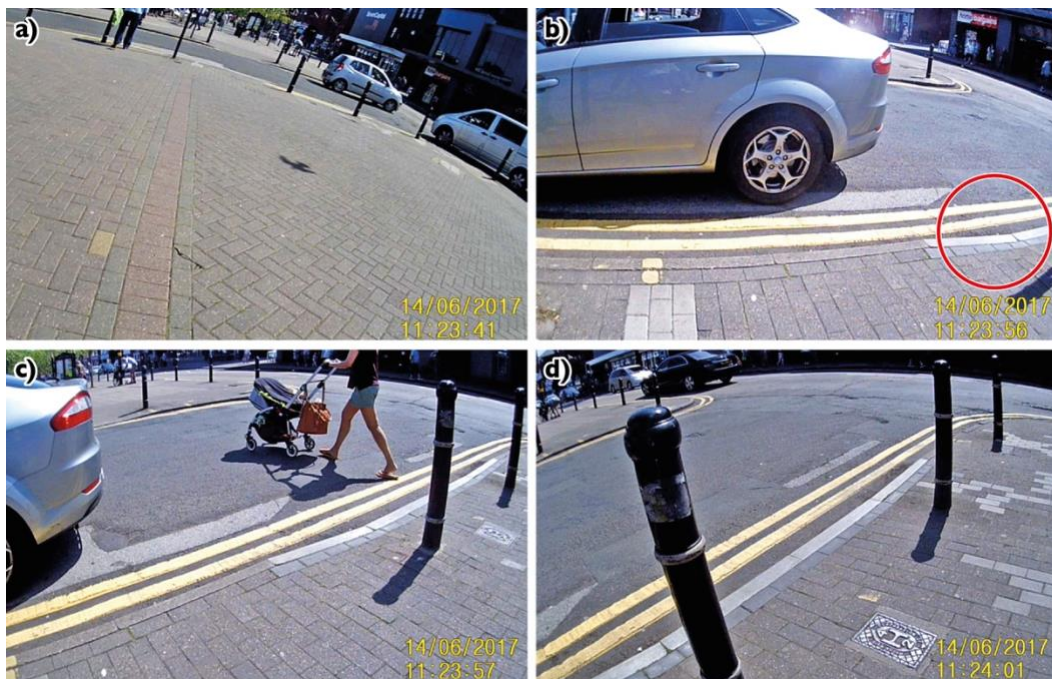
Participant: No no. For the people that are waiting because the chair is light you see.

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

Participant: Yeah.

A key issue was that it was difficult to see where the dropped curbs were. The GoPro, for example, 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 5).





**Figure 5.** 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:

James: 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...

James: Support it?

Carer: Yeah.

Both Ben and his carer acknowledged that this method of negotiating the dropped kerb was potentially dangerous, but that it was necessary 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:

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

Ralph: It can be.

James: 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 6). Luckily in this situation the carer was there to catch the participant and prevent him falling backwards into the road. Nevertheless, the scene demonstrates that, with more careful design, Ralph would 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 his mobility and safety. The failure here was not one of completely overlooking the access needs of wheelchair users, but one of planning and testing; the dropped kerb was not level enough to be useful for the purpose for which it had been intended. This reflects similar findings from Matthews et al. (2003) where dropped curbs were found to create obstacles due to 'lips', awkward cambers and the fact they were sometimes difficult for wheelchair users to see.

Similar design faults were experienced at pedestrian crossings, which participants found impossible to operate independently. David demonstrated that the crossing panels were too high for some people in wheelchairs to reach. Meanwhile, Isobel and Ben both commented that the push-button to operate the crossing was too small. Figure 7 illustrates the difficulty of pressing the button for Isobel, who struggles with motor skills and does not have full range of movement in her hands. In most cases, the participants relied on the accompanying carers to operate the pedestrian crossings, but in the interviews, they expressed the frustration that this caused. Participants do not want to be dependent on others whilst out in Harborne and would far prefer to carry out these actions, that may seem small, meaningless and everyday to onlookers, by themselves.



**Figure 6.** Sequence showing Ralph nearly falling out of his chair when negotiating the dropped kerb: a) Ralph is approaching the dropped kerb; b) 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.

The barriers to safe access, and therefore the differentiated mobility (Massey, 1996), discussed in this section relate to design features of the public infrastructure of Harborne. The failures of Harborne’s urban planning to meet the needs of wheelchair users illustrates a disregard for the needs of disabled people at a structural, and therefore unequivocally political, level, underpinning an unequal politics of mobility (Cresswell, 2010).





**Figure 7.** Isobel experiencing difficulties trying to press the operation button at the pedestrian crossing.

### *Exclusion as both an emotional and physical experience*

Once participants made it out of CPM's 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. Such exclusion from shops due to lack of safe access was experienced affectively by the participants.

James: How does that make you feel?

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

James: 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]

James: Disappointed, yeah?

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

Isobel: Yeah, yeah.

James: 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]

James: A haircut?

Carer: Is it a barber's shop?

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

Ben: Mhmm.

James: 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 James noted 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 shop, Ralph commented:

Ralph: That's got two entrances.

James: Yep.

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

Ralph's concerns suggest 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... 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 at best only partially addressed 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). 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 (2001) 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, 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 (see DWP, 2014).



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

## **Mobility, emotional work and ‘commoning’**

In considering the implications of our findings, we return to our framework of movement 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, 2010; Nikolaeva et al. 2019; Shaw and Docherty, 2014, 2019). Our research reveals the participants’ everyday movement as uncomfortable, hazardous and difficult. Stares, 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 necessarily the participants’ physical or cognitive inability to navigate the environment, but design failures, social stigmatisation and careless behaviour of others 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 access work or basic services independently. The differentiated mobility (Massey, 2008) of having to travel with an able-bodied companion may be infantilising and prevents the development of normal inter-personal interaction between friends or with acquaintances.

An important issue that emerged relates to the way in which mobility experiences were represented. While the representation of any mobility experience may for various reasons be inherently ‘imperfect’ (Cresswell, 2006), the impairment experienced by some of the participants makes such communication additionally difficult, as might too 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 the participants and a CPM carer using a video prompt. Still, James’ presence on visits and his own experiences provided both complementary and conflicting data. The latter was 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. 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?

One issue that did not come up, though, was that of intersectionality. All of our respondents were white, but other identity markers such as age, gender and sexuality were not reported as having impacted upon their mobility experience. Perhaps this was because occupying a wheelchair is subject to such an extreme stigma, that this identity ‘trumps’ other, non-racial, identity markers to the point where they do not register with passers-by (see Galli et al, 2015; Lenney and Sercombe, 2010;

Santos and Santos, 2017; Zitzelsberger, 2005)<sup>5</sup>. Nevertheless, the movement of our participants as a culmination of socio-economic and political processes – the politics of who can do things and who can't, and in what conditions (Cresswell, 2010) – is both implicit and explicit within the narratives explored in this paper. We 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: cars parked in a manner that blocks pavements, the small size of pedestrian crossing button, or the wider socio-economic and political processes that led to a lack of inclusion of disabled people or their representatives (such as CPM) in urban planning consultations.

In their work discussing the constrained mobility and accessibility experiences of new mothers and visually impaired young people, Middleton and Spinney (2019: 84, original emphasis) refer to the concept of 'emotional work' (Hochschild, 1979; Edwards, 1997), defining it as 'the extra emotional work and impact on the individual of having to adapt to, and perform within, a mobility system that does not accommodate their needs.' The emotional work manifests itself in the form of the stress, anxiety, frustration and so on, experienced by some users of transport infrastructure that was not necessarily designed with their needs in mind. Middleton and Spinney argue that a truly just mobility system would place the same (ideally minimal) burden on all users, and that including emotional work as a consideration in urban design / accessibility audits would result in an improved understanding of the accessibility constraints inherent in existing mobility systems. A key challenge, however, is that emotional work is generally internalised and less easily measurable than 'objective' and 'tangible' qualities of accessibility, such as 'distance from a bus stop' or 'availability of dropped kerbs', that remain the focus of much transport policy and delivery (Johnson et al., 2017; although see Curl and Clark, 2019). This seems something of a missed opportunity if a better appreciation of the emotional work involved in negotiating urban environments could lead to more genuinely universal design of public spaces and infrastructure (see also Martens, 2017).

One potentially positive recent development can be found in the UK rail industry, with notable proposed changes to the obligations placed upon rail operators in providing disabled people with access to the network (Office for Rail and Road (ORR), 2019). Although the term 'emotional work' is not used explicitly, some of the underpinning logic is clearly at play in the way the ORR is suggesting train companies will, in future, have to work not only to eliminate 'objective' and 'tangible' barriers to

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<sup>5</sup> There is a significant body of research that has explored the gendered and racialised experiences of disabled people (see Gaete-Reyes 2015). The fact that intersectionality did not feature as a key theme within our project should not be read as a critique of the importance of this body of work.



network accessibility, but also the social context in which accessibility issues are addressed. Providing wheelchair access to trains will no longer in itself be enough, for example; disabled people will be able to expect the same level of ‘turn up and go’ service as everyone else, rather than having to provide up to 24 hours’ notice of their need for assisted travel.

Painter and Philo (1995:115) question 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”.’ Given the extent to which the barriers to mobility and additional emotional work faced by our respondents are the result of careless actions (staring, cars parked on pavements) or unintended (poor push-button or dropped-kerb design) consequences, any meaningful way forward needs to involve an approach to mobility that actively involves (representatives of) the whole community. CPM already works with several groups to promote empathy for and awareness of the mobility difficulties encountered by those in its care (e.g. the Community Assets Forum Group of Birmingham City Council), but perhaps a broader, ‘commoning’ approach is required (Nikolaeva et al. 2019). Through commoning, existing power-relations are challenged to seek more socially equitable outcomes. It is based on the idea that a renewed emphasis on shared responsibility can form the basis of processes to ‘assemble more inclusive, just and sustainable spaces’ (Jeffrey et al. 2012: 2) that represent a new politics of mobility. Although Nikolaeva et al. (2019: 356-7) discuss the concept in rather more broad terms, we are struck by their argument that:

[c]ommoning mobility proposes a reconsideration of the value of mobility and its collective repercussions in addition to the communal management of transport. This means rethinking the value of mobility as what keeps communities both connected and diverse. Mobilities may be the means through which we interact with each other and the environment around us... something we share and can collectively govern rather than something we value only as it is converted into financial equivalent, square kilometres and minutes of commute... So some kinds of austerity might be imposed upon the kinetic elite, while new opportunities for mobility... might be provided to the kinetic underclass.

In practice this would mean a collective effort capable of bringing together CPM with at least: the local public to help them understand the nature of disabilities that force people into wheelchairs; local drivers, to enable them to appreciate why it is better not to leave their cars parked on the pavement; the city council and others involved in designing well-meaning but nevertheless sometimes problematic street furniture (e.g. push-button crossing controls) and other features (e.g. dropped kerbs, uneven pavements); and local business owners, to make it easier for them to access grant funding to improve the accessibility of their premises and to minimise careless pavement barriers such as ill-placed sandwich boards..

## Conclusion

In this paper, we have examined the mobility experiences of adult participants 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 demonstrated how our respondents' local environment is both a product of, and a catalyst for, the inequality they face, and reflected on both the material reality of their journey – the discomfort, the barriers to access and the danger – and the experiential reality of stigma, fear, dependence, 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 cameras. Together, they demonstrate the politics of mobility in Harborne: in the context of this study, these politics favour a 'kinetic elite' (people without disabilities) over a 'kinetic underclass' (people with disabilities) through various mechanisms that include careless actions, unintended consequences in the framework of an established order of transport governance. Our respondents face considerable additional emotional work as a result, and in the absence of much capacity to account for such things in traditional transport appraisal and policy, we have suggested a 'commoning' approach involving (representatives of) the entire community as one means of working towards a new politics of mobility in the vicinity. In the final analysis, the issues of urban design and localised mobility discussed here are squarely questions of social justice (Martens, 2017). They are crucial to attaining the Equality Act's (2010) 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 people without disabilities.

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