Powered Wheelchair Users' Experiences of Urban Mobility: Researching Access and Disablement through Mobile Methodologies and Digital Technologies

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Abstract

Inaccessible environments and transportation exclude disabled people from full participation in society. Accessibility is affected by a wide range of socio-material factors, including the interaction between the environment and mobility devices. Yet to date, little research has investigated powered wheelchair users' experiences of mobility, or how their knowledge might inform policymakers or service providers.

In this thesis, I have worked with powered wheelchair users to document their experiences of mobility and explore how these might be conveyed to other people. An observational go-along method was used, travelling with thirteen participants as they captured their experiences using 'JourneyCam', a bespoke smartphone video and data collection tool. The data were used as prompts in semi-structured interviews following each journey. Two further participants were interviewed without first using JourneyCam. Finally, through a series of group workshops, nine participants explored how their collective experiences and knowledge might be used to create more accessible environments.

Powered wheelchair users accumulate situated knowledge which they use to navigate disabling barriers, but this knowledge is gained through significant personal labour and experiences of psycho-emotional disablism. Participants highlighted a wide range of socio-material enablers and disablers to their mobility, including barriers associated with poorly implemented 'accessibility' features. However, their efforts to convey their knowledge to service providers were met with indifference, and funnelled through individualised complaints processes. In response participants sought more effective modes of engagement that might bring about systemic change, in line with their commitment to social model principles of confronting structural disablement.

I conclude that not only could powered wheelchair users' situated knowledge be a valuable resource for service providers and policymakers, but it is also a form of collective resistance to ableist societal practices. The social model of disability remains relevant for disabled people's efforts to counter disablement, serving as an 'oppositional device' that fosters shared resistance.

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Dedication

This thesis is dedicated to all of those who try to improve the world by confronting injustice.

In memory of Professor Ian Taylor, Dr Kimberley-Joy Knight Ford, Philip Wilson, and Dr Brian Hellyer.

Publications

A paper on JourneyCam, with a particular focus on the technology and its implications for human-computer interaction, was published at the ACM Conference on Human Factors in Computing Systems in May 2019 (CHI '19):

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Chapter 1. Introduction

1.1 Introduction

Disabled people are often excluded from built environments and modes of public transport that do not accommodate their needs. These spaces incorporate a variety of socio-material barriers which restrict disabled people's everyday mobility and thereby hinder their free movement and full participation in society. Wheelchair users, for example, are prevented from accessing many buildings and urban environments by steps, rough surfaces, and a lack of accessible toilets. The weather and season may make otherwise accessible environments more challenging or even impassable. Difficult interactions with non-disabled others can also compound material inaccessibility, while many factors affecting mobility, such as ramp assistance for boarding trains, are simultaneously both social and material. For powered wheelchair users, socio-material barriers are magnified: such wheelchairs are typically larger and heavier than their manual counterparts and therefore may not fit into environments that could accommodate manual wheelchairs. The users of these kinds of wheelchairs must also consider distinct factors, such as the risk of breakdown or depleting the battery, that do not apply to manual wheelchair users. These distinctions between the factors that even users of different types of wheelchair must consider are just one example of the complexity of the socio-material factors affecting disabled people's experiences of mobility and access.

However, even though the socio-material issues affecting disabled people's access to built environments and public space have been highlighted for more than two decades (see for example Imrie, 1996b; Butler & Bowlby, 1997; Kitchin, 1998), and despite the passage in the United Kingdom of both the Disability Discrimination Act 1995 and the Equality Act 2010 (HM Government, 1995, 2010), these barriers remain. In 2016, the House of Lords Select Committee on the Equality Act 2010 and Disability highlighted that the needs of disabled people were an afterthought when planning services and buildings, with reactive processes, poor communication, and difficulties in enforcement (House of Lords Select Committee on the Equality Act 2010 and Disability, 2016). Similarly, the House of Commons Women and Equalities Committee noted in 2017 that disabled people still face needless restrictions in housing, workplaces, and the built environment, and called on the Government to take a strategic leadership role to drive accessibility through law and policy (House of Commons Women and Equalities Committee, 2017).

The continued prevalence of these barriers demonstrates that disabled people in Britain still lack equitable access to built environments and public transport. Given the complexities of the socio-material factors described above, this suggests a lack of understanding amongst decision-makers of the ways that particular environments or situations can pose specific barriers to disabled people. This in turn suggests the need for a deeper understanding of these barriers and their effects, grounded in the everyday lives of disabled people.

In this context, this research aims to explore experiences of mobility and access amongst powered wheelchair users in the United Kingdom, by working with this group of disabled people to understand the factors influencing their experiences from their perspectives and how they perceived and respond to these experiences. This introductory chapter first briefly describes the research context, highlighting the importance of accessible environments to disabled people. Building on a social understanding of disability, it shows how they are often excluded from environments by socio-material barriers, and discusses those barriers faced by powered wheelchair users specifically. Noting how such barriers are not well-understood by non-disabled people, and the challenges associated with articulating them to others, this introductory chapter describes how mobile phones are a technology that has the potential to capture and convey aspects of powered wheelchair users' experiences of mobility and access. It then outlines the research questions that the thesis explores, before providing an overview of the structure and content of the remaining chapters.

1.2 Research Context

1.2.1 Accessibility and mobility for powered wheelchair users

Individual mobility is usually regarded as a fundamental part of democratic freedom for all people, both as an intrinsic good and because it opens up other opportunities (Imrie, 2000a). Correspondingly, a lack of access to mobility can be both a cause and a result of social exclusion (Kenyon et al., 2002; Cass et al., 2005). As such, accessible environments are critical to enabling the full participation of disabled people in society, permitting them to access employment and leisure opportunities on equitable terms to non-disabled people.

Yet prior research has identified how the design of built space and public transport often excludes people who do not conform to the bodily norms of the non-disabled majority. Building on the social model of disability, which highlights how people with impairments are disabled by society which unnecessarily isolates and excludes them from full participation (UPIAS, 1976), such critiques have noted that the material organisation of society leads to

disablement (Gleeson, 1997, pp.193–194). They have identified the socio-spatial nature of 'ableist environments' which perpetuate physical and social barriers (Chouinard, 1997). As such, they highlight how disabled people's experiences in such environments are affected by closely linked socio-material factors relating to both the fabric of built environments and transport and to the interactions that happen within them. These spaces are places where people with different embodiments and mobility requirements interact, and these meetings can sometimes be fraught or difficult (Garland-Thomson, 2006; Scully, 2010).

Such environments are rife with barriers that exclude disabled people, such as steps that do not allow passage for wheelchair users or those with limited mobility, uneven and unsafe surfaces for people with balance or visual impairments, temporary or permanent street clutter that poses obstacles, and an absence of dropped kerbs or accessible toilets (for examples, see Salvage & Zarb, 1995b; Butler & Bowlby, 1997; Kitchin, 1998; Imrie & Kumar, 1998; Kitchin & Law, 2001; Matthews et al., 2003; Beale et al., 2006; Bromley et al., 2007; Wiseman, 2019). Disabled people experience similar barriers when using public transport, with prior work implicating a range of socio-material factors that overlap with those experienced in the wider built environment (Heiser, 1995; Salvage & Zarb, 1995a; Wilson, 2003; Bromley et al., 2007; Rodger et al., 2016). Indeed, transport itself is only one part of a 'journey chain' that must be accessible throughout if disabled people are not to be excluded from society (Wilson, 2003). Many disabled people therefore either rely on private vehicles if available (Pyer & Tucker, 2017), or on residual, 'special' forms of transport that mark them out as different to the non-disabled majority such as Dial-a-Ride (Imrie, 2014, p.19).

The persistence of these socio-material barriers in the built environment and transport reflects disabling design discourses that are seldom challenged (Imrie, 2014), and which reproduce disabling spatialities through socio-political processes such as weak planning systems that rely on developer voluntarism to improve access (Imrie & Wells, 1993; Imrie, 1996b; Imrie & Hall, 2001a). Where disabled people's needs are considered, they are often narrowly conceptualised as being those of an 'archetypical' wheelchair user (Imrie, 2000a), failing to recognise diverse needs and requirements (Hall & Imrie, 1999). Although recent parliamentary inquiries have noted improvements over the past two decades, they have also highlighted that there remain significant socio-material barriers to disabled people's access to built environments and public transport (House of Lords Select Committee on the Equality Act 2010 and Disability, 2016; House of Commons Women and Equalities Committee, 2017).

1.2.2 Powered wheelchair users' particular experiences of mobility and access

The socio-material barriers described above highlight the multifaceted nature of disabled people's experiences of built environments and public transport, and the ways in which interlinked socio-material factors affect their experiences of access and mobility. However, to date little research has investigated how these complex experiences unfold amongst users of powered wheelchairs specifically. This particular group of disabled people face different challenges to their mobility compared to users of manual wheelchairs, many of which relate to the nature and physicality of powered wheelchairs as a mobility technology. Powered wheelchairs are typically considerably larger and heavier than manual wheelchairs, which can heighten accessibility issues in environments that are not built to accommodate them. Users also face challenges imposed by limited battery life that can fluctuate across different terrains and weather conditions, and the potential for technical failure or breakdown. The characteristics of powered wheelchairs therefore influence distinctive experiences of mobility and access amongst their users which, while sharing certain commonalities with manual wheelchair users, deserve closer examination.

Prior research has highlighted the importance of engaging with the specificities of disabled people's use specific forms of technology, and how these interact with wider socio-material environments to produce either smooth passages or disablement (Moser & Law, 1999). In this context it is necessary to examine the particular experiences of powered wheelchair users in order to understand how environments may pose barriers that are different to those experienced by other wheelchair users or disabled people more broadly. Engaging with these specificities is necessary to characterise powered wheelchair users' experiences of mobility and access, which is a necessary pre-requisite in seeking to remove disabling barriers. While the social model of disability helps us to identify the structural nature of these socio-material barriers and creates the political imperative to address them, its focus on the structural aspects of disablement can at times restrict such engagements with the specificities of individual disabled people's experiences.

This research therefore aims to respond to calls for more experientially based accounts of disabled people's lives (Scully, 2011), by working with powered wheelchair users to explore their experiences of mobility and access built environments and public transport. While these experiences may be highly diverse, individual powered wheelchair users often face

shared challenges in accessing these environments and are confronted by similar socio-material barriers.

1.2.3 Conveying complex experiences of access and mobility

Drawing on feminist understandings of the political value of individual disabled people's experiences as conveyed in their own words (Morris, 1992; Thomas, 1999), this research adopts a methodological approach that foregrounds the individual experiences and situated knowledge (Haraway, 1988; Harding, 1993) of powered wheelchair users. This approach recognises that those most affected by oppressive environments can contribute particular forms of socio-spatial knowledge about these environments (Laws, 1994), and that investigating how disabled people are prevented from free movement in these spaces also sheds light on wider social and material power relations (Sawchuk, 2012).

In prior work I had undertaken with disabled people campaigning on the issue of accessible transport, participants had highlighted the challenges of capturing these complex embodied experiences of disablement and articulating them to others (Rodger et al., 2016). Travelling with wheelchair users on journeys by public transport gave me an insight into some aspects of their experiences. During one journey, a participant said he would like to 'just whip out my phone' to take a video of some police horses walking past. However, such a swift use of technology was prevented due to a combination of the nature of his impairment and the physical and software interface of the phone. This incident prompted me to consider what a more accessible way of enabling people to capture experiences of journeys through mobile phones might look like, and how it could be combined with the insights generated by going along with participants on journeys.

This led to the development of the novel observational go-along method which I used in this research and which is described in more detail in Chapter 3. I travelled with participants on journeys of their choice as they used a smartphone to record their experiences of mobility through video and sensor data, which was used in subsequent semi-structured interviews. This approach built on methods that recognise the value of in situ discussion for generating rich understandings about place (Kusenbach 2003, 2017), and drew on work demonstrating the value of visual data in prompting reflections on people's lives (Harper, 2002; Clark, 1999; Van House, 2006).

1.3 Research Questions

Due to my previous professional experience working in the field of neuromuscular research, and the prior work I had undertaken with staff and volunteers in a national charity that was campaigning on the issue of accessible transport (Rodger et al., 2016), I initially framed and planned this research as working with people living with neuromuscular conditions. This was with the intention of working with and recruiting participants through the charity.

My initial research questions were therefore:

- What is the role of digital technology in supporting people with neuromuscular diseases to articulate their experiences of the built environment and transportation?
- What are people's motivations behind sharing their experiences of the built environment, and how might technologies be used to enable such sharing?
- How can personal experiences, in relation to accessible transport and built environment, be brought into use to inform policy and service provision?

However, during the preparatory stages for fieldwork, I experienced challenges relating to recruitment, which are discussed in Chapter 3 and resulted in the reassessment of my plans. Alongside these pragmatic considerations, however, I was informed by my engagement with disability studies literature. As I read more widely during the course of the first year of my PhD, I came to recognise that what was particularly significant in this context were shared experiences of barriers to mobility that are associated with using powered wheelchairs.

These factors resulted in a shift of my research focus and recruitment approach onto shared experiences of using powered wheelchairs for mobility, and away from the unintentional foregrounding of a medicalised understanding of disabled experiences. They also resulted in a slightly revised set of three research questions that guided the remainder of the project, which were as follows:

- **What is the role of digital technologies in supporting powered wheelchair users to capture and articulate their experiences of mobility and accessibility?**
- **What are people's motivations behind sharing their experiences of the built environment, and how might technologies be used to enable such sharing?**
- **How can personal experiences of mobility and accessibility be used to inform policy and service provision?**

1.4 Outline of Thesis

The remainder of this thesis is structured as follows:

Chapter 2: Literature Review

This chapter situates the thesis within the existing literatures that I have drawn upon while planning and conducting the research. It frames my work as building on a social approach to understanding disability and disablement, and especially the social model of disability. This provides a focus on identifying exclusionary societal barriers faced by disabled people, and a political imperative to remove these barriers. It also advocates adopting an approach to research that seeks to elucidate and find ways of removing those barriers by doing research that works for disabled people. This thesis also draws upon aspects of critical disability studies that question totalising narratives of disability, and that open space for disabled people to craft new narratives about their experiences in a predominantly non-disabled society.

The chapter engages with work by feminist scholars who argue that disabled people's personal experiences are not divorced from the public sphere, and that sharing such experiences is a political act that challenges dominant epistemologies. In addition, it draws on literature from human geography and 'geographies of disability' which document the environmental and social barriers faced by disabled people in towns and cities, and the links between these barriers and dominant societal attitudes which create such environments to fit the requirements of non-disabled bodies. Finally, it builds on work from Digital Civics and human computer interaction which discusses how digital tools may be built and used by citizens to highlight issues of concern such as access and mobility, and engage with decision-makers around those issues.

Chapter 3: Methodology

The Methodology first builds upon the feminist work discussed in the Literature Review to outline the epistemological and methodological approach of the thesis, explaining why it is important to ground data collection for this project in the individual experiences and situated knowledge of powered wheelchair users. It describes how accompanied 'go alongs' offer a productive way of engaging with lived experiences of mobility and place. It goes on to outline the development and design considerations of 'JourneyCam', a smartphone tool that enables powered wheelchair users to capture and convey aspects of their journeys through video and data. It describes how I approached participant recruitment, and gives a summary of the people who took part in the research. It provides an overview of the fieldwork itself, including the go-along journeys and data-led interviews, as well as the process of data

analysis. Finally, it discusses the process of ethical approval and the ethical and political challenges that I faced as a non-disabled person conducting disability research.

Chapter 4: Enablers and Disablers of Powered Wheelchair Users' Mobility

This first data chapter explores the factors that participants identified as important in either enabling or disabling their mobility, exploring social and material issues that participants characterised as being most significant to their experiences. It draws upon the accompanied journeys in which they used JourneyCam to capture aspects of their experiences, and the subsequent semi-structured interviews during which we talked through the data they had collected. It discusses material concerns expressed by participants, including the qualities of different surfaces, the challenges associated with unpredictable, temporary barriers, and aspects of the natural environment. It then discusses social issues, highlighting how both direct actions of other people and indirect actions could influence people's experiences, and emphasising the pivotal role of staff in helping to make a journey 'good' or 'bad'. Finally, it explores how some things which are meant to reduce barriers can, at times, themselves be disabling: how factors such as lifts, accessible toilets, and dropped kerbs can be absent or so poorly implemented as to actively cause disabled people problems.

Chapter 5: The Value and Costs of Powered Wheelchair Users' Situated Knowledge

This chapter, which also draws on the accompanied journeys and semi-structured interviews, explores how powered wheelchair users possess situated knowledge and expertise which they develop through the experience of the enablers and disablers discussed in Chapter 4. Built up over time and tied to their experiences as disabled people, this knowledge exists at the intersection of their own bodies, the powered wheelchairs they use for mobility, and the environments through which they travel. It enables them to circumvent the disabling barriers that would otherwise hinder their mobility. However, although it enables them to exert agency, their situated knowledge is acquired at a cost: they incur physical and psycho-emotional labour in order to make their way in a world that does not accommodate their needs. Moreover, although their situated knowledge could provide society with valuable insight into how to remove disabling barriers, they often find that their attempts to bring about change are funnelled into processes of complaint. Aside from being time-consuming and frustrating, complaints procedures individualise the systemic issues participants faced, imposing additional labour on them and seldom bringing about the systemic changes that are needed or desired by participants.

Chapter 6: Beyond complaint: pragmatic approaches to collective political action

Chapter 6, the final data chapter, draws upon data generated in the group Skype workshops, conducted several months after the end of the first phase of fieldwork. These sought to validate initial findings from accompanied journeys and semi-structured interviews, before exploring how the participants felt their experiences and situated knowledge might be best brought into conversation with policy makers and service providers to bring about more accessible environments. The chapter first sets out the group workshop method, and the activities participants undertook, before discussing the findings from the workshops. These included themes such as pragmatism in engaging with policymakers, seeking alignment between different groups, and the workshops themselves as enabling knowledge-sharing. Participants also drew links between the barriers they faced and wider ways in which society did not take disabled people's rights seriously enough, and the chapter will draw in a discussion of how these aspects link back to the value of the social model in fostering a disability politics and collective action.

Chapter 7: Conclusion

This chapter draws together the findings of the thesis, reflecting on its contributions to our understanding of powered wheelchair users' experiences and situated knowledge, and noting the theoretical and policy implications of the research. It also considers the research itself, reflecting on the strengths and challenges of using JourneyCam as a tool to capture aspects of disabled people's experiences and convey them to others. It also notes the limitations of this project, and highlights directions for future work.

Chapter 2. Literature Review

2.1 Introduction

This thesis builds upon a range of previous work in disability studies, human geography, science and technology studies, and human-computer interaction. This chapter explores this prior literature, contextualising my research within these fields. In particular, I situate my work within social understandings of disability, which emphasise how people with bodily differences that are classed as impairments by medicine and society are disabled by environments which do not accommodate these differences. The full participation of disabled people in society is constrained by needless socio-material barriers, which particularly restrict their mobility and access to public and private spaces. Within social approaches to understanding disability, I particularly draw upon the social model of disability, which highlights the political imperative that such barriers both can and should be dismantled. I also draw on insights from feminist disability scholars, who emphasise both the intrinsic and epistemological value of paying attention to individual and embodied experiences of disablement. Work from critical disability studies provides a nuanced understanding of how disablement can be situational, challenging a binary dichotomy between disabled and non-disabled people. Alongside insights from science and technology studies, this highlights the challenges faced by people whose needs do not accord with standardised socio-technical norms, and the importance of society accommodating a diverse range of requirements. Destabilising norms and assumptions around 'able-bodiedness' also offers the opportunity to consider how the needs of different groups might align, and how technologies might be designed to support these alignments.

Developing these concepts in the context of spatial access and mobilities, I draw on work on (and influenced by) the geographies of disability, which explores the nature and impact of disabling socio-material environments on disabled people. In addition, it shows how these environments have their roots in societal structures and processes such as land planning frameworks. In so doing, this work demonstrates how a utopian reliance on technology to 'solve' disabling socio-material barriers is inadequate because it does not engage sufficiently with the wider societal relations and processes that exclude non-disabled people. A further aspect of disabling environments that is informed by this literature, and builds on some of the feminist work in the first part of the chapter, is then discussed: that of psycho-emotional disablement of disabled people stemming from socio-material barriers. This again highlights the importance of engaging with disabled people's individual and embodied experiences of

place and transport, and of considering disabled people's experiences of mobility and access holistically. The chapter concludes by situating my research in relation to this prior work, and frames how these diverse literatures have informed my approach.

2.2 Disability, Disablement and Technologies

2.2.1 The Social Model

This thesis is based on a social understanding of disablement, grounded in key insights from the social model of disability as articulated by disability rights advocates during the 1970s. In the context of a dominant societal understanding of disability being a personal tragedy stemming from biological impairment and necessitating medical intervention to 'cure' or otherwise 'rehabilitate' a disabled person, these activists highlighted the many ways in which society actively disabled people with physical impairments (Goodley, 2011, p.11)[1]. This is most clearly articulated in the 1976 "Fundamental Principles of Disability", which reported on discussions between the Union of the Physically Impaired Against Segregation (UPIAS) and the Disability Alliance, wherein the former set out its position that "disability is a situation, caused by social conditions" and emphasised how "it is society which disables physical impaired people. Disability is something imposed on top of our impairments, by the way in which we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society" (UPIAS, 1976, p.3).

This distinction between impairment and disability has become a defining characteristic of the British social model of disability. In the British context, the distinction between individual biological impairment and socially imposed disability has often been expressed as a stark divide between a 'medical' and a 'social' model, although Shakespeare notes that there have been other social-contextual approaches both before and since the UPIAS declaration (Shakespeare, 2006, pp.15–26). The social model was a deliberate attempt to "switch the focus away from the functional limitations of impaired individuals onto the problems caused by disabling environments, barriers and cultures… [it is] a holistic approach" (Barnes, 2007, p.206). Its proponents have argued that the social model "does not deny the importance or value of appropriate individually based interventions in the lives of disabled people… [including medical or re/habilitative interventions] but draws attention to their limitations in terms of furthering their empowerment and inclusion in a society constructed by 'non-disabled people' for 'non-disabled people'" (Barnes, 2007, p.206). The social model thereby

[1] While the original UPIAS socio-political definition of disability focused on physical impairment, it has since expanded to include physical, sensory and cognitive impairments (Barnes, 2012, p.14).

explicitly highlights the ableist societal practices and norms that create barriers to disabled people. These barriers, including inaccessible material environments and negative or hostile interactions, prevent full participation in society by people with impairments and are therefore a form of oppression by the non-disabled majority.

The social model reframed previously dominant individualised and medicalised conceptions of disability, with several important consequences. It enabled the imagination of an alternative to the status quo, emphasising that disabling environments were not inevitable but the result of a societal choice not to cater to the needs of people with impairments; it identified barrier-removal as a political strategy to challenge the status quo; and it empowered disabled people to demand such a change (Shakespeare, 2006, p.30). Moreover, the social model helped disabled people to understand and conceptualise their experiences, with a significant effect on how they perceived both themselves and the world around them. As Crow recounts, the social model was "the proverbial raft in stormy seas… Suddenly what I had always known, deep down, was confirmed. It wasn't my body that was responsible for all my difficulties, it was external factors, the barriers constructed by the society in which I live" (Crow, 1996, p.55). Furthermore, given the roots of the social model in material concerns of disabled people's participation in the labour market, it permitted a critical focus on material barriers faced by disabled people in other fields such as leisure and transportation (Thomas, 1999, p.17). Building on Marxist analysis, a materialist perspective emphasises not simply material environments but rather the structural nature of systemic inequalities: "the social construction of physically impaired people as *disabled* people arises, in the first instance, from the specific ways in which society organises its basic material activities", including "work, transport, leisure [and] domestic activities" (Gleeson, 1997, pp.193–194). In this way, it permits an analysis of the disabling nature of society itself. The social model has thus been described as having "created the space which makes everything else possible" (Thomas, 1999, p.26). Furthermore, being developed by disabled activists themselves it provided a base for grass-roots political activism. Barnes and Mercer (2001, pp.20–21) note that a hallmark of the disabled people's movement which emerged during this period was its critical evaluation of how society oppresses disabled people through barriers based on individualised, medicalised understandings of disability, and how removing these barriers therefore requires reappraising disability itself and recognising that deprivations experienced by disabled people are an outcome of hostile physical and social environments.

However, as suggested above the social model has also attracted criticism for the clear distinction it makes between impairment and disability, which has been described as an "untenable separation between the body and culture, impairment and disability" that has "concede[d] the body to medicine" (Hughes & Paterson, 1997, p.328). This critique suggests that by de-emphasising the role of individual impairment in the everyday lives of disabled people, the social model has not just 'written out' important aspects of these experiences which relate to a person's impairment but has also left these embodied experiences within the purview of the medical domain, *contra* one of the fundamental drivers of the social model itself. For Hughes and Paterson, the social model should be expanded to produce an embodied understanding of disability. Others have gone further, ultimately arguing that the social model's impairment-disability dichotomy is unsustainable and that the model itself is an unchallengeable 'sacred cow' that is no longer fit for purpose (Shakespeare & Watson, 2001). While noting its value in highlighting societal oppression and exclusion of disabled people that had hitherto been neglected in disability research, what Shakespeare (2006) identifies as flaws and inconsistencies in the social model leads him to conclude that disability should be considered a 'complex interaction', a perspective to which I will return in subsequent sections.

Such readings of the social model are challenged by its chief proponents, who suggest that the notion that it cannot deal adequately with the realities of impairment "is based upon a conceptual misunderstanding… the social model is not about the personal experience of impairment… but the collective experience of disablement" (Oliver, 2004, p.8). They highlight instead how the social model of disability is a "tool with which to gain an insight into the disabling tendencies of modern society in order to generate policies and practices to facilitate their eradication" (Barnes, 2007, p.206). As such a "heuristic device", which emphasises material and structural causes of disabled people's disadvantage, it played a crucial role in the mobilisation of disabled activism during the 1980s and 1990s that led in turn to legislative and policy gains (Barnes, 2012, pp.18–20). The notion of society as disabling is a unifying principle for the disabled people's movement, underpinning solidarity around a collective identity and vision (Beckett, 2006, p.747).

As evident above, there has been significant and heated debate around the meaning and the implications of the distinction between impairment and disability as conceptualised in the social model. I discuss some aspects of this in more detail below, where I outline how

feminist approaches and critical disability studies engage with the social model and provide more nuance to these perspectives. However, this literature review and thesis does not aim to take sides in this complex and contested terrain. Rather, I build upon those contributions of the social model which are regarded by those from different perspectives as being the most valuable and insightful. These commonalities include: the social model's significance in enabling a focus on societal-level disabling environments as a significant aspect of disabled people's experiences and a critical source of their disadvantage; the political and practical focus that this provides relating to the removal of these barriers, around which disabled people could coalesce; and the way in which the social model offers an alternative vision of the future, one in which things could be different. Even those critical of the social model highlight these aspects as key strengths, noting that the main priority for disability politics should be the significant social and environmental barriers to disabled people (Shakespeare, 2006, p.198).

While I have discussed above the contributions of the social model in relation to highlighting societal barriers and identifying them as a locus for political action, I briefly wish to discuss the importance of the social model in providing an alternate vision of the future. Barton (2001) describes how transformative social change depends on hope in the possibility of an alternative future, and in the belief that "the possibilities of change of the current situation are not foreclosed. Without hope the kind of social transformation that is being advocated will not be realised" (Barton, 2001, p.3). As described above, the social model offers such hope: in locating the source of disadvantage disabled people face in societal oppression, it highlights not only that the status quo is unjust but also how through the removal of barriers it could be different. In this respect, the social model has been described as "oppositional device" (Beckett & Campbell, 2015) that has prompted new ways of thinking. It introduced contingency, showing how both the 'handicapped body' and disabling barriers were socially produced: "if the conditions of disablement were made socially, then they could be made differently… [and] because it positioned disability as oppression… disability not only became contingent, it also became unjust" (Beckett & Campbell, 2015, p.278). As such, these aspects of the social model help to enable a politics of disability that coalesces around identifying and removing disabling barriers, in the knowledge that this is indeed possible. The origins of the social model in disability activism are a critical aspect of this, as it was both the result of disabled people's resistance and enables further resistance practices (Beckett & Campbell, 2015, p.271). The social model retains ongoing relevance in this respect. Recent research

with young disabled people has shown how it permits them to envision their preferred future, supports activists to create resistance practices, and enables a focus on emancipatory goals (Griffiths, 2019). The social model has been described as the "jumping off point for political action aimed at transforming relations" (Peters et al., 2009, p.544). While insufficient on its own, these authors go on to use the notion of resistance as a unifying concept to suggest a theory of political action stemming from the social model.

The political and practical value of the social model therefore remains highly relevant to the struggle for disabled people's equality. It contributes several key insights that I will return to over the course of both this chapter and the thesis. First, the social model highlights the structural nature of the multitude of needless material and social barriers to disabled people's participation in society, which persist today more than four decades after the UPIAS declaration. Second, the social model provides both a practical and political focus: the removal of these disabling barriers from society. These profoundly political ideas are the core contributions of the social model to this thesis and remain as relevant today as they were almost half a century ago. However, other schools of thought have also contributed important insights that extend, and at times challenge, aspects of the social model, and which I have built upon in this research. The next two sections examine two of these areas: feminist approaches, which brings aspects of disabled people's personal experience 'back in' to discussions of disability; and critical disability studies, which questions how society values and represents 'normal' forms of embodiment and behaviour.

2.2.2 Feminist approaches

As noted above, raising the issue of impairment and how it affects disabled peoples' lives has been controversial in the context of the social model, as it risks the resurgence of an individualised notion of disability as a 'deficit'. Yet some authors, especially those writing from a feminist perspective, have identified areas of compatibility between the social model and discussions of impairment. They often seek to advance the social model, but emphasise that impairment is an important aspect of disabled people's lives and as such should be included in discussions about their experiences. These efforts can be seen as part of a wider movement within feminist epistemology towards acknowledging diverse lived experiences as a form of situated knowledge, which is also discussed below.

Morris (1992) acknowledges that while the social model has highlighted the socially constructed nature of disabled people's experiences (politicising what had hitherto been the

‘personal’), in its attempt to challenge the ‘personal tragedy’ narrative of disability it has sometimes denied personal experiences of disability. Arguing that feminism offers researchers the tools to understand the subjective reality of disabled people’s individual and collective experiences, she calls for an emphasis on a second understanding of ‘making the personal political’: “owning, taking control of the representation of the personal experience of disability – including the negative parts to the experience” such as impairment and pain (Morris, 1992, pp.163–164). Nonetheless, she acknowledges the potential dangers of discussing impairment, as “to articulate any negative feelings about our experience of our bodies may be to play into the hands of those who feel that our lives are not worth living” (Morris, 2001, p.9). She describes how this has sometimes led disabled people to denying the experience of their own bodies (Morris, 2001, p.10). Similarly, calling for impairment to be brought ‘back in’ to the social model, Crow (Crow, 1996, p.58) notes how it is an integral part of disabled people’s everyday reality that deserves being considered “for the sake of our own physical and emotional well-being, and, subsequently, for our individual and collective capacity to work against disability”.

Also highlighting the social model’s tendency to downplay personal in favour of structural issues, Thomas (1999) emphasises the significance of both ‘telling one’s story’ and ‘writing the self’ in feminist work. Giving voice to individual experiences is itself “a key political act”, making the personal political, and furthermore “giv[ing] rise to new ways of understanding what knowledge is and how it is produced… it reminds us that all knowledge is situated… a social product bearing the marks of time, place and social positionings” (Thomas, 1999, pp.68–69). Feminist approaches thus fundamentally challenge the epistemological underpinnings of social science, particularly that knowledge is unconnected to the social conditions of its own production. By unsettling the notion that some ‘private’ areas of life are divorced from politics, they also provide support for the idea of telling individual, experiential stories of disabled lives, reminding us that by denying personal experience we can miss social factors of oppression in areas of life such as self-identity and ‘the private’ (Thomas, 1999, pp.73–74). Feminist approaches thus suggest that these personal stories and situated accounts serve an epistemological purpose, reframing what are considered as valid forms of knowledge.

Such accounts offer what Haraway describes as ‘feminist objectivity’ by engaging with situated, embodied knowledges (Haraway, 1988, p.583), rather than performing ‘God tricks’

of totalising narratives (which promise an impossibly detached objectivity) or relativism, whereby individual experience is reduced to 'just' an opinion. She argues for a multiplicity of partial and critical knowledges, which at least offer the possibility of solidarity and of shared conversations between groups with different knowledges. She emphasises how the situated knowledges of certain groups, such as disabled people, offer 'preferred' positioning as they are in principle more likely to be attuned to the "critical and interpretative core of all knowledge" (Haraway, 1988, p.584). Ultimately, she calls for politics and epistemologies to be rooted in these situated knowledges, as "partiality and not universality is the condition of being heard to make rational knowledge claims" (Haraway, 1988, p.589).

Similarly, Harding explains how feminist standpoint epistemologies prompt us to engage with the value inherent in socially situated knowledges (Harding, 1993, p.50). These emphasise the socially situated nature of all knowledge claims. Harding notes that the dominant social positioning of those at the top of social hierarchies constrains their understanding of the nature of society, preventing the most critical questions about received beliefs (Harding, 1993, p.55). Instead, an analysis of social relations that starts from the bottom of social hierarchies offers greater insight: the "experiences and lives of marginalised people, as they understand them", offer the most compelling research agendas (Harding, 1993, p.54). The multiplicity of marginalised lives does not preclude this approach: just as there is no archetypical woman's life from which critical analysis should begin (Harding, 1993, p.60), so the diversity of disabled lives is a source of situated knowledges from which to start such an analysis. Nor, in this account, are marginalised standpoints privileged with knowledge that is entirely unknowable to others. Some non-disabled people, such as personal assistants, family members, and friends, may be acutely aware of disabling barriers, while spaces that are inaccessible for certain disabled people like wheelchair users may likewise be inaccessible for other groups such as parents with buggies or people with luggage. Rather, standpoint theories argue that marginalised lives offer a starting point for a critical investigation of society. The social situatedness of subjects of knowledge is therefore itself a resource for maximising objectivity (Harding, 1993, p.69). To begin from the standpoint of marginalised lives, such as disabled people in a predominantly non-disabled society, enables us to not only explore their experiences but also to ask critical questions about the wider nature of society. This requires attentiveness and reflexivity: "understanding ourselves and the world around us requires understanding what others think of us and our beliefs and actions, not just what we think of ourselves and them" (Harding,

1993, p.72). In this reading, disabled people's situated knowledge offers the possibility of generating 'strong' objective knowledge about the disabling nature of society as a whole through bringing standpoints into dialogue with each other.

The value of bringing diverse perspectives into dialogue is developed by Young (2004), who contends that democratic decision-making processes benefit from involving all groups in a society. This increases the collective knowledge available and helps to "promote a shift in the perspective of everyone from self-regard to a more objective view, which takes into account the legitimate interests of everyone" (Young, 2004, p.20). In this view, objectivity is collectively assembled from the partial, situated perspectives of those with different social positions. In this exchange of views, any given situated knowledge has to be expressed in a way that is persuasive and understandable to others, appealing to justice rather than self-interest. While different claims may conflict with each other, rather than being expressed in terms of a shared interest, confrontation with different perspectives "teaches each the partiality of their own and reveals to them their own experience as perspectival… [this] contextualising of perspective is especially important for groups that have power, authority or privilege" (Young, 2004, pp.26–27). These groups not only take their own experiences as uncontroversial but can also represent their experiences as more general norms. In a society which is predominantly non-disabled, the ways that society is itself disabling are likely to be invisible to the non-disabled majority. Bringing disabled people's situated knowledge into democratic discussions therefore offers the chance for a critical assessment of the nature of society and the position of disabled people within it. These are, at heart, political questions that are rooted in disabled people's situated experiences and knowledge. Given that the relationship between knowledge and politics is core to standpoint epistemologies (Harding, 1993, p.55), the assertion of some social model proponents that a focus on personal experiences of disability is "a discredited and sterile approach to understanding and changing the world" (Finkelstein, 1996, p.34) is therefore misplaced. Rather, personal experiences are a key aspect of the knowledge base of standpoint epistemologies.

Engaging with disabled people's accounts of their everyday lives can therefore tell us much about societal disablement, and this thesis is underpinned by a recognition of the value in such individual, embodied accounts as articulated by the feminist work discussed above. Acknowledging these experiences means emphasising the importance of specific contexts, spaces, and geographies. Individual stories, taken together, form a diverse patchwork of

experiences that can help to shed light on issues of disablement in relation to mobility and access. But more than this, these experiences are important to the identity and selfhood of disabled people, as they are ways in which individual disabled identities are expressed. Disabled people have historically been offered little opportunity to portray their own experiences and have been left isolated and individualised by societal definitions and judgements around individual capacities and personalities (Morris, 1992, p.161). Even when disabled people are able to convey their experiences, they are sometimes disbelieved if these conflict with a non-disabled person's view: their knowledge is dismissed and they are subject to diminished credibility by virtue of being disabled, a form of testimonial injustice (Scully, 2018, pp.7–8).

This thesis is therefore indebted to feminist writers who emphasise the importance of such accounts coming from disabled people themselves in the first instance. Moreover, it also draws upon a feminist recognition of the value inherent in the situated knowledge that informs these accounts, and how this knowledge can be a starting point for a critical investigation of society as a whole. Such an engagement with the situated, partial knowledge of individual powered wheelchairs users involves seeking to understand not just how barriers affect their experiences, but also how they perceive, interpret and act upon these experiences as well as how such interpretations are shaped by structural factors. In this respect, the ways in which disability is described, and the narratives about disablement and disabled people, are critical. This is an area that is highlighted by work from critical disability studies, which also offers a critique of the impairment-disability dichotomy proposed by the social model. The following section briefly outlines the contributions of critical disability studies to this research.

2.2.3 Critical disability studies: toward a relational understanding of disablement

In addition to feminist critiques, the social model has been challenged by critical disability studies, which has questioned the ideas, assumptions, and categories used to discuss disability (Vehmas & Watson, 2014, pp.638–639). By examining how notions of disability are historically and socially contingent, this has highlighted how discourses around 'impaired' and 'disabled' bodies are created and sustained. Critical disability studies sheds light on the ways in which societies label and react to those that do not fit 'acceptable' bodily norms. Whereas medical understandings see bodily deviations themselves as the unifying feature of disability, these are challenged by both the heterogeneous nature of impairment and the

contingent nature of 'normality' itself (Scully, 2011, p.38). From the perspective of critical disability studies, binary dualisms such as able-bodied/disabled, normal/abnormal, and impairment/disability are questioned, as they impose a totalising, modernist worldview of fixed categorisation (Thomas, 2007, pp.65–69). Instead critical disability studies highlights the diversity of differences that are labelled as 'disabled' or 'impaired' by society, and how such labels intersect with myriad other concerns such as ethnicity, class, age, sexuality and gender (Shildrick, 2012, p.33). By blurring the boundary of those categorised as 'disabled', this implies we might all be considered 'temporarily able bodied', and perhaps that disabled people's needs for accessible environments are more universal than society acknowledges. However, this reinforces the idea that disabled bodies are somehow 'less than' non-disabled bodies, ignoring why it is that non-disabled people find disability threatening and failing to recognise the plurality of forms of acceptable embodiment (Shildrick, 2012, pp.34–35).

Critical disability studies itself has been critiqued on several grounds. Vehmas and Watson (2014) note that Critical disability studies suggests ethical relativism in its implication that all impairments, even those leading to early death, are neutral. They highlight its endless deconstruction, which could undermine a shared disability identity and political purpose. They also note that the very real mechanisms producing diversity and difference "cannot be challenged, let alone abolished, merely by pointing out the wanton nature of difference, and deconstructing the meanings attached to disability" (Vehmas & Watson, 2014, p.647). In rejecting the distinction between impairment and disability, and implicitly between the biological and social, critical disability studies has even been condemned as philosophical navel-gazing with "little, if any, meaningful or practical value in terms of research, policy and practice" that undermines the social model (Barnes, 2012, p.22). However, an examination of why it is that society labels some types of body as disabled also allows for the possibility of questioning and challenging such labels and the stigmatising accounts that accompany them (Coleman-Fountain & McLaughlin, 2013, p.137). From this perspective, not only do individual bodies and the spaces they inhabit matter, but so also do the stories which are told about them. Post-structural accounts demonstrate not only the historical and social contingency of disability but also how particular societal discourses around disability are replicated and sustained. In doing so, they at least open up the opportunity for new identities and narratives to be created around disability and impairment, in turn offering the possibility for dominant, disabling narratives to be challenged (Coleman-Fountain & McLaughlin, 2013, p.144).

This is an area where critical disability studies shares certain broad commonalities and alignment with the previously discussed feminist approaches in understanding disabled experiences. Accepting disabled people's experiences as valid, and accepting their epistemic credibility (Scully, 2018), acknowledges the right and capacity of any individual disabled person to articulate their selfhood in ways "that are in keeping with [their] own experience, rather than someone else's understanding of it" (Scully, 2011, p.41). This enables disabled people to align themselves with narratives that are true to their experiences, rather than those that may be externally ascribed to them, and can serve to support consolidation of collective political and cultural disability identity. Indeed, such alignment can have a transformative impact on individuals (Scully, 2011, p.43). Being able to express and articulate their lives on their own terms contrasts with the disempowerment that they may experience when others adopt ableist narratives about their lives. These can invoke pity for or revulsion of the disabled person, who is 'othered' from the dominant 'able-bodied' majority. As Morris notes, "while one social group has the power to represent, through whatever media, the reality of those perceived as different, there is always a danger that the "other" will be seen as not quite human. As long as non-disabled people retain the power to represent our reality, impairment will always mean at best a cause for treatment and cure, at worst a life not worth living" (Morris, 2001, p.6).

Ceding the representation of disabled people's reality to non-disabled people runs the risk of returning to 'personal tragedy' understandings of disability, highlighting the importance for disabled people in being able to define and articulate their own narratives about their experiences. Enabling disabled people to convey their own experiences can itself be an expression of agency (McLaughlin et al., 2016, p.75), and moreover a way of dealing with oppression (Thomas, 1999, p.47). It is therefore important to recognise the authority of disabled people's testimonies, and to support their expression through experiential accounts of their experiences (Scully, 2011, p.50). For some in critical disability studies, however, this does not mean privileging the voices and experiences of disabled people through "a hierarchy of truth telling"; rather that we should acknowledge the absence of an 'absolute' form of truth about their experiences that "could, under the right conditions, be accessed" (Shildrick, 2012, pp.36–37). This returns to some of the issues raised by feminist critiques that have already been discussed, on the situated nature of all knowledge. Both feminist approaches and critical disability studies show us that individual and collective experience is always mediated and re-presented in particular accounts, and that how these accounts are

formed is itself worthy of examination: “there is not a straightforward relationship between experience, ‘truth’ and knowledge, and accessing experiences as researchers does not mean we access and reproduce something unmediated” (Thomas, 1999, p.80). It is therefore also important to consider the ways in which disabled people’s experiential accounts of disablement are generated and represented.

One way of drawing together insights from feminist approaches and critical disability studies is to consider disability as a product of an interaction between individual and environmental factors. For example, in dealing with the issue of impairment, Thomas describes “impairment effects” as restrictions of activity that are “associated with being impaired but which are not disabilities in the social relational sense” and contends that both impairment and its effects are shaped by the interaction of biological and social factors (Thomas, 1999, p.43). Similarly, disability has been described as an ‘emergent property’ (Williams, 1999, p.813), or a ‘complex interaction’ between individual and contextual factors, “the whole interplay of different factors which make up the experience of people with impairments” (Shakespeare, 2006, p.58). The stance of these authors on the social model varies: some such as Thomas and Morris, argue for its continued relevance while others such as Shakespeare have called for it to be replaced with a wider social approach that is less rigid (in their view) about the distinction between impairment and disability. As already discussed, the nuanced semantics of the social model are of less relevance to this research than the insights it provides into the experiences of disabled people in a disabling society. Similarly, insights from critical disability studies are compatible with those of social approaches: what matters are individual experiences within wider disabling structures. While the body in situ is highly relevant to disability (Freund, 2001), this does not deny socio-material barriers, nor the value of the social model’s focus on political actions to address such barriers.

Critical disability studies makes several contributions to understanding disabled experiences on which this thesis draws. First, by questioning totalising categories of disability, critical disability studies (like feminist perspectives) highlights the importance of attending to individual, embodied accounts of disabled people’s experiences. From this, I take the importance of acknowledging the significance of different embodiments, which can some times lead to differential experiences of disablement, within a wider social approach that recognises and focuses on societal barriers. Secondly, and linked to this, through its

emphasis on the interactional aspects of disablement, critical disability studies enables a focus on how particular bodies in specific environments may be disabled in situ. Again, this can help to shed light on how different people are disabled differently, as well as opening the possibility for finding areas of alignment between disabled and non-disabled people in relation to what might make more enabling environments. This focus on interaction is also picked up by writers in science and technology studies (STS), which is discussed in the next section. Finally, critical disability studies highlights how narratives help shape social reality. By acknowledging that the ways society talks about disability shapes disabled people's experiences, it emphasises the potential for disabled people to challenge and contest these dominant, disabling narratives through their own accounts of their lives.

2.2.4 Technologies, knowledge, and representing disabled people's experiences of place

Understanding disablement as a result of interactions between people and environments allows for a conceptual engagement with work in science and technology studies (STS) that analyses the complex interconnectedness between humans and technologies. By examining how socio-technical norms are created, STS highlights the experiences of those who do not conform to such norms, enabling the questioning of stabilised networks of socio-technical relations by suggesting that such networks could be otherwise (Star, 1990). This contributes to our understanding of disabled people's experiences and wider societal processes of disablement in several ways. First, it can help us to understand processes of knowledge formation through its analysis of how scientific knowledge is socially created, which has parallels with the feminist and critical approaches discussed above. It questions science's positivistic underpinnings and the conclusions drawn from its findings (Star, 1990, p.31). This critique goes beyond science criticism, that would implicitly suggest that science 'done right' would be unbiased; rather, it questions the very possibility of 'doing right', by identifying processes of rationalisation, classification, and quantification through which science helps form our taken-for-granted assumptions and freezes specific knowledge in 'socio-technical networks' (Star, 1990, p.32). STS acknowledges the existence of these processes, which enables us to question both the processes themselves and the inevitability of particular socio-technical outcomes and knowledge. Like feminist approaches discussed above, this forces us "to explore the ways in which different kinds of knowledges butt up against one another, [and] how it is that matters are decided locally" (Law, 1990, p.7).

Highlighting how socio-technical networks help to create and maintain what is considered 'valid knowledge' allows us, at least potentially, destabilise such understandings.

Secondly, and linked to the notion of disablement as a 'complex interaction', STS provides insights into the relationships and dependencies between humans and technologies. This not only highlights the ways in which socio-technical norms and standardised forms of technology come to be, but also how they sometimes break down when confronted by those who do not 'fit' them. In a world physically and socially constructed around 'standardised' (in other words, non-disabled) bodies and practices, those who do not conform to such norms encounter particular kinds of friction. Garland-Thomson describes this as a 'misfit', the awkward juxtaposition of a particular body with a wider environment that does not sustain that body, and notes how environments commonly fit majority bodies while 'misfitting' disabled bodies (Garland-Thomson, 2011, pp.593–594). The ways in which physical environments do not cater to the needs of disabled people will be discussed in more detail in section 2.3, where I examine prior work on the geographies of disability.

Adopting an STS lens enables us to see how those who 'misfit' are compelled to undertake different forms of labour in an attempt to better align with their environments, and moreover highlights how this work, and the effort it involves, is typically invisible to those who do not misfit. An allergy to onions, "precisely because it is so minor and yet so pervasive", gave Susan Leigh Star the opportunity to critically examine the costs that occur where individuals, organisations and standardised technologies meet (Star, 1990). She describes the inability for standardised food production processes to cater to her unusual (i.e. non-standard) needs, the disbelief of waiters when told about her requirements, and the added costs of surveillance to ensure her needs are met which are borne entirely by her. Disabled people undertake similar work in order to make their way in standardised socio-technical environments where they 'misfit'. They contend, for example, with environments that 'fit' the non-disabled majority, and mobility technologies and processes that struggle to fulfil their particular requirements. At times, they deal with incredulity from non-disabled others who are ignorant of their needs, and they are compelled to undertake additional surveillance to ensure that those needs are met.

Yet even when they achieve 'good passage', the labour imposed upon disabled people is concealed (Moser & Law, 1999, p.207). STS illuminates how particular combinations of bodies and technologies are privileged: "passages are smoother for some than others. Stairs

don't mix with wheelchairs. They mix better with legs – but legs, for instance, without the pain that comes from lower limb atherosclerosis" (Moser & Law, 1999, p.208). Moreover, work is not simply physical effort: what is considered as 'work' is highly contextual, varying on a spectrum from strenuous manual labour to deep concentration without physical movement, and therefore "the visibility and legitimacy of work can never be taken for granted" by others (Star & Strauss, 1999, p.15). The work undertaken by disabled people in achieving good passage is not restricted to the physical effort of working around disabling material environments. Significant emotional labour, for example, is involved in managing social interactions as a disabled person and controlling one's self-presentation through strategies such as passing, normalising, parading or performing disability (Scully, 2010, pp.29–31). The forms of work undertaken by disabled people are highly diverse, and may include aspects such as pre-emptive journey planning to find accessible routes and ensure they have back-up plans should things go wrong, the physical effort expended in controlling their wheelchair in inaccessible environments, and emotions engendered by experiences of inaccessibility or discrimination. The latter will be discussed in more detail in Section 2.3.3, where I explore how disabling geographies engender psycho-emotional effects. However, here it is worth highlighting how STS helps us to understand these factors: by blurring boundaries between humans and the technological aids on which they rely (Law, 1990), it highlights that all of us experience lives that are largely structured by and around different forms of technology (Blume, 2012), challenging not just the assumption that only disabled people are 'dependent' on technology but the very notion of dependency itself.

Indeed, examining the diverse ways in which disabled people use technologies illuminates the complexity of this relationship. While many use 'assistive' technologies in their everyday lives to aid with functional tasks (Scherer, 2002), through processes of embodiment such as becoming 'en-wheeled' these technologies can become a part of disabled people's identities rather than just tools (Papadimitriou, 2008). For people with particular impairments, specific types of medical technologies such as full-time ventilation are life-preserving or extending (Eagle et al., 2002; Gibson et al., 2007). In these ways, specific technologies can become an integral and indeed inviolable aspect of a disabled person's identity and being (Gibson, 2006, p.194). Highly specialised technologies such as sports wheelchairs can be perceived as desirable objects, and are sometimes valued for highlighting bodily capability (Apelmo, 2012). They provide an opportunity for disabled people to demonstrate sporting prowess, in doing so creating new narratives around disabled bodies that refute the notion of

‘dependence’, although this in turn also risks validating the paternalistic norm that disabled people should ‘overcome’ their impairment (McLaughlin et al., 2016, pp.127–132). Involvement in sports such as powerchair football also offer a chance for in-person social interaction, which is often denied to disabled people due to barriers such as inaccessible buildings (Skyrme, 2017).

However, it is also worth noting that technology can sometimes be problematic or even intrusive in the lives of disabled people. It can mark disabled people out as different to non-disabled people (McLaughlin et al., 2016, p.293) or medicalise everyday lives; in some cases it can also serve as a reminder of the progression of particular medical conditions or impairments (Kirk, 2010). Even when disabled people find digital technologies beneficial in their everyday lives, they can face a range of barriers in its use (Baumgartner et al., 2021). New forms of mainstream technologies can serve to disable as well as enable (Mairs, 2007), paradoxically causing new forms of disablement even as they reduce others (Roulstone, 2016, pp.3–4). The form and function of assistive technologies, in particular, can influence disabled people’s social interactions with others and researchers have identified the need for technologies to be designed to balance their social and functional requirements (Shinohara & Wobbrock, 2016; Shinohara et al., 2018). Technologies can also uphold idealised, normalising discourses of rehabilitation and what is considered as ‘ordinary’ functioning (Moser, 2000, 2006), which serve to further ‘other’ disabled bodies. They can also be associated with biomedical ‘cure’ or enhancement and thus recall problematic individualised, deficit-based conceptions of disability (Shakespeare, 2006, pp.103–117). Yet this is not inevitably the case. It is also possible to imagine how technologies might be used to recast existing narratives, enabling self-expression and discourses of value rather than stigmatisation (McLaughlin et al., 2016, p.93). Even in highly techno-scientific processes, such as genetic diagnoses, people have agency in interpreting knowledge provided by a given technology, and they create particular narratives around this knowledge (McLaughlin et al., 2016, pp.68–86).

These examples show how different forms of technology play a range of diverse roles in disabled people’s lives, whether or not they are explicitly regarded as ‘assistive’. Indeed, rather than being something worthy of undue attention, for many disabled people what others ascribe as their ‘dependence’ on technology is just their way of getting on in life (Gibson et al., 2012). Furthermore, the boundaries of what are considered to be ‘assistive’

technologies are increasingly amorphous. Technologies such as home automation that were considered 'advanced' and cost-prohibitive for many disabled people barely a decade ago (Harris, 2010) have become increasingly mainstreamed, built into smartphones alongside tools like voice assistants which are either implicitly or explicitly useful to disabled people. Smartphones also incorporate many features designed and advertised directly as assistive technologies[2]. They also offer a wide range of tools that enable users to express themselves, such as on-the-go video and audio recording, software for editing and presenting the data that is captured, and social networking for sharing these data. This permits a reimagination of disabled people's use of such technologies, from being 'assistive' to being 'expressive'. For example, Rice (2017) describes the use of wearable cameras by a disabled media makers, and notes how the appropriation of smartphone cameras could enable disabled activists to take ownership of social media representations of their experiences (Rice, 2017, pp.209–210). Similarly, smartphone video can support the authenticity of accounts of someone having 'been there' (Puikkonen et al., 2009). As such, it is possible to imagine these having the potential to enable disabled people to capture particular experiences and situated knowledge in ways that are meaningful to them, and convey this to others through narratives that affirm rather than stigmatise.

Recent research on 'digital civics' in human-computer interaction (HCI) has explored how technologies might support citizens to engage in matters of civic concern, and particularly focus on how community knowledge of local issues might be brought into engagement with policymakers (DiSalvo et al., 2014; Olivier & Wright, 2015; Vlachokyriakos et al., 2016). This is underpinned by the idea that places are constructed through plural forms of participation enabled by linking social and technical resources to enable capacities for civic action (Le Dantec, 2019, p.171). As discussed in the next section, experiences of local environments are embodied and political, and work in this tradition has focused on facilitating dialogues about place through techniques like digitally supported city walks (Crivellaro et al., 2015), participatory media and storytelling (Manuel et al., 2017), and platforms for community consultation (Johnson et al., 2017). This work has highlighted how digital technologies can potentially bring together diverse accounts and perspectives on urban spaces (Crivellaro et al., 2016). In some cases it has engaged with communities whose needs are marginalised,

[2] Apple's iOS operating system, for example, includes built-in support for features such as screen-reading, magnification, sound recognition and external switch control (https://www.apple.com/uk/accessibility/).

such as older adults (Clarke et al., 2016), cyclists (Le Dantec et al., 2015; Asad & Le Dantec, 2017), children (Peacock et al., 2018), and disabled people (Rodger et al., 2016).

Many such efforts to bring place into civic technology have been supported by the ubiquity of smartphones and geo-located media, which support the collection of data while out and about. This has enabled, for example, cyclists to capture 'annotated routes' of their journeys, augmenting GPS traces with in-the-moment audio comments or post-journey textual description to support reflection and discussion for civic engagement (Maskell et al., 2018). Visual imagery has been used to log maintenance issues in the physical environment with civic authorities (Foth et al., 2011), an approach that has also been explored with wheelchair users (Steinfeld et al., 2010). While sensor-triggered video to automate logging accessibility barriers has been explored with manual wheelchair users (Kirkham et al., 2017), conceiving of video as 'objective' evidence for dispassionate post-journey review precludes important emotional or affective aspects of disabled people's embodied experiences, and limits their agency in determining what matters to them in-the-moment. Indeed, work with cyclists and urban planners has demonstrated that the data that result from the use of such technologies forms a mutable resource for stakeholders, representing particular 'ways of knowing' about the city rather than an objective measure of ground truth (Le Dantec, 2019). Such work has highlighted how technologies become actors in socio-technical networks, not just augmenting or amplifying publics but aiding in their formation (Jenkins et al., 2016). How data is produced is shaped by the social and material qualities of particular places, so both the form and the content of data representing disabled people's experiences of place is an important consideration, as is the wider ecosystem in which such data is used (Taylor et al., 2015). One challenge identified by this literature is the ways in which designers of socio-technical systems might go beyond merely providing technological tools for civic engagement, and help instead to support redesigning processes of policy-making (Manuel & Crivellaro, 2020). Such a vision has some parallels with the STS notion of hybrid forums, which have been suggested as arenas where concerned groups carrying out 'research in the wild' can negotiate with credentialed experts such as scientists and engineers to collectively modify the enactment of disability in the city (Galis, 2011).

This work on civic technologies opens up ways of conceiving of how disabled people might use technologies to challenge ableist barriers, narratives and attitudes. One way in which this might be done is through surfacing place-based situated knowledge and expertise, using

mobile technologies to convey their perspective of mobility and access. In this respect, prior work on 'life-logging' is insightful, showing that the data generated by such tools is not an analogue to memory but rather a resource for digital narratives that enable users to tell evocative stories about even prosaic events in their everyday lives (Harper et al., 2008). The choice of topics, and the identities and narratives told around them, support the telling of 'small stories' about people's lives (Lindley, Randall, et al., 2009) and retrospectively enable new insight into everyday routines (Lindley et al., 2011). Videos captured by wheelchair users, from their own 'wheeling' perspectives, have been used to campaign and share stories around access issues and explicitly to tell narratives that counter ableist discourses (Parent, 2019). As discussed in the following chapter, videos like this have also been adopted as a research method, highlighting in particular the embodied dynamics of wheeling and moving together with others (Parent, 2016). Combining ethnographic methods with digital tools might help others to understand disabled people's experiences, and has the potential to link them with other stakeholders involved in urban design, as well as being a resource for disabled communities themselves (Rebernik et al., 2020).

Yet as discussed in the next section, disabled people's experiences in built environments and public transport are multifaceted and complex, and are linked to wider structural and societal factors. In this respect, enabling disabled people to convey their own narratives and experiences opens up the possibility for resistance in inhospitable places, epitomised in the direct action campaigns of the disability movement in the 1990s (Freund, 2001, p.701). It is nonetheless important to consider that while such narratives could be used for political resistance, the agency disabled people express in telling their own stories is not necessarily activism, and as discussed in Section 2.2 has intrinsic value. Some people may not identify with a political conception of disability (Shakespeare, 2006, p.74), and may not wish to bring their disabled status to the fore and risk it becoming a dominant identity (Thomas, 1999, p.109). As such it is important to think of civic technologies broadly, and allow for their use in unexpected, open-ended ways. This would enable people to express their own narratives around their experiences of mobility in ways that will not constrain them to the singular purpose of 'fixing' accessibility.

The STS, HCI and related literature discussed above highlights the complexity of the relationship between humans and technologies, underlining how socio-technical systems are not only central to people's everyday lives and mobility but may also be a means of

conveying their experiences around these issues to others. This thesis builds on how this work highlights the interactional aspects of the relationship between people and technologies, and how dominant socio-technical norms cause friction for those who do not conform to them. This opens up the possibility for generating alignment and understanding, by demonstrating similarities in processes of enablement and disablement between groups with ostensibly different needs. It also adopts the critical approach that STS brings to questioning how particular and partial forms of knowledge come to be embedded in such socio-technical norms in the first place. It draws on the ways that this literature highlights the place of technologies in the lives of disabled people in particular, and how these are not only used for functional or 'assistive' tasks but rather are appropriated to fulfil a range of other roles. Finally, it draws on the HCI conception of civic technologies that seeks to enable particular communities to express their views around issues of concern, and bring these into policymaking discourses. Taken together, these insights allow for a nuanced perspective on the ways in which people may be disabled by socio-technical systems and norms. They also open up space for how dominant knowledges that are frozen in these systems may be unsettled and reframed through disabled people's appropriation of particular technologies such as smartphones and civic technologies.

2.2.5 Conclusion

This prior work on disability, disablement and technologies provides a base from which to explore disabled people's experiences of mobility and access. It enables a focus on the ways in which socio-material environments and socio-technical systems serve to disable or enable particular groups. It emphasises the importance of individual narratives around these particular embodied experiences, as they are expressed by disabled people on their own terms, in both collective experiences of disablement and in the consideration of wider societal structures and attitudes towards disability. It highlights the importance of understanding the ways in which particular situated knowledges become embedded in socio-technical systems, and the importance of considering the processes and tools that are used in the generation and representation of disabled people's experiential accounts of disablement. This thesis draws on the these insights in investigating disabled peoples' experiences of mobility, through a focus on the ways in which specific environments disable users of powered wheelchairs. It considers the interactional aspects of how users of these particular mobility technologies find that they 'misfit' environments built around dominant socio-technical norms that are predicated on particular embodiments and ways of moving

through space. It foregrounds the individual and collective disabled voices of powered wheelchair users by working with them to understand their experiences in their own terms, thus attending to their situated knowledges and expertise about how they are disabled by particular socio-technical environments, and the ways in which these might be reimagined.

In the following section, I explore how work from human geography has begun to engage with these concepts, and has come to recognise the situated knowledge of disabled people in relation to mobility, place, and what makes for enabling or disabling environments. This work, broadly conceptualised as being on 'geographies of mobility', forms the second broad area of prior research on which this thesis is built.

2.3 Geographies of Disability and Disablement

This section provides an overview of research on 'geographies of disability', and how it informs this thesis. This literature explores the ways that particular socio-material environments can spatially exclude disabled people from participation in society, by limiting their access to public space and transport. First, this section provides some background to and summarises the development of this research, which has expanded significantly in scope since emerging in the mid-1990s. This shows how it engaged with and responded to wider theoretical currents about the nature of disability and disablement, including the insights provided by the social model and critical disability studies that have been discussed above. Then this section engages with some of the common findings in this and related literature that describe ways in which disabled people, and wheelchair users in particular, have been excluded from material environments. It goes on to discuss in more detail one particular aspect of social exclusion, psycho-emotional disablement, that both stems from and reinforces material exclusion. It concludes by summarising how insights from geographies of mobility and related literatures on disabled people's experiences of place and space have influenced this research.

2.3.1 The development of geographies of disability

As discussed in Section 2.2 above, social understandings of disability and disablement offer an insight into how disabled people are excluded from specific socio-material environments, including public space and transport. Prior research in geography has highlighted how places may affect different groups of people in different ways, and lead to particular patterns of movement and spatial relations. For example, feminist researchers identified the gendered nature of the built environment, drawing attention to specific patterns of mobility that were

associated with fear of men's sexual violence, and to particular characteristics of women's work trips (Law, 1999). Places are therefore not neutral, but rather can have distinctive and sometimes detrimental impacts on people's lives (Laws, 1994). Moreover, this research has shown how those who are most affected by oppressive environments can contribute particular forms of socio-spatial knowledge about those environments (Laws, 1994).

Public spaces and transport are two socio-material environments where differences in individual embodiment may 'misfit' most visibly and publicly, and in which disablism is made manifest through the friction that results. Furthermore, they are particularly important to full participation in modern society. Transport between locations is a critical aspect of this, for "however much progress may be made in improving the accessibility of buildings, public spaces, employment and educational facilities, [it] will be wasted if the people at whom these improvements are aimed are unable to travel to their chosen destination" (Salvage & Zarb, 1995a, p.1). As such, accessible transport "is essential for disabled people to access education, employment, health services, social events and leisure pursuits" (Wilson, 2003, p.6). Moreover, the (in)accessibility of transport is intrinsically linked to that of the wider built environment: public transport is just one link in the journey or travel 'chain' from origin to a destination, and the physical accessibility of a vehicle cannot be considered in isolation in disabled people's experiences of mobility (Heiser, 1995; Jensen et al., 2002; Tyler, 2015). A lack of access to mobility can be both a cause and a consequence of social exclusion (Kenyon et al., 2002; Cass et al., 2005). Mobility is also generally considered a fundamental aspect of democratic freedom for all people, both as an intrinsic good and as a means to an end in opening up other opportunities (Imrie, 2000a, p.1643). Accessible public spaces and transport therefore enable disabled people to access to societal opportunities on the same terms as non-disabled people, while environments that hinder their mobility constrain such choices. As such, the study of how people move (or are obstructed from moving) through space can provide an insight into systemic social and material power relations, showing whose time and bodies are valued in particular contexts (Sawchuk, 2012). Despite being more reliant on public transport than non-disabled people, disabled people are also less satisfied with it, and are more likely to see it as unreliable and to feel that their needs are not considered by public transport operators (Jolly et al., 2006). These factors highlight the imperative of understanding how disabled people experience both location and mobility, which have received increasing attention in a wider context of increasing engagement by

geographers with the spatial properties of social and cultural factors (Butler & Parr, 1999, p.6).

Chouinard *et al* (2010) describe how, prior to the mid-1990s, disability occupied a marginal place within the discipline of geography that was characterised by three broad areas of research. These were first, positivistic studies of the epidemiology of disabling conditions; second, studies of access and mobility of disabled people in urban environments, which documented spatial exclusion but did not examine the structural nature and production of barriers (for example, Golledge (1993)); and finally, studies that focused on the sense of difference experienced by those with mental health conditions around deinstitutionalisation. Although this early work was later critiqued for a lack of engagement with structural factors, it laid the foundations for the subsequent critical turn by contributing "spatial insights… [including] the prevalence of disabling conditions, the significance of social and cultural environments in shaping the lives of disabled people, and the embedded discrimination in mainstream communities and in welfare services" (Chouinard et al., 2010, p.2). This early research did not, however, go beyond a medicalised framing of disability and so "the significance of socio-political and environmental contexts, in the production of disabling spatialities" were not considered (Imrie & Edwards, 2007, p.625).

Following on from this, there has since the mid-1990s been an increasing range of research on what has come to be known as 'geographies of disability', which has shed analytical light on a range of issues relating to disability and space. Stemming partly from a consideration of 'geographies of exclusion', this led to work exploring the social, institutional, and political processes that produce disabling built environments (Imrie & Edwards, 2007, p.626). The subsequent research, in fields of development, planning and design, has been therefore informed by a critical, social understanding of disability and disablement (Butler, 1994; Gleeson, 1996, 1999b; Hall & Imrie, 1999; Imrie, 1996a, 1996b; Kitchin, 2000; Imrie & Hall, 2001a, 2001b). As such, this work critiques the framing of disability as individual impairment and highlights the socio-political and environmental contexts that produce disabling spaces. It has sought to contest these 'ableist geographies', the "lived environments which incorporate and perpetuate physical and social barriers to the participation of disabled persons in everyday life" (Chouinard, 1997, p.380). It notes the importance of challenging the supposed inevitability of disabled people's marginalisation, and calls for "critical explanations of disablement as a sociospatial process" (Chouinard, 1997, p.383).

In several cases, this 'first wave' of critique is an explicit response to what authors perceive as ableist norms and assumptions in prior geographical work on disability. For example, Butler (1994) challenges Golledge's (1993) assertion that visually impaired people lack spatial awareness and understanding, noting the existence of place-specific cues available through non-visual senses, and highlighting the lack of spatial information in accessible formats that are suitable for them. Emphasising the need to consult disabled people about their spatial experiences, she highlights that:

> *"the blind live in a world built by and for the sighted. Their awareness of the spatial problems that they face in their everyday lives underlines their awareness of the environment around them, the lack of society's efforts to meet their needs and the lack of insight into how these needs can be met. The problems must be confronted from a blind person's perspective and not from that of a sighted person attempting to imagine what being blind entails" (Butler, 1994, p.368).*

Likewise, Gleeson (1996) rejects Golledge's notion of disability as physiological weakness, and disabled people as inhabiting and enduring 'distorted' spaces; drawing instead on the social model of disability, he outlines a historical-materialist understanding of disability and space that is socially contingent: "far from being a natural human experience, disability is what may become of impairment as each society produces itself socio-spatially" (Gleeson, 1996, p.391). Repudiating Golledges' positivism, he outlines how such a materialist view calls for an emancipatory effort by geographers to understand how socio-spatial structures oppress people with impairments. Moreover, as does Butler, he argues that it is disabled people who "are the best authors for an authentic description of their own experiences" (Gleeson, 1996, p.394), calling on geographers to participate in the struggle with disabled people in pursuit of material justice and political emancipation. Similarly, Imrie (1996a) notes that Golledge's adoption of a 'functional limitations' paradigm of disability led to the depoliticization of his analysis and highlights that disabled people's lived experience was downplayed in favour of the analytical gaze of the 'expert' researcher (Imrie, 1996a, p.400). Echoing calls made by disabled researchers for an emancipatory research paradigm grounded in the social model (Oliver, 1992), Imrie's critique reflects wider concerns amongst this first wave of critical studies about research methodologies that were done to, rather than for or with disabled people. As such, these studies foreground a focus on the power relations that exist in the production of geographical research on disability, and have helped spur a movement towards research on 'enabling geographies' (Gleeson, 2000).

While this critical turn is influenced by the social model of disability's focus on societal production of disabling barriers, it also focuses on the importance of the material body. Indeed, some authors suggest that concepts such as ableism and disablement are more helpful than the social model of disability, which they characterise as paying scant attention to different mind and body states (Butler & Parr, 1999, p.7). Work in this tradition, building on feminist insights, has emphasised the link between disabling environments and disabled people's embodied experiences of them. It has highlighted how acknowledging embodied experiences does not signal an inevitable return to individualised understandings of disability and, in fact, is critical to achieving political and social equality for disabled people (Butler & Bowlby, 1997). In this regard, it mirrors the concerns of feminist disability scholars described in Section 2.2.2, who highlight the importance of particular accounts of disabled experiences in all their diversity and specificity. It suggests the critical importance of attending to how different bodies, who may be using diverse technologies for mobility, may experience particular socio-technical environments differently. It also emphasises paying close attention to how these different environments may serve to enable or disable particular embodied people: the existence of stairs, or the presence of faulty equipment such as lifts, are issues that exist alongside disabled people's interactions with other people as important factors in their experiences. Considering these 'bodies in space' also reflects STS concerns of how transport and the built environment are examples of a "socio-technical order", wherein "what appears to be social is partly technical. What we usually call technical is partly social. In practice nothing is purely technical. Neither is anything purely social" (Law, 1990, p.9). All bodily experiences, including those of disabled people, are "the outcome of a reflexive relationship between bodily materiality and social processes" (Butler & Bowlby, 1997, p.411). While each person is different, there are certain commonalities to the experiences of powered wheelchair users, who use specific forms of socio-technical systems for their everyday mobility. These in turn interact in complex ways with wider socio-technical systems including modes of transport and the built environment. A social approach to understanding disablement, as adopted in this thesis, must therefore attend to the diverse experiences of differently embodied disabled people and how they use and interact with particular socio-technical systems.

A 'second wave' of geographies of disability research has developed since the early 2000s which Chouinard characterises as encompassing four themes: a broader understanding of disability; an increased concern with embodied experiences of disability and chronic illness;

the opportunities and challenges posed by technologies; and the relationship between geographical disability research and policy (Chouinard et al., 2010, pp.3–4). These are briefly outlined below, along with their implications for this research.

A broadened understanding of 'disability' opens up the analytical space to examine how a range of bodily differences can influence the spatial experiences of different groups. These include people with a range of visible and invisible differences, older people, 'fat' people, 'little people', and those with living with chronic illnesses (Chouinard et al., 2010, p.4). This has highlighted how, for example, attitudinal environments affect people with facial acne who often withdraw from these disabling spaces (Hawkesworth, 2001). A widening of what is considered as disability, and how this relates to different forms of embodiment and spatial disadvantage, must be considered carefully. If it leads to a reductionism in which bodily differences are crudely equated to disability, it may return the focus to individualised and medicalised understandings of disability and thereby undermine the social model's focus on the socio-political conditions that create disabling barriers for those with different embodiments. For example, including experiences of chronic illness within broadened understandings of disability requires a consideration of medicine, health care, and impairment which may be at odds with some interpretations of the social model (Crooks et al., 2008, p.884). However, a broader conception of disability, that examines how differently embodied people may be disabled in place and mobility, also enables a focus on similarities between the spatial processes of disablement as they are experienced by different groups of people. It also opens up the possibility of considering the role of mutual interdependence and shared requirements for smooth mobility between differently embodied people, including between disabled and non-disabled users of space and transport.

In this vein, work on disabled people's embodied experiences has highlighted the links between diverse bodies and the spaces they inhabit. Drawing on Massey (2005), Imrie describes how we are all spatially emplaced, and that space is not simply the context in which things occur but constrains and enables specific embodied practices (Imrie, 2014, p.15). The experiences of wheelchair users as they navigate around uneven surfaces in their neighbourhood, their expertise in knowing the best routes to follow for their own comfort or the protection of their chair from damage, and the emotions they experience as they negotiate disabling barriers are not easily disentangled. Through poor physical design, therefore, space itself produces disability as outlined in the social model. This has led to a

call for research to focus on the production of (disabling) spaces, the fluidity of disabled people's identities, and the diversity of embodied encounters and experiences, all of which are "intimately connected to place and space" (Imrie & Edwards, 2007, p.634). Similarly, highlighting the 'normality of doing things differently', other authors have demanded a rethink of the ways in which all people, not only disabled people, "occupy worldly spaces of all kinds… [we should not] stop at accounts of bodily difference… but instead imagine a sustained dialogue between all sorts of people with all sorts of bodies… wherein the normality of very different ways of human being, doing, relating and place-making is uppermost" (Hansen & Philo, 2007, p.502). This requires engaging with diverse embodied experiences and situated knowledge about spatial experiences and socio-technical systems of mobility, transport, and access to places. Moreover, it requires considering how these different narratives may be conveyed, and how such dialogues between different people might be supported.

The third broad area of recent research on 'geographies of disability' engages with how new technologies affect the lives of disabled people. New technologies pose a wide range of opportunities and challenges. While they have the potential to improve access for disabled people, for example through the provision of information or services via the Internet, they may also be viewed as a quick technical solution that obviates the need to make meaningful changes to physical and social environments (Chouinard et al., 2010, p.11). As previously highlighted, technologies can even introduce new barriers while removing others (Roulstone, 2016, pp.3–4; Mairs, 2007). For example, where information is provided on websites that are inaccessible to screen reading technologies, it may preclude access to those with visual impairments. The digitisation of previously analogue processes such as mobile ticketing or payment can lead to disablement in the interaction between people and digital objects (Egard & Hansson, 2021). Moreover, all technologies, including those systems that are designed and implemented to improve accessibility for disabled people, are not value-neutral: access "is entwined with socio-cultural and political relations" (Imrie, 2012b, p.877). As noted in the previous section, both mobility technologies and those representing experiences of mobility and place do not exist outside of social context: they are imbued with wider values associated with the society in which they are created and deployed.

The role of different technologies and how they affect the lives of disabled people are thus linked to how a predominantly non-disabled society values disabled people and as such to

the relationship between disability research and policy more broadly. While Chouinard highlights work that combines critiques of disabling environments with policy analyses in several fields (Chouinard 2010:14), some of which are discussed in more detail below, they note an ongoing disengagement between geographers and policymakers and a need to consider the different scales of geographical analysis to facilitate such engagement. This suggest the need for research that explores disabled people's experiences to also consider how its findings and implications could be brought into productive engagement with decision-makers and service providers.

The geographies of disability literature that has emerged since the mid-1990s therefore complements the work on disability and disablement underpinning this thesis. As already noted, its 'first wave' helped re-orientate geographic sensibilities towards an understanding of disability that acknowledges the structural forces influencing disabled people's spatial experiences. It emphasises the need to work with disabled people to understand their experiences, and acknowledges their expertise in describing and analysing disablement. In addition, these critical accounts highlight how social approaches to understanding disablement must be attentive to different embodied experiences, and to different interactions between individuals and particular socio-technical systems used for mobility. Such contributions reflect and build upon key insights from social approaches to disability and disablement described in Section 2.2. Work on geographies of disability has also suggested areas where it can contribute towards spatial understandings of disablement, including closer engagement with policymakers. In the following section, I explore some of the specific issues identified through this and related literature on disabled peoples' experiences of public space and transport, and the structural factors that influence these barriers.

2.3.2 The structural context of disablement in the built environment and transport

As discussed above, work that has been influenced by 'geographies of disability' has not only provided insights into how socio-material barriers constitute disabling environments, but has also sought to explain the processes that lead to this exclusion. In this section, I begin by outlining how wider social and political processes of spatial planning and accessibility legislation sets the context for specific disabling barriers, before examining the substantive nature of these barriers in the contexts of the built environment and public transport.

A central insight of the 'geographies of disability' is that it demonstrates how the design of built space and public transport excludes people who do not conform to the bodily norms and comportment of the non-disabled majority. The disabling design of these environments is not only insensitive to the needs of disabled people but remains unchallenged due to predominant attitudes to disability: it "is illustrative of the power of disabling design discourse as a naturalistic part of the crafting of the designed environment and, as such, it is rarely problematised or subject to critique" (Imrie, 2014, pp.16–17). The materiality of urban spaces "often (re)produces distinctive spatialities of demarcation and exclusion, from the lack of access to public transport systems to the absence of visual clues or guides in towns to enable vision-impaired people to move with ease" (Imrie, 2001, p.232), with the result that disabled people are effectively debarred from aspects of public life. Meanwhile discourses of mobility prioritise independent, non-disabled, 'mobile bodies' and reinforce structural inequalities that exclude disabled people (Imrie, 2000a).

These issues are reflected in the way that disabled people's needs are poorly understood and represented in urban planning, with development processes that are often insensitive to diverse requirements (Hall & Imrie, 1999; Imrie & Hall, 2001a). This is more than a purely technocratic issue: rather, disablement is embedded in the entire development ecosystem: "the socio-institutional structures and relations of the development process are… implicated in the production and perpetuation of disabling barriers… Inattentiveness to, and exclusion of, the needs of disabled, and other, people is evident at all stages" (Imrie & Hall, 2001b, p.7). Where disabled people are considered they are often narrowly defined as wheelchair users or people with restricted mobility; however such definitions reinforce a 'medicalised' view of disability and, moreover, "fail to recognise the diversity of physical and mental impairments, and the often conflicting and different mobility needs of different categories of (disabled) people" (Imrie, 2000a, p.1644). People with visual impairments may have very different requirements for accessibility to those with hearing impairments. Even the category of 'wheelchair users' makes no distinction between the different experiences of those who use different types of wheelchair (powered, manual, power-assisted) to say nothing of other powered mobility devices such as scooters. Each of these has different characteristics, which are entwined with particular socio-technical experiences of mobility and access as well as with wider socio-political conditions of their creation and use (Koontz et al., 2010; Cooper et al., 2008; Woods & Watson, 2003, 2004).

Research on the history of accessibility suggests little understanding in the mid-20th Century of the need for disabled access, with officials noting the limited presence of disabled people in public spaces but not recognising that this was itself likely an outcome of inaccessibility (Watson & Woods, 2005, pp.102–103). Despite increasing political attention paid to the accessibility of public buildings during the 1980s and 1990s, the UK planning system placed little obligation on developers to ensure access, relying instead on the goodwill of developers through a voluntary rather than a coercive framework of regulations (Imrie & Wells, 1993). Although the increasing institutionalisation of access as a concern drew attention to disabled people's marginalisation, the wider socio-legal context reinforced a 'clientist' relationship between disabled people and the state, while the provision of access remained subservient to market considerations of cost and affordability (Imrie, 1996b, 1996c; Edwards, 2001). A plethora of legislation and guidance now nominally governs the accessibility of built environments and buildings, including the National Planning Policy Framework (Ministry of Housing, Communities and Local Government, 2021), Part M of the Building Regulations (HM Government, 2015), and the Equality Act (HM Government, 2010). However, these form part of what remains a highly complex "accessibility jigsaw" with no cross-departmental strategy that brings together all aspects of built environment accessibility (House of Commons Women and Equalities Committee, 2017, pp.10–12). In this respect, the long-standing problem of weak and poorly enforced accessibility legislation that encourages minimal levels of compliance (Imrie & Wells, 1993; Imrie, 1996b, 2000c) is still an issue, and ableist assumptions around particular forms of embodiment and specific bodily competencies remain embedded in the built environment (Imrie & Kumar, 1998). This is despite active efforts by disabled people to improve accessibility by means such as local access groups, which are constrained by the nature and extent of support received from councils and the wider political culture in a given area (Imrie, 1999). There are difficulties in measuring disabled people's involvement in the planning process given the barriers they face to participation and because 'involvement' might range from passive information provision to delegated control (Begum & Zarb, 1996).

The result of the pervasiveness of these ableist norms in policies and practices is that many of the specific material barriers that identified during the 1990s and 2000s by geographical and geospatial research still exist. The built environment retains streets that resemble obstacle courses and many buildings remain entirely inaccessible, thereby preventing disabled people from moving easily in urban spaces (Imrie & Kumar, 1998, p.361; Salvage &

Zarb, 1995b). Specific problems include a wide range of issues that impede free movement, such as poorly maintained paths or routes; the presence of steps or deep gutters, steep ramps or cambers, or temporary 'street furniture'; and an absence of dropped kerbs and accessible toilets (see, for example Kitchin, 1998; Imrie & Kumar, 1998; Matthews et al., 2003; Beale et al., 2006; Bromley et al., 2007; Rodger et al., 2019). Many of these barriers remain commonplace (House of Lords Select Committee on the Equality Act 2010 and Disability, 2016; House of Commons Women and Equalities Committee, 2017). Disabled people are also still excluded from public spaces through inadequate provision of essential facilities such as accessible toilets, which is not simply a spatial issue but a political and social one as well (Kitchin & Law, 2001; Jones et al., 2019; Wiseman, 2019). Indeed, recent years have seen the closure of many public toilets and an increasing reliance on private provision, disproportionately affecting disabled and other marginalised people (Jen & Jones, 2018). These environmental barriers mean that wheelchair users experience "hidden geographies of place", and have a distinct way of seeing the built environment and planning routes through it that do not reflect those of non-disabled people (Matthews & Vujakovic, 1995; Kitchin, 2002).

Understanding the marginalisation and exclusion of disabled people requires engaging with how socio-spatial processes reproduce social relations by keeping disabled people 'in their place' (Kitchin, 1998). Marginalisation helps to enforce dependency on specialised provision, and in doing so prevents the exercise of rights typically associated with full citizenship such as privacy, respect and individual choice (Young, 1990, p.54). It has been reinforced during austerity through the framing of those who rely on social welfare programmes, including disabled and chronically ill people, as 'shirkers and scroungers' (Garthwaite, 2011). Such discourses and policy regimes have further served to spatially marginalise disabled people, who often do not conform to hegemonic conceptions of mobile, productive, 'self-activating' bodies (Imrie, 2014). Instead, they relate to wider issues around the place and valuation of disabled people in society, and how issues of inequality and citizenship are materialised in everyday, embodied interactions and (im)mobilities (Gaete-Reyes, 2015). Disabled people sometimes find themselves being obliged to play the 'disabled role', and conform to societal and bureaucratic-administrative labels and classifications, to qualify for the services they require for mobility and access (Porter, 2000). The wider implications of spatial arrangements and the design of environments in relation to society's valuation of disabled people are developed further below.

In addition to the inaccessibility of the built environment, disabled people's exclusion is perpetuated through inaccessible modes of public transportation. As with many material barriers in the built environment, these have been readily identified by disabled activists and those writing from a social perspective, who draw attention to 'transport disability' as "the unnecessary exclusion of disabled people from current forms of transport, especially public transport" (Heiser, 1995, p.49). As already noted, transport exclusion constrains a range of other opportunities. Critically, it cannot be seen in isolation from the wider accessibility of the built environment as a whole, and must be seen as part of a wider journey or transport 'chain' (Salvage & Zarb, 1995a; Wilson, 2003; Jensen et al., 2002; Porter, 2002). An outcome of this is that many transport barriers overlap to a significant degree with barriers identified in the built environment, and can be related to different aspects of the transport chain. For example, a 1995 working paper identified barriers relating to information about service provision, the process of buying tickets and making enquiries, getting to public transport stops, physical access to and inside vehicles, and in-vehicle information provision (Salvage & Zarb, 1995a). An illustrative set of physical barriers described the same year include steps up to and inside buses, narrow gangways, a lack of assistance and absence visual or audio information, inaccessible trains and toilets (Heiser, 1995, p.51). Many of these issues were found to be problematic not only for disabled people, but also for a wide range of other users of public transport (Hine & Mitchell, 2001).

More recently, a 2003 literature review highlighted a range of inadequacies identified in prior literature on the accessibility of public transport, including poor information provision, staff attitudes, transport in rural areas, and disabled people's confidence that the journey would be able to be completed (Wilson, 2003). A 2007 study of wheelchair users' experiences of accessibility in a large city centre found that most who shopped there travelled by car and none used local buses, noting that Britain lagged behind other countries in the provision of accessible buses (Bromley et al., 2007). While the proportion of local buses with an accessibility certificate indicating compliance with low floor accessibility standards[3] has risen from 28% in 2004-5 to 99% in 2020-21 (Department for Transport, 2021), this does not automatically result in greater use or better experiences for disabled people. For example, it there is a tendency for access standards that have been set and intended as a minimum to become ossified as the norm, resulting in a basic standard at the

[3] Disability Discrimination Act PSV (Public Service Vehicle) Accessibility Regulations 2000 (DDA PSVAR 2000 Certificate). PSVAR mandated that public service vehicles be accessible to disabled people by 1st January 2017.

worst acceptable level while reducing the possibility for improvements over time (Tyler, 2002, p.10). Indeed, wheelchair users still face a range of interlinked technological, spatial, and social barriers which restrict their access to public transport (Muscular Dystrophy Campaign, 2009; Muscular Dystrophy UK, 2016; Velho et al., 2016; Rodger et al., 2019; Velho, 2019, 2021).

One aspect of this is that where alternatives to an inaccessible mode of transport exist, they have their own disadvantages. For example, much of the London Underground network is inaccessible to wheelchair users: 89 of 272 stations offer step-free access from the street to the platform (Transport for London, 2021a), but many of these require a manually deployed ramp to board the train and 'step-free' can still involve a step of up to 320mm and a gap of up to 250mm (Transport for London, 2021b). More accessible modes, such as the Docklands Light Railway or London Overground, are only available in certain areas. While buses offer an alternative for many journeys across London, and all are now low-floor with an electric ramp, they are not a panacea: buses are slower than trains, are prone to traffic delays and damaged ramps, and typically have only one wheelchair space. These factors detract from the experience of travelling by bus. For example, the single wheelchair space prevents more than one wheelchair user travelling together and results in friends being forced to split up to wait for the next service, while the loud siren that accompanies the deployment of the ramp on London buses draws unwelcome attention to the disabled travellers and demonstrates how technologies designed to improve material accessibility can in turn lead to other socio-technical barriers (Rodger et al., 2016; Velho, 2019). It is important to note that wheelchair users are not passive in these situations: they develop a range of problem-solving skills and inclusion mechanisms to work around the barriers they face, and contest the disablement they experience (Velho, 2019, 2021). Such contestation is based in their situated knowledge of making their way in the world, and what works to achieve their goals.

Nonetheless, aspects of these experiences of inaccessibility can be hard to articulate and to express to others, including campaigners for more accessible environments and the policymakers who must be engaged to bring them about (Rodger et al., 2016). Transport barriers also have pernicious effects. Research has shown that they contribute to young disabled people's experiences of growing up and becoming independent being significantly different to that of their non-disabled peers, and can lead to isolation, transport anxiety and mobility dependency on private forms of transport (Pyer & Tucker, 2017). While transport

exclusion affects a range of other groups alongside disabled people (Hine & Mitchell, 2001), the overall result of inaccessible forms of public transport is that for many disabled people, access "is often dependent on specialised, residual, modes of mobility [such as Dial-a-Ride], which increasingly resembles a form of post-welfare transit that serves to reinforce spatial inequalities of mobility" (Imrie, 2014, p.19). Such segregated provision restricts disabled people's freedom of choice over their mode of travel, and marks them out as different to a non-disabled majority. As with the inaccessibility of the built environment more generally, this reflects wider societal attitudes towards disabled people, and their marginalisation by hegemonic norms of 'productive' and mobile bodies discussed earlier in this section.

Even studies foregrounding individual framings of disability have recognised the significance of environmental socio-material barriers to powered mobility. For example, a 2004 survey highlighted a range of concerns amongst users of a regional UK powered wheelchair service, which included personal safety and appropriately fastening the chair in vehicles, the failure of ramps and ramp assistance services (Belcher & Frank, 2004). Similarly, a 2019 Australian survey of mobility aid users highlighted a range of material concerns about the accessibility of various modes of transport (Unsworth et al., 2019). A recent literature review noted a range of barriers to disabled people's journeys, including physical access to public transport stops, the provision of inaccessible information, staff attitudes, and the internal material configuration of vehicles (Unsworth et al., 2021). While these works may not be directly in the tradition of the 'geographies of disability' perspective outlined earlier, they reflect many of the same barriers identified by such geographical work.

Although there have been efforts to make places and transport more accessible for disabled people, these are not without their own problems. Universal Design (UD) is one notable approach to design which aims to make "products, buildings and exterior spaces to be usable by all people to the greatest extent possible" (Mace et al., 1995, p.2). In doing so, it seeks to remove environmental barriers, or "environmentally induced handicaps", so as to enable disabled people to "integrate as fully as possible into the mainstream of daily life" (Mace et al., 1995, p.3). Rather than adopting a compensatory approach, in which existing inaccessible designs are adapted to add specialised accessibility features (which may add stigma by marking their users out as different), universal design "seeks to *infuse* accessibility into the design of objects and spaces marketed to the general public" (Connell & Sanford, 1999, p.36). It does this through promoting design principles that focus on, amongst other

attributes, equitability, flexibility, simplicity and intuitiveness (Story, 1998). Although this focus has the potential to address many material barriers, including those in transport and the built environment, it has been critiqued for its optimistic technological utopianism toward issues of access, its emphasis on market discourses and professional expertise as the basis for designing 'better' environments, and its focus on a 'universalism' in design which may not be feasible when confronted by particularities (Imrie, 2012b).

While acknowledging that UD principles encourage the development and implementation of user-friendly design that is focused on disabled people's dignity and independence, it has been described as apolitical, with "little or no recognition of the interrelationships between the social, technical, political and economic processes underpinning building and design" (Imrie & Hall, 2001b, p.16). Yet as has been suggested above, examining underlying social relations is essential in challenging disablement. Technological optimism alone cannot 'fix' disabling environments that are the outcome of, and are rooted in, deep societal structures and relations (Gleeson, 1999a). In addition, universal design strongly positions the people who use these designed artefacts and environments as 'customers', which reinforces a consumer-centric notion of accessibility and does not challenge design professionals nor question their position as knowledgeable experts (Imrie & Hall, 2001b, p.17). This has led to calls for more inclusive processes for designing built environments that engage meaningfully with the diversity of disabled users of space and their different needs (Luck, 2000; Imrie, 2004, 2012a, 2013). The limits of universal design reinforce the notion that 'one size does not fit all' when it comes to bodily forms, despite standards and norms for different 'types' of human (Imrie, 2000c). Given potential incompatibilities in need between those with particular impairments, there may be an inevitable and inherent tension in the strategy of barrier removal (Shakespeare, 2006, pp.46–47). In response to these challenges, Hamraie calls for a "feminist disability theory of UD, based on disability justice, collective access, and interdependence" that involving participatory design "with and by misfitting bodies" (Hamraie, 2013). A practical strategy for universal design should consider the relational aspects of disability, in the form of the interactions between bodies and environments, incorporate many different individual perspectives, and integrate "situated knowledge from disability advocates" alongside that of professional expertise (Lid, 2014, p.1348).

All of the factors described above highlight the importance of considering a plurality of corporeal forms in the design and implementation of the built environment (Imrie & Luck,

2014). Failure to do so perpetuates a status quo where "places continue to be designed with little understanding of the interrelationships between design, disability and space" (Imrie, 2013, p.3446). Just as work on gendered geographies has identified the need to engage with grounded knowledge and practices around mobility (Law, 1999, p.573), so too is it necessary to engage with disabled people's knowledge and understandings rooted in their experiences of place and movement. This is a starting point for identifying and tackling the various socio-material barriers described earlier in this section (Hine & Mitchell, 2001). Building on these insights, this research therefore seeks to engage with individual aspects of disabled people's experiences of socio-material disablement in built environments and transport in their totality. An important aspect of this, touched upon in some of the literature discussed earlier, is the psycho-emotional disablement that is caused by socio-material barriers. The following section explores this aspect of disablement in more detail.

2.3.3 Psycho-emotional disablement and emotional labour

As indicated above, disabled people's physical exclusion from built environments and public transport is not the only consequence of socio-material barriers. Inaccessibility also imposes psycho-emotional disablism on disabled people, who are forced to undertake emotional labour in response to disabling environments and situations. This section explores the nature of psycho-emotional disablism and how it is entwined with the disabling material and social factors discussed above.

It is important to distinguish these psychological aspects of disabled people's experiences, which have been described as the "socially engendered undermining of [disabled people's] psycho-emotional wellbeing" (Thomas, 1999, p.60), from that of a 'psychopathology' of disability rooted in a (biomedical) framing of disability and impairment as individual deficits requiring rehabilitation (Reeve, 2006). Reeve identifies three forms of psycho-emotional or psychosocial disablism, noting that not all disabled people may be affected by them in the same ways, at the same intensities, or even consistently over time. The first of these is disabled people's responses to experiences of structural disability, such as being physically excluded from particular environments. This kind of experience "reminds them that they are different and can leave them feeling that they don't belong in private and public spaces" (Reeve, 2004, p.85). In this respect, exclusionary environments inscribe symbolic messages that send a signal to disabled people that they are different and 'out of place', and which serve to reproduce cultural representations and myths (Kitchin, 1998). This facet of

psychosocial disablement is thus directly linked to how society (de)values disabled people, and serves to compound physical marginalisation by reinforcing a sense of exclusion.

The second aspect of psycho-emotional disablism is through the direct 'acts of invalidation' by non-disabled people when they interact with disabled people, through negative looks, words or other actions. Being in public means being co-present with strangers and subject to their gaze, and those who do not conform to what society as a whole deems to be 'appropriate' or 'normal' appearance and behaviour risk social challenge (Butler & Bowlby, 1997, p.419). Such acts of invalidation against disabled people may be manifested through actions such as staring, unwelcome and/or inappropriate questions, or disablist and discriminatory comments (Reeve, 2004, pp.86–87). They can also extend to physical assault or damage to property, alongside a wide range of low-level harassment (Hall, 2019; Healy, 2020; Wilkin, 2020). The latter, in contrast to more extreme acts of physical violence, may not be widely recognised by the public or in policy spheres as a hate crime (Hall, 2019). Again, this aspect of psycho-emotional disablement is linked to the worth that is assigned to disabled people in cultural discourses, and the ways in which disabled embodiments or comportment are perceived by others.

The final aspect of psycho-emotional disablement is the way in which societal prejudices about disabled people may, in certain circumstances, become internalised by disabled people themselves, affecting not only their immediate sense of self-esteem and self-worth but also directly restricting their conception of who they can be (Reeve, 2004, pp.87–89). This internalised oppression of dominant non-disabled prejudices can sometimes impact on the decisions disabled people take about their lives (Reeve, 2006, pp.101–103). This serves to ascribe an external, societal valuation of a disabled person's capacities or self-worth onto them. Yet again, this is closely linked to cultural representations of disabled people and how society values disabled lives.

It is important to recognise that the structural and psycho-emotional aspects of disabled people's experiences are also often closely entwined. This is exemplified in how wheelchair users described the emotions associated with travelling on London's bus network in Velho's (2019) study: they talked of their happiness at new enabling infrastructure, the stress and anxiety associated with inaccessible journeys, and the difficulties of some interactions with other passengers (Velho, 2019). Moreover, there are complex linkages and feedback loops between different aspects of psycho-emotional disablism itself: a person might be forced to

play the role of a 'grateful disabled person' to obtain the assistance they require, be left feeling unwanted or worthless if their request is rebuffed, and feel angry or embarrassed that an inaccessible environment compels them to ask for assistance in the first place (Reeve, 2006, p.98). Similarly, they may be forced into accepting particular societal or administrative classifications to be considered eligible for the privileges they require for access, even when this diverges from people's own perceptions of themselves (Porter, 2000). Such a mismatch is itself a form of disablement. All of these factors impose hidden labour on disabled people in managing their interactions with non-disabled people in order to make their way in the world, which can come at the cost of damage to their own self-respect and emotional or physical wellbeing (Scully, 2010, p.36). Similarly, as already intimated, the pathways along which psycho-emotional disablism operates are influenced by cultural factors such as how disabled people are represented in the media, which not only influences how disabled people see themselves but also how society perceives them (Reeve, 2006, p.96). The impact of these diverse aspects of psycho-emotional disablism on the wellbeing of disabled people, including wheelchair users, is therefore significant, as is the emotional and indeed physical labour they must undertake to address its effects.

In the face of ableist environments and interactions, and the emotions they engender, wheelchair users therefore adopt a range of strategies to manage their emotions in public. These include using humour to defuse the awkwardness experienced by other people in embarrassing situations (Cahill & Eggleston, 1994). Such work often involves the masking of their own emotions in order to manage the emotions of others. They may, for example, not feel able to give voice to their righteous anger at poor treatment due to personal embarrassment, the risk of retaliation, and societal norms of non-confrontation. There may also be the consideration that in environments which are not friendly to their needs, they cannot afford to alienate non-disabled people whose assistance they may require to overcome barriers. In all of these ways, "wheelchair users commonly assume primary responsibility for alleviating whatever strain occurs in their public relations with strangers" (Cahill & Eggleston, 1994, p.310). Scully highlights the various motivations behind the management of disabled people's self-presentation, including to gain formal or informal support, to maintain relationships with others, to drive social change, and to maintain self-respect (Scully, 2010, pp.30–31). Such management involves physical and psychological labour to control self-presentation, to identify the needs of the other person in the

interaction, and to evaluate and implement strategies to meet these needs. Moreover, this labour has to be concealed (at a personal emotional cost) from others:

> *"[it] is necessarily hidden, because if the manipulation were obvious, and the nondisabled party were conscious of being managed or manipulated, it would defeat the objective of getting the observer to accept the identity or emotion being presented as the reality; and this would in turn compromise the achievement of the ultimate goal (of obtaining services, protecting relationships, and so on)" (Scully, 2010, p.32)*

As the work in this section shows, disabled people undertake substantial psycho-emotional labour in order to successfully make their way through disabling environments, and this labour is very closely linked to the socio-material barriers that these environments present. This implies that strategies which seek to address socio-material disablement cannot simply be technological, but must engage holistically with experiences of mobility and access from the perspective of individual disabled people. This includes understanding the ways in which psycho-emotional disablement is caused by socio-material barriers, and the ways in which some technical 'solutions' to barriers themselves can cause psycho-emotional effects by marking disabled people out as different. A ramp on a bus that is physically accessible but imposes the embarrassment of a loud siren, or compels a difficult interaction with a bus driver, must be considered as part of a wider understanding of an accessible socio-technical system as whole.

2.3.4 Conclusion

The above literature, broadly within or influenced by work on the geographies of disability, provides examples of the persistence, form, and societal context of specific barriers in the built environment and public transport. It shows how, notwithstanding legislation that has mandated and led to improvements in accessibility, disabled people still face considerable socio-material barriers in built environments and public transport. Moreover, it notes that technologies and processes that have sought to address some barriers have led to the emergence of other different barriers. This demonstrates that 'fixing' technology alone will not resolve wider issues of societal relations and the valuation of disabled people. Instead, through the ways in which it links the socio-material outcomes of disablement with the structural factors that underpin it, this work emphasises the need to consider inaccessible environments within broader consideration of how society values disabled people. It further demonstrates the need to consider disabled people's situated experiences holistically, being

attentive not only to issues of physical or material access but also to social considerations, mindful of the psycho-emotional disablement and emotional labour that can be inflicted by socio-material environments and socio-technical systems on disabled people. In turn, this literature highlights the critical importance of listening to disabled people, and being guided by their individual and collective situated knowledges about their embodied experiences of disablement, barriers, and (in)accessible environments. This is imperative even if one seeks to design environments that 'work for all'. In these respects, this work reflects many of the concerns highlighted by the literature in Section 2.2.

2.4 Discussion

The literature described in this chapter provides a theoretical framing and practical context for this thesis. Based on a social understanding of disability and disablement, it shows how socio-material barriers in society disable people whose bodies or comportment does not fit the norm. Disablement is rooted in social and political structures, and cannot therefore be addressed in isolation: transforming the material environment alone will not fully address the barriers experienced by disabled people.

This work has also shown that understanding disabled people's experiences of the built environment and public transport requires sensitive engagement with diverse individual and collective situated knowledges of mobility and access. This means attending to individual stories and experiential accounts, rather than ascribing totalising identities or experiences. These accounts highlight the complexity and nuances of these contexts, which are places of both socio-material and psycho-emotional disablement. It also requires enabling disabled people to craft and convey their own narratives around these embodied experiences, which are rooted in their situated knowledge as powered wheelchair users.

Work in this chapter has also demonstrated the complexities associated with socio-technical systems in the lives of disabled people, including those used for mobility or functional tasks. It has shown how technologies can play both enabling and disabling roles in people's lives, and can be adapted and adopted for a range of expressive and civic purposes. This suggests ways in which disabled people might utilise these technologies to capture aspects of their complex experiences of disablement and convey them to others. However, it has also shown that there are always limits to technological 'solutions', and that new technologies may address some disabling barriers while introducing other new ones.

Mindful of this prior work and contextual framing, this thesis responds to calls for more experientially based accounts of disabled lives (Scully, 2011) through an exploration of powered wheelchair users' experiences of urban mobility. It seeks to understand access and disablement for this group of disabled people in the built environment and public transport, by enabling them to capture and convey their experiences through digital technologies and a 'go-along' method. In doing so it aims to provide an opportunity for these experiences and situated knowledges to be surfaced, and for strategies to convey this situated knowledge to other groups such as policymakers and the wider public to be explored. These are essential first steps of working towards a practical strategy of not only removing socio-material barriers in urban spaces, but also of the wider political and societal ambition of reframing how disabled people are conceived of and valued by non-disabled society. The following chapter describes how my research methodology responds to the issues identified in this literature review.

Chapter 3. Methodology

3.1 Introduction

This chapter discusses my approach to gathering data about disabled people's experiences of mobility. As already set out in the literature review, I start from the premise that it is imperative to listen to disabled people in order to understand their experiences. Powered wheelchair users' situated knowledge (Haraway, 1988) offers insights into the ways that dominant environments and practices may enable or disable them, as well as helping to identify how such environments and practices might be improved. To engage with this situated knowledge requires exploring how participants perceive their experiences and the factors that shape them. It was critically important to attend to these experiences in a sensitive manner, cognisant of my own positionality as a non-disabled researcher.

This chapter begins by explaining my epistemological approach to the research, building on the prior work discussed in Chapter 2. The first section of the chapter frames my choice of the foundational data collection method used in this project: 'go-along' accompanied walks with powered wheelchair users on journeys of their choice. During these journeys, they used a smartphone-based tool to capture video and data about their experiences of mobility, which were then used as a resource for subsequent semi-structured interviews. Together, these two activities formed the first phase of fieldwork, which took place between January and August 2017. Building on this, the second phase of fieldwork sought to bring these individual experiences into dialogue with other powered wheelchair users. Data and findings from the first phase of research were used as a resource for group workshops, which were held via Skype with some of the same participants during February 2018. This first section of the chapter provides an overview of the rationale for all fieldwork activities, and how they worked together within the project.

The second section of the chapter describes in more detail the methods that I used during the first phase of fieldwork: the go-along walks and individual semi-structured interviews. It describes the design considerations for "JourneyCam", the smartphone-based tool used by participants; the software and hardware that comprised this tool; and the overall method of using JourneyCam for go-alongs and semi-structured interviews. The second phase of the fieldwork is described in Chapter 6, where I show how the workshops helped validate findings from the first phase of fieldwork and functioned as a forum where disabled people

shared their situated knowledge and expertise. As the method used is closely tied to the findings from the second phase of fieldwork, these are discussed together in Chapter 6.

The third section of this chapter describes the recruitment of participants to this project, beginning with revisions to the focus of the project that were necessitated by practical challenges that I encountered. An overview of the participants is then provided, along with a short descriptive profile of each participant. I then give a detailed account of the go-alongs using JourneyCam and the individual semi-structured interviews which comprised the first phase of fieldwork, followed by a discussion of the data that was gathered and the analysis process I undertook. Finally, the chapter concludes with reflections on ethical issues in this research, including the presumption of vulnerability that is found in formal ethics processes, specific challenges I faced during fieldwork, and a discussion of my own positionality as a non-disabled researcher conducting research about the experiences of disabled people.

3.2 Research Questions

As described in the Introduction, this project was guided by three slightly revised research questions due to challenges with my initial project plan and my own better understanding of the nature of barriers faced by powered wheelchair users. These revised questions were:

- **What is the role of digital technologies in supporting powered wheelchair users to capture and articulate their experiences of mobility and accessibility?**
- **What are people's motivations behind sharing their experiences of the built environment, and how might technologies be used to enable such sharing?**
- **How can personal experiences of mobility and accessibility be used to inform policy and service provision?**

Although the focus changed to working with powered wheelchair users rather than people with neuromuscular conditions, the core issues that I was seeking to understand remained broadly the same: to understand experiences of mobility and accessibility, to explore how these might be captured and shared and the role that digital technologies could play in this, and to investigate how these experiences could inform policy makers and service providers. As such, my underlying epistemological and methodological approach remained unchanged: I aimed to work with participants to understand their experiences from their perspectives, as explained in the following section.

3.3 Epistemological and Methodological Approach

This research aims to explore disabled people's experiences of mobility and public space, and to investigate ways in which these experiences might be utilised to bring about more accessible environments and interactions. In doing this, I draw upon ideas from feminist epistemology on the nature of situated knowledge, the inherent value of starting from marginalised lives, and the importance of bringing situated perspectives into dialogue on important social issues such as the full inclusion of disabled people in society. I also draw on feminist disability research, which emphasises both the necessity of understanding disabled people's experiences of disablement, and enabling them to convey such experiences in their own terms.

I begin from the premise that disabled people, including powered wheelchair users, have particular forms of knowledge and expertise that are grounded in their experiences. The situated nature of all knowledge has been identified by theorists such as Harding (1993), who highlight the unsustainability of a detached, supposedly objective 'view from nowhere' and argue instead that our social situatedness both enables and constrains what we can know. Societies are shaped by those at the top of social hierarchies, whose critically unexamined position results in a limited ability to critique the very nature of those societies (Harding, 1993, p.55). By contrast, starting from the experiences of marginalised groups offers the opportunity to ask more critical questions about received beliefs. This enables the possibility of a 'strong objectivity' that brings standpoints into dialogue with each other, whereby situatedness is itself a resource for maximising objectivity (Harding, 1993, p.69).

The notion that bringing different standpoints into dialogue might result in better outcomes has been further developed by Young (2004). She describes how including a wide range of social perspectives in democratic discussions and decision-making processes increases the collective knowledge available, helping to shift people's perspectives away from self-regard towards accounting for others' legitimate interests. Objectivity in this context is collectively constructed from partial, situated perspectives. Because it requires an exchange of views, particular perspectives must be made understandable to those who do not share them. This contextualisation is particularly important for those with power, such as non-disabled people in a predominantly non-disabled society, who might otherwise take their own experiences as uncontroversial norms. This bringing together of different perspectives is what Haraway describes as 'feminist objectivity', the interplay of different "situated and

embodied knowledges" (Haraway, 1988, p.583). These situated knowledges are explicitly partial and located: they do not try to pull off the 'God trick' of detached objectivity. Moreover, bringing situated knowledges into dialogue offers at least the possibility of solidarity and of shared conversations between different groups. Haraway also notes how the knowledge of subjugated groups in society offers a 'preferred' positioning, as these groups are more likely to be aware of the interpretative and situated nature of knowledge (Haraway, 1988, p.584).

These feminist authors highlight the value of explicitly engaging with the situatedness of particular, typically marginalised knowledges, to better understand society itself. To begin from disabled people's lives enables us not simply to understand those lives better but also to ask critical questions about the wider nature of society and the relationship between disabled and non-disabled people. In the context of this research, engaging with the situated knowledge of individual powered wheelchairs users requires examining how their experiences, interpretations, and actions as a marginalised group in society are shaped by wider structural factors.

Building on a key insight from the social model, that structural barriers create disablement, disabled researchers have likewise identified how knowledge about disability is intrinsically linked to the conditions of its own production. In the context of the historical exclusion of disabled people from research processes, they have argued instead for an explicitly political 'emancipatory paradigm' of disability research, in which disabled people's inclusion is itself a way of transforming the social relations of research production. This approach highlights the importance of critically assessing society, contending that "it is not disabled people who need to be examined but able-bodied society… emancipatory disability research [should examine] the disablism ingrained in the individualistic consciousness and institutionalised practices of what is, ultimately, a disablist society" (Oliver, 1992, p.112). Adopting a social model understanding of disability enables research to "have less to do with the ability of disabled people to 'cope with' or 'adapt to' their situation and more to do with the identification and removal of barriers" (Stone & Priestley, 1996, p.702). Feminist disability scholars have highlighted the importance of disabled people's accounts of their experiences, while linking them to and retaining a focus on structural barriers and societal disablement. Morris highlights the importance of the personal, subjective experiences of disabled people and in particular of affording them control in representing these experiences (Morris, 1992).

This notion of voicing individual experiences as part of telling one's story is itself a political act that challenges how knowledge is produced and emphasises its situatedness (Thomas, 1999, pp.68–69). Indeed, contesting ableist representations of their experiences by showing their own perspectives is itself a form of activism by disabled people (Parent, 2019, p.201).

My research draws upon these epistemological considerations, which together emphasise a social understanding of disability that starts from the experiences and situated knowledge of powered wheelchair users. The latter is essential in countering ableism, as part of a commitment to identifying and addressing structural barriers that affect disabled people and underpin the social model. To start from disabled people's experiences enables us to ask the most critical questions about the way things are, and to build on disabled people's situated knowledge of ways that these things could be different. Moreover, to not to engage with this knowledge and expertise is in itself an act of epistemic injustice with real consequences, as to "exclude[e] a marginalised group's knowledge from the common epistemic stock is a persistent and powerful way to ensure that its members stay pushed to the edges of social life" (Scully, 2018, p.20). An epistemological framing that values powered wheelchair users as legitimate 'knowers' in this manner therefore necessitates a methodological approach that recognises and engages with the situated nature of their experiences of mobility, and which seeks to assist them in telling their stories.

3.4 Methodology

3.4.1 Overview

In light of the epistemology discussed above, I wished to ensure that the research design I adopted would enable powered wheelchair users to convey their situated knowledges as disabled people, and their particular experiences of mobility. I therefore sought to ground the process of data collection in participants' individual experiences, and to provide them with an opportunity to highlight and discuss on their own terms the aspects of these experiences that held particular meaning for them. The process of doing this would also be an initial step in thinking more widely about how complex, individual experiences of mobility amongst different powered wheelchair users might be brought into conversation with each other, as part of a process of the collectivization of experience.

This necessitated a two-phased approach to conducting fieldwork, as described above. The following provides an account of the first phase of the fieldwork, in which I sought to explore together with participants their experiences of mobility as powered wheelchair users by

adapting and expanding the 'go-along' approach (Kusenbach, 2003) and data-led semi-structured interviews.

3.4.2 The 'go-along' as a research method

Given the focus of this research on experiences of mobility amongst powered wheelchair users, I begin from the premise that 'going along' with them as they travel offers a starting point for understanding both their spatially located experiences and their experiences of mobility (Kusenbach, 2003, 2017). Not only is human knowledge inherently socio-spatial (Anderson, 2004, p.254), but within the wider 'new mobilities turn' in the social sciences (Sheller & Urry, 2006) mobility itself is understood to influence how people both engage with and know the world: "being in motion is somehow different to being stationary, both in terms of the kinds of engagement with the world that it prompts, and the kinds of knowledge and identities that it therefore engenders" (Hein et al., 2008). The sharing of conversations in place and at the participants' own pace attunes researchers to the embodied nature of social dynamics: when walking, for example, "walkers' relationships with cities are fraught with obstructions, interference, fear, hurt and sadness. At the same time, privilege is paced out through cities, with some bodies able to go wherever they want, whenever they want" (Bates & Rhys-Taylor, 2017, p.3). Accompanying and conversing with people who do not enjoy such privilege, such as powered wheelchair users, offers an insight into their experiences. Adopting a 'go-along' approach allows not only for the observation of participants' interactions with their social and physical environment, but also the discussion of these experiences with them in situ as we travel together. This combination of observing spatial practices, whilst simultaneously accessing their experiences and interpretations about those practices has been identified as a unique advantage of the go-along approach over sedentary interviews or observation alone (Kusenbach, 2003, p.463). Go-alongs can provide access to topics that are otherwise very difficult to uncover, such as how a person's practical knowledge or expertise helps guide their spatial practices, or how certain locations may hold particular relevance to them.

What characterises a go-along and makes it particularly suited to this project is that it also "refers to a particular kind of relationship between researchers and research participants, and is linked to theoretical ideas on the ways and possibilities of knowing" (Kusenbach, 2017, p.348). A go-along allows a researcher to be "led along a spatialized journey… learning about the local area via the interplay of the respondent's ideas and the researcher's own

experience of the respondent's environment" (Carpiano, 2009, p.267). In asking participants to literally guide them on a journey, a researcher recognises the participant as a situated 'knower' in that spatial and temporal context. This is particularly the case where the routes and timings of the journeys are determined by the participants, rather than the researcher (Kusenbach, 2017). Anderson (2004) also argues that go-alongs can create a bond between researcher and participant that can facilitate conversations, in turn helping to overcome the power dynamics of a traditional interview.

Although many applications of the go-along approach have focused on walking as a mode of mobility, it can be used in a range of contexts in which researchers accompany participants (Kusenbach, 2017, p.345). However, this approach has seldom been applied to the context of wheeled mobility. A 'wheeling interview' approach was successfully adopted by Parent, a wheelchair user herself (2016, 2019). She especially highlighted the collaborative dynamics of these interviews, and complexities of go-alongs that brought together various different ways of wheeling, walking and communicating. She found that she "did not learn so much about how participants move in their city as much as I learned how we move together. My presence changed everything. The participants did not move like they usually do. They moved with me. We moved together. Talking while moving also shaped how we move together" (Parent, 2016, p.528).

Parent's comments highlight a potential limitation of the go-along approach in seeking to understand participants' experiences, namely that the very presence of the researcher will alter the dynamics of the situation. As such, the participant is unlikely to behave as they would had the researcher not been present. This is particularly the case where a participant may be explaining particular experiences to the person going along with them. Even if accompanying someone on a trip they would have been making anyhow, "[go-alongs], like interviews and even participant observation are always 'contrived' social situations that disturb the unfolding of ordinary events…[they] intentionally aim at capturing the stream of perceptions, emotions and interpretations that informants usually keep to themselves. The presence and curiosity of someone else undoubtedly intrudes upon and alters this delicate, private dimension of lived experience" (Kusenbach, 2003, p.464)

There is also the possibility of research participants giving performative responses, which was perhaps more likely given the relatively brief nature of the interaction between us in this project compared to longer-term ethnographic research. In addition, accessibility is an

issue of significant importance to these participants, which may be manifested in the things they chose to show me and the emphasis they put on particular aspects of their experience. In this context, my presence offered a conduit through which a conscious political message about the nature of disabling barriers might be delivered. My reflections and analysis of the data were therefore conscious that such factors could shape the research process.

A researcher's presence is also something that others present in a particular situation, such as members of the public or transport staff, will try to account for and understand. Given societal attitudes towards disabled people, it is possible or even likely that other people would perceive me as the personal assistant of a wheelchair-using participant. In turn this could lead to different kinds of interactions than if I were not present, such as staff speaking to me rather than the participants themselves, reflecting widespread ableist presumptions of disabled people's 'global epistemic incapacity' (Scully, 2018). The interactions that others have with us as I go along with participants may therefore not be representative of the interactions that would take place in my absence. Nonetheless, situations in which a bystander interacts with a personal assistant or co-traveller rather than the disabled person themselves are relatively common, so if these were to happen during the fieldwork it would not be unrepresentative of disabled people's experiences.

The presence of a researcher during a go-along therefore influences the social setting of the research in several ways, and affects how others including the participant themselves behave in that situation. Yet as discussed above, this is not unique to go-alongs. While I acknowledge the possible limitations that the presence of a researcher creates I feel that the benefits of being able to accompany disabled people in their 'mobile habitats' are a critical strength of the go-along approach for this research topic as they facilitate access to powered wheelchair users' experiences and practices "as they unfold in real time and space" (Kusenbach, 2003, p.478). This is not to suggest that this will uncover an 'objective truth' about disabled people's experiences of mobility; rather that I will witness and engage in conversation with participants about their experiences as they happen, enabling us to co-construct meaning in that spatial context.

Finally, there are a range of practical challenges associated with the go-along method. One is the requirement to be able to record on-the-go interactions between the researcher and the participant alongside spatial location (Carpiano, 2009). This has become easier over the past decade, with the widespread adoption of smartphones that include geolocation and audio-

visual recording features. Other challenges of the go-along method are associated with environmental factors, such as inclement weather or poor lighting, which can make conducting a go-along difficult or even impractical, as well as uncomfortable for the participant. Such environmental factors may cause particular challenges for wheelchair users (Lindsay & Yantzi, 2014; Ripat et al., 2015, 2018), and have been highlighted as affecting mobile video-making practices by wheelchair-using activists (Parent, 2019). In addition, there are various technical challenges associated with conducting interviews on the go with wheelchair users, including background noise and difficulties mounting of recording equipment on participants' wheelchairs (Parent, 2016).

3.4.3 'JourneyCam': digitally supported go-along journeys

It is worth emphasising at this point that go-alongs and other 'mobile' methods are not the only way of accessing people's experiences of mobility. Merriman cautions against an over-reliance on mobile methods, noting that while co-presence can provide a beguiling illusion of authenticity and closeness to an experience, it does not fully replicate it: one person's experience of going along with someone will not be the same as another's (Merriman, 2014). He calls instead for a plurality of methodological approaches to studying mobilities. Yet go-alongs need not happen at the expense of other forms of data collection, such as participant observation or interviews; indeed, their respective strengths and perspectives accumulate when they are used in combination (Kusenbach, 2003, p.465). I therefore chose to combine the go-alongs with post-journey semi-structured interviews, in which I would discuss with participants our journeys together and their wider experiences.

A key advantage of interviews as a method is that they enable a researcher to explore participants' beliefs around specific events or practices (Lamont & Swidler, 2014). This makes them well-suited to exploring how powered wheelchair users perceive and understand their experiences of mobility and access, and how they account for these experiences in relation to society as a whole. In the context of exploring disabled people's situated knowledge, the meanings that participants ascribe to their experiences are critically important. While I may gain an understanding of some socio-material barriers through observing the journeys of powered wheelchair users, it is only through the dynamic of talking with them about their experiences that I can gain an insight into what these experiences mean to them.

Interviews can also be augmented through the use of prompts such as photographs, which can help elucidate rich reflection from participants (Harper, 2002). Visual imagery generated by participants themselves can give particular insight into the significance of specific events or situations in people's lives (Clark, 1999; Clark-Ibáñez, 2004). Participant-collected visual imagery can provoke detailed accounts of the context in which it was captured and the meanings ascribed to that situation, as well as serving to refresh memories and unearth latent patterns of behaviour (Van House, 2006). Moreover, different kinds of prompts can lead to particular kinds of reflection and discussion in interviews. For example, rediscovering forgotten photographs can prompt a reinterpretation of their meaning in people's lives (Frohlich et al., 2013), while augmenting still images with audio can bring them to life, providing additional context and triggering specific memories (Frohlich & Tallyn, 1999; Frohlich, 2015).

Wearable 'life-logging' tools have likewise shown that the types of data captured, and the qualities of that data, affect the reflective practices that are undertaken around them (Hodges et al., 2006; Lindley, Harper, et al., 2009; Lindley et al., 2011). Videos can be particularly evocative, as they go beyond the visual realm and evoke sensory aspects of experience through sound and movement (Bates, 2014, p.1). Videos of everyday life and movement can enable particular forms of reflection and communication about these experiences. Pink has described how 'walking with' video can enable embodied communication about, empathetic understanding of, and representations of other people's perceptions of their environment (Pink, 2007). The video that is captured by body-worn cameras is not simply a record of experiences of mobility; rather it has the capacity to generate new knowledge by creating a video 'trace' that enables "a process of reflection, discussion and understanding" around those experiences (Sumartojo & Pink, 2017, p.40). The use of such videos captured by powered wheelchair users offers the possibility for them to reflect on and discuss their experiences of mobility with a researcher, and to create new understandings of those experiences.

Other forms of geographic data have also been used to prompt reflection during interviews. GPS-captured location, for example, has been shown to add spatial context that is helpful in understanding people's experiences of moving through their environments (Evans & Jones, 2011). As well as video clips, I therefore also sought to capture supplemental data relating to location and movement, recording the GPS location of each video as it was taken. I hoped

that when this data was later plotted on a map, it would help orientate the participant to the places they had travelled through as they captured each video, and be a resource for conversation about those places. In addition, given the significant role played by different material surfaces in shaping wheelchair users' experiences of mobility (see e.g. Imrie & Kumar, 1998; Matthews & Vujakovic, 1995; Bromley et al., 2007; Matthews et al., 2003; Beale et al., 2006) it is possible that providing a visual representation of these surfaces through captured data about the bumpiness of travelling over them could additionally prompt reflections.

The research discussed above demonstrates the value of in situ engagement, and especially 'going along', as part of a process of knowledge generation about how people experience mobility and place. It also shows how technologies that capture aspects of such experiences, such as photography, life-logging, and video, can help people to reflect and discuss these experiences with others. I sought to extend this previous work by adopting an approach that combined the strengths of these two methods: go-alongs, during which participants led me on journeys of their choice, and sedentary, semi-structured interviews that drew upon the visual and spatial data captured by participants to facilitate rich discussion. I anticipated that these prompts, which directly linked to the lives and geographically-rooted experiences of individual powered wheelchair users, would help stimulate deeper reflection and discussion which could overcome some of the disadvantages of a static interview (Kusenbach, 2003, p.463). The static nature of the follow up interview would also help to address some of the practical difficulties associated with a go-along interview such as background noise.

I aimed to bring together 'going along' with participants to explore their experiences in situ, with post-journey reflections around the place-based visual media and data that they had captured during these journeys. This required me to adopt a technological approach that would enable the capture of video, location and movement data while on accompanied journeys with powered wheelchair users, and permit subsequent reflection on that data. Because off-the-shelf technologies did not provide these features and had accessibility barriers, I created JourneyCam, a bespoke tool for this purpose.

3.4.4 JourneyCam design considerations

JourneyCam is a smartphone tool to enable powered wheelchair users to capture data about the journeys they make. It consists of hardware and software elements that work together to permit the capture of short video clips, alongside supplemental accelerometer and GPS

data, and to arrange these data for later review. Following a discussion of my initial ideas and specification for the tool, I jointly designed JourneyCam with my Open Lab colleague Dan Jackson, who coded the iOS application and Python scripts which together make up the JourneyCam software. The key design considerations were that JourneyCam should enable the capture of both video and metadata whilst on-the-go, be accessible to powered wheelchair users, and permit the capture of unanticipated events or situations. These aspects are discussed in more detail below.

The default camera applications in smartphones capture the location a photo or video recording is initiated, not a trace showing the movement of the phone over time. Likewise, at the time of planning this research in early 2016, GoPro cameras did not record the GPS trace of the videos they captured[4]. This, as well as data about the bumpiness of the surfaces, could however be captured using the built-in accelerometer in a modern smartphone through a custom application. Finally, as described in more detail below, I was interested in enabling participants the ability to selectively capture things which had 'just happened', not only things that were about to happen. Off-the-shelf technologies did not offer this feature at the time of conducting this research, though the ability to capture 30 seconds of footage prior to the shutter being pressed has at the time of writing this thesis been added to the latest flagship GoPro camera (GoPro, 2020).

At the time of planning this research, off-the-shelf technologies for mobile video capture had variable and often limited accessibility for disabled people. Previous research I had undertaken with a charity campaigning for accessible transport highlighted the challenges of generating evidence around complex lived experiences of mobility (Rodger et al., 2016). In line with the literature discussed above, campaigners explained that video recordings might aid with this process. One participant in that project said they would like to just 'whip out their phone' to capture a video of what was going on around them. However, to do this required rapidly manipulating both the physical device and its software, which made such a possibility inaccessible to him. His experience reflects previous work on the configurations of particular embodiments and standardised technologies (Star, 1990; Moser & Law, 1999), and on the inaccessibility of smartphones for people with motor impairments both generally (Naftali & Findlater, 2014) and relating to mobile photography (Mott et al., 2018). Powered wheelchair users' embodiments may be incompatible with these devices' small, fiddly user

[4] The ability to capture GPS traces was added to the GoPro Hero 5 Black in autumn 2016.

interfaces, an issue compounded by the wheeled context in which they are used (Carrington et al., 2013, 2014). Meanwhile, GoPros use “uber-ablist” imagery to appeal to a core target demographic of non-disabled extreme sports enthusiasts; with little representation of disabled users “the company’s videos position disability and an event-worth-wearing-a-camera-to-record as mutually exclusive categories” (Rice, 2017, p.204). Despite this, disabled people have repurposed these wearable cameras to capture aspects of their lived experiences of mobility, though such reuse requires adaptability and creativity, and can pose unexpected challenges such as finding mounts that are accessible to disabled people who are not GoPro’s target audience (Parent, 2016, p.525). These factors underlined the importance of making JourneyCam as accessible as possible.

A linked issue is that if participants had to manually commence a recording they might miss part of something that they wished to capture, and it would be unrealistic to expect them to anticipate all unexpected situations and pre-emptively begin a recording in advance. We thus wished to enable users to ‘retrospectively’ capture something that had just happened. Recording an entire journey would have removed this operating burden from the user (Kalnikaite et al., 2010). However, reviewing the large amounts of data gathered by such an approach is time-consuming, and continuously recording entire journeys raises privacy concerns. I wished to afford participants as much control as possible over the process of data capture, as well as to minimise non-essential data that was collected. JourneyCam was therefore designed to enable participants to take an active role in video capture, through a purposeful interaction to commence video and data recording.

JourneyCam thus modifies a technical approach used by ‘dash cams’, mounted cameras that record a journey from the point of view of a vehicle driver. These typically use a loop of video that is overwritten when the device recording capacity or a predefined time period is reached. Extending this principle, we designed JourneyCam to capture footage through the use of a short temporary video loop, which is discarded unless the user makes the explicit decision to save it by operating a trigger button. The explicit intent of initiating a recording also acts as a natural marker for indexing and subsequent retrieval. JourneyCam is therefore designed to achieve a balance between enabling accessible and purposeful recording of events, while limiting unnecessary recordings. The use of a video loop also permits both ‘retrospective’ and ‘prospective’ recording: participants can capture both anticipated and unanticipated events. Recording is initiated by the participant pressing a Bluetooth button,

which saves the contents of the loop of footage at that moment in time (capturing events that took place immediately beforehand). The recording continues for a short period of time after the point of activation. Initial testing with the first two participants led us to set the former 'pre-roll' period to 60 seconds, and the latter 'post-roll' period to 20 seconds. Participants can extend the duration of the recording through additional presses of the Bluetooth button, which enables them to capture an ongoing event as a single video clip.

3.4.5 JourneyCam hardware and software

JourneyCam consists of hardware and software components. The former includes a smartphone (Apple iPhone 5s) and case, a clamp and phone holder to attach it to the user's wheelchair, and a Bluetooth trigger button used to activate recordings (Figure 1). Software consists of smartphone application to capture video and data recordings, as well as data processing and visualisation software to support post-journey sharing and discussion.

Figure 1: JourneyCam hardware: clamp/phone holder, Bluetooth button, and iPhone 5 in case

Once the JourneyCam hardware is securely mounted on a wheelchair in a position of the user's choosing using the phone holder and clamp (Figure 2), the software is started and they can begin their journey.

Figure 2: A common JourneyCam mounting position was level with the wheelchair armrest or control stick

During the trip, JourneyCam records GPS and accelerometer data. These add spatial and geographic context to the video clips, allowing the latter to be displayed alongside location and velocity on an aerial map in Google Earth (Google, n.d.). After each journey, the JourneyCam data are downloaded to a laptop. These consist of two comma separated value (CSV) files containing location and movement data, and one video file for each clip the user captured. If JourneyCam was paused (such as when taking a lunch break) this results in several sets of data.

The files are processed with Python scripts[5] to generate a GPS track for each journey showing location over time, which are stored as KML[6] files. Each video is geolocated along the GPS track, and to aid in quickly identifying specific clips when visualised, the Python scripts generate thumbnail images for each video. They also store the accelerometer magnitude data as an additional data track alongside the users' location and time. The data is then imported into Google Earth, where the GPS tracks show users' journeys with a clip of each of the captured videos located along the route at relevant waypoints (Figure 3).

[5] Python is a programming language often used for processing text files (Python Software Foundation, 2021).
[6] Keyhole Markup Language, a standard format for geographic annotation data (Open Geospatial Consortium, 2021).

Figure 3: Visualisation of one participant's route through an urban area, showing thumbnails of each video clip at waypoints along the journey where they had captured video data. Each thumbnail could be clicked to play the video clip.

The semi structured interviews that take place with JourneyCam users after their journeys are therefore directly structured around the geo-located data that they collected on those journeys. This enables participants to draw upon a range of different information when reflecting on their experiences: not only the content of the video clips they captured, but also the spatial and temporal sequence of those clips accessed via an interactive aerial map of the places they had passed through. The accelerometer data is also available as a graph within Google Earth. The visualisation also enables participants to consider the collation and presentational aspects of the data they collect, and how that data might be reviewed, used, and shared with others. Together, these provide users of JourneyCam with rich prompts for reflection and discussion in the context of the interviews.

Both the hardware and software aspects of JourneyCam were therefore designed to enable accessible control of video and data capture for powered wheelchair users while on a 'go-along' with a researcher, as well as allow for rich prompts in subsequent discussions around this data. This aimed to ensure that the go-along and interview fieldwork would build on the strengths of each method identified in prior literature, and contribute to enabling participants to share their situated knowledges about mobility and access.

3.5 Recruitment and Participants

3.5.1 Recruitment

Recruitment took place in two phases: initially working closely with a UK charity, Muscular Dystrophy UK (MDUK), before recruiting participants directly. This dual approach was the result of challenges associated with establishing recruitment through a charity, and delays to the development of JourneyCam.

Phase 1: Working primarily through a partner charity

I had originally intended to work with and recruit participants through a partner charity, Muscular Dystrophy UK (MDUK), and their young campaigners group Trailblazers (Muscular Dystrophy UK, 2021; Trailblazers, 2021). Before my Ph.D. I worked in research in rare neuromuscular diseases and knew that charities like MDUK campaigned on issues including mobility and access for disabled people. During my M.Res. in summer 2015, I worked with Trailblazers to understand how they campaigned around accessible transport (Rodger et al., 2016). This catalysed my interest in framing my Ph.D. research around this topic, as I knew how significant it was in disabled people's lives. Having built up a good relationship with the charity I hoped to continue working with them, and my initial ethics application was on this basis. Appendix A: Original project documents contains the project information sheets, debriefing sheets, and consent form associated with this application. This ethics application and project plan was based on my intention to conduct fieldwork with MDUK's primary stakeholders, people living with neuromuscular conditions, in North East England and was approved on 5th August 2016.

However, I faced several challenges to this approach to recruitment. During summer 2016, JourneyCam development took longer than anticipated due to resource constraints within Open Lab. Due to this, a planned workshop organised alongside an existing Trailblazers meeting on 13th August 2016 in Newcastle, where I had originally hoped to show and discuss JourneyCam with potential participants, was redesigned to include card-sorting exercises around possible barriers to accessibility. Approximately ten people had been anticipated but none attended, and the only people present were the MDUK organiser and a Community Relations representative from the local transport authority. Further attempts to recruit participants through MDUK and Trailblazers during August and September 2016 were unsuccessful. I was unable to establish the reasons for this, but I recognise that charities have multiple priorities and limited resources.

Phase 2: Recruiting powered wheelchair users directly

In light of these challenges I took the decision, in consultation with my supervisors, to adapt my research and my recruitment approach. First, I chose to widen my focus to work with anyone who used a powered wheelchair for mobility. This was informed by my recognition, through engaging with work in disability studies, that the significant factor in experiences of mobility amongst people with neuromuscular conditions was the shared socio-material barriers that affected all powered wheelchair users. Focusing on the shared technology that these disabled people used for mobility also avoided an unintentionally medicalised framing of disability. In addition, as a pragmatic issue I also sought to recruit participants directly from across the United Kingdom.

These decisions had the potential benefit of increasing the number and breadth of experiences amongst participants. While I aimed to work with participants flexibly, leaving the level of participation open to them, to take part in a journey and interview was time-consuming and I recognised that only some of those who expressed an interest would ultimately take part. Given the widespread nature of access barriers (Department for Transport, 2018), I also hoped that working nationally might provide an insight into a wider range of experiences. I gave this revised focus the name “Journeying”.

This changed focus led to my revision of the research questions which guided this project, described in Section 3.2. The changes also required a revision to ethical approval, granted in November 2016. The revised and simplified information sheet, debrief sheet, and consent form are provided in Appendix B: Revised documents (Journeying).

Notwithstanding the changed research focus described above, I was conscious that many people with neuromuscular conditions use powered wheelchairs for mobility, and knew from my career and my work with MDUK and Trailblazers that social issues like accessible environments remained a focus of campaigning and activism. As an initial step in publicising the research, I therefore approached several UK charities with whom I had good working relationships, including Muscular Dystrophy UK (MDUK) and Trailblazers, Spinal Muscular Atrophy UK (SMA UK), and Action Duchenne. In each case, I asked if they would publicise the project via their email lists, websites, and/or social media channels. I also contacted the registry curators at the TREAT-NMD Network with whom I had previously worked, to ask if they would be prepared to circulate information about the project via email lists and to their

charity partners. Examples of communications are provided in Appendix C: Example letters to charities and neuromuscular registries.

In addition, I created resources to provide interested parties with further details about the project. This included a website with background information and an explanation of how to take part (Appendix D: Project website), as well as Twitter and Facebook accounts (Appendix E: Project Twitter and Facebook profiles). The latter were used to promote the project, and to direct prospective participants to the website. Finally, I created A4 and A5 flyers to hand out at in-person events, which I had professionally printed (Appendix F: Project flyers).

These outreach efforts led to the research being promoted by several organisations via their websites, social media, and email lists (Appendix G: Example publicity). These included the MDUK and SMA UK websites and social media feeds, and a blog post by Limitless Travel, a travel agency providing accessible and disabled-friendly travel. My social media posts and engagement were also picked up by various other organisations including Transport for All, a charity focused on accessible travel, and several individuals with an interest in accessible travel. In addition, I attended two events run by Trailblazers in York and (19th November 2016) and London (28th November 2016), where I gave short informal presentations about the project, handed out flyers, and answered attendees' questions.

All of these efforts were aimed at ensuring as many participants had the opportunity to take part as possible. However, it was hard to gauge the relative effectiveness of the different recruitment strategies. In several cases, organisations who agreed to publicise the project did not let me know when they did so, or following initial interest in publicising the project did not respond to follow ups. I recognise that charities especially have limited resources and did not wish to put them under additional pressure by repeatedly chasing them.

In addition, the routes through which participants reported finding out about the project were varied and sometimes unclear or even interwoven. Several said they heard about the research via charities, came across it on social media, or were forwarded information by friends. As noted above, my social media posts were amplified by several organisations. Overall, however, the people who took part were generally highly motivated about accessibility, with the majority having been in some way involved in campaigning or activism around these issues.

Potential participants were invited to email me on a dedicated project email account hosted by Newcastle University. I replied with a short email including the project information sheet

and explaining the next steps. If they expressed continued interest, I arranged an informal phone chat to discuss the research and answer any questions. Some participants also used this opportunity to quiz me about my understanding of disability, being concerned that I understood it in social model terms. This issue, of having the 'right' politics, is one I will return to in Section 3.8 where I discuss my positionality as a non-disabled researcher. This phone call also enabled the logistics of fieldwork to be planned co-operatively between us. I tried to make this as flexible and convenient for the participant as possible. I was conscious, for example, that when recruitment began it was the start of winter, and some participants would find taking part in outdoor fieldwork challenging or even impossible in poor weather. As we could not control such factors, I was keen to ensure that there was flexibility around aspects that we could control in order to make participation was as easy as possible.

This sometimes led to logistical challenges: I was travelling by public transport to work with participants around the country, sometimes scheduling to work with several people within a few days of each other in a particular area. Although I did my best to accommodate any last-minute rearrangements caused by their personal commitments or unexpected health issues, it was not always possible to do so. For example, one participant in London cancelled due to illness when I was already on the way to our meeting point. Another had to postpone with only couple of days' notice due to a forecast of torrential rain, which would not only have made fieldwork very challenging but posed a direct threat to their health.

3.5.2 Participant overview

I was contacted by 34 potential participants expressing an interest in the research, of whom fifteen took part in fieldwork between January and August 2017. Thirteen took part in journeys and interviews. Two participants did not undertake journeys and only took part in interviews for health reasons.

Of the fifteen participants, thirteen were current users of powered wheelchairs, while one was no longer a wheelchair user due to the effects of their impairment and one used a manual wheelchair with power-assisted wheel hubs. While two participants did not provide their exact age, the majority were between 30 and 60 years old. Although some had used powered wheelchairs their whole lives, others previously did not use a wheelchair at all, and/or had used manual wheelchairs or mobility scooters before moving on to a powered wheelchair.

Summary demographics of each participant and their involvement are provided in Table 1, followed by short profiles of each participant. Pseudonyms are used in all cases. It is worth noting that the recruitment approaches I adopted are likely to have influenced the sample of people with whom I worked: for example, several were people living with neuromuscular conditions despite widening recruitment to all users of powered wheelchairs, and all had an active interest in accessible transport and environments.

NAME	GENDER	AGE	UK REGION	PARTICIPATION			JOURNEYING FIELDWORK						INTERVIEW LENGTH (MIN)	RECRUITED
				Journey	Interview	Workshop	Environments traversed	Date	Mode of Transport (if used)	Fieldwork Duration[7]	Footage Duration	Number of clips		
DAVID	M	50-59	London	Y	Y	Y	Urban	January 2017	2x Bus, London Underground	1h 50m	26m	39	114	Unknown
AMBER	F	30-39	Yorkshire and the Humber	Y	Y		Urban	July 2017	Bus	1h 9m	13m	6	169	Friend
JAMES	M	40-49	South West	Y	Y	Y	Urban/semi-rural	May 2017		2h 35m	49m	32	225	Charity
MATTHEW	M	30-39	South East	Y	Y	Y	Urban and intra-urban	January 2017	Train, bus	3h 12m	10m	14	55	Charity
TOM	M	60-69	London	Y	Y	Y	Urban/semi-rural	February 2017	Train (x2), Bus	3h 35m	1h 13m	52	170	Friend
MELISSA	F	50-59	East of England	Y	Y		Urban	August 2017	Bus	49m	26m	17	124	Via Rachel
RAVI	M	18-29	East Midlands		Y		N/A	January 2017	N/A	N/A	N/A	N/A	46	Via Jane
RACHEL	F	30-39	East of England	Y	Y	Y	Urban and intra-urban	June 2017	Train, London Underground	2h 55m	11m	8	103	Friend
GEOFF	M	50-59	North East		Y		N/A	January 2017	N/A	N/A	N/A	N/A	137	Local access panel
ANNE	F	50-59	South East	Y	Y	Y	Urban/semi-rural	February 2017		1h 20m	24m	17	150	Charity
PETER	M	50-59	North West	Y	Y		Urban	June 2017		1h 35m	53m	40	265	Charity

[7] Fieldwork Duration is from initiating a JourneyCam journey to ending the journey, and where indicated with * includes refreshment break(s).

NAME	GENDER	AGE	UK REGION	PARTICIPATION			JOURNEYING FIELDWORK						INTERVIEW LENGTH (MIN)	RECRUITED
				Journey	Interview	Workshop	Environments traversed	Date	Mode of Transport (if used)	Fieldwork Duration[7]	Footage Duration	Number of clips		
JANE	F	18-29	West Midlands	Y	Y		Urban	January 2017	Train	1h 28m	22m	15	95	Travel blog
JESSICA	F	40-49	Yorkshire and the Humber	Y	Y	Y	Urban and intra-urban	January 2017	Train, Bus (x2)	3h 48m	41m	29	206	Twitter
ANTHONY	M	18-29	North West	Y	Y		Urban	June 2017	Car[8]	3h 26m	40m	30	210	Unknown
MARGARET	F	50-59	North West	Y	Y		Urban	June 2017		2h 10m	18m	7	176	Unknown

Table 1: Participant Overview

[8] Car was only used as transport between two urban areas, as public transport was not available.

3.5.3 Participant profiles

David

David is a retired office worker in his 50s, who lives in London and frequently travels by public transport including buses, trains and the London Underground. He has access to both a powered and a manual wheelchair, using the former while participating in this research. David has previously campaigned with a charity about issues of inaccessible transport and environments, and complained to service providers about these issues, so was very motivated to take part in the research. We met at a major London station, before travelling on a bus to central London and walking around Soho. We went to a large department store to use the toilets, before taking another bus to King's Cross and then the Victoria line to another part of London. The interview was conducted in a nearby coffee shop.

Amber

Amber is in her 30s and lives in a large city in Northern England with her partner and young child. She has used a wheelchair for ten years, initially part time and now full time. She uses public transport to get around and described this as challenging. Amber explained how she encounters barriers that non-disabled mothers do not, explaining how "when it comes to being a parent, there's just no understanding" of disabled people's needs such as accessible changing tables. I met her at her home, before we walked through her neighbourhood to a nearby main road and caught a bus to the city centre. We walked around the city, ending up near one of the tourist attractions, where we met her family and ended the journey. The interview was conducted the next day in a local café.

James

James is in his 40s, and lives with family members in an urban area of South West England. He uses an all-terrain 6-wheel mid-drive powered wheelchair and employs a full-time PA. James has a degree, and is a very keen user of computers and technology. He mostly travels by private car, as he has found that public transport can be hit-and-miss when using a bulky powered wheelchair: he once had to travel in a train vestibule as the doors to the passenger saloon were too narrow for his wheelchair to fit through. We met at James' house, before we walked together with his PA on a journey to a café elsewhere in town.

Matthew

Matthew is in his 30s and lives in a small town in South East England. He often travels into the London by train to meet family and friends. He currently uses a manual wheelchair with

powered hubs but was considering whether to move to a powered wheelchair at the time of the fieldwork. He has been involved in charity campaigning in the past. Our journey was an example of one he might take when going to see friends. We met a coffee shop near his local station, and travelled together by train without pre-booking assistance to London. We then took the Underground to King's Cross, before catching a bus to Oxford Street and walking to a café for lunch. After lunch, we walked a bit more through central London. The interview was conducted in a coffee shop near Oxford Street.

Tom

Tom is in his 60s and is self-employed, working from home in London. He has a keen interest in technology and home automation gadgets which he uses around the house. He uses two powered wheelchairs for mobility, choosing between them depending on the journey, and has previously taken part in research on accessibility. He often travels by public transport, mostly by bus or train to central London or to nearby commercial areas. We met at his house, walking to a nearby station before travelling by train elsewhere in London with a large commercial area where he often goes to do his shopping. We had lunch together in local café, before he did his shop at the local supermarket and we returned home. Due to access issues at local station, we came back via a different train line and a local bus, before I interviewed him at his home.

Melissa

Melissa is in her 50s and lives in the East of England. Her health and mobility are affected by changes in ambient temperature, so she sometimes spends long periods without leaving her home. Her job, which she described as her 'passion', is one that can be done from home. She used a mobility scooter and walking sticks before becoming a powered wheelchair user four years previously. We went on a journey of around a mile and a half in her local area, catching a bus for one stop to shorten the duration of the journey, before I interviewed her at home. Although she has an assistance dog, this did not accompany us on the journey.

Ravi

Ravi is a young man who lives in the Midlands, and has used a powered wheelchair since he was a teenager. He doesn't use public transport often, so when he travels he is typically driven by a member of his family. He is actively involved in charity campaigning and fundraising and was keen to be involved in the research as he recognises the importance of

accessible environments to disabled people. We did not go on a journey together, so I interviewed him at home one afternoon.

Rachel

Rachel is in her 30s and is a disability campaigner living in the East of England. She also works as a consultant and adviser to organisations on disability issues, which involves train travel on a regular basis. She uses a height-adjustable powered wheelchair for mobility, and she described how the different positions of the chair can help her squeeze into different environments such as cramped trains. I met her at her home, before walking with her to a railway station and taking a train together to London where she had a work meeting. I went with her part of the way to her destination by London Underground. The interview took place a couple of weeks later at her home.

Geoff

Geoff is in his 50s and lives in the North East of England. He used a manual wheelchair in his mid-teens, and learned to drive which he described as having given him 'considerable freedom' when he was younger. He enjoyed travelling internationally before he had to give up driving, and later used a powered wheelchair for mobility. Geoff emphasised the social nature of the barriers he encountered as a disabled parent. He had pursued a professional career in several sectors as well as being politically active, but is now retired due to ill-health. We did not go on a journey, and I interviewed him at his home.

Anne

Anne lives in a suburban commuter town in South East England and is in her 50s. She has used a powered wheelchair since she was a teenager. She is retired, though used to work in a local council as an Access Officer, and remains involves in a local access group to try and ensure that developments in the area are suitable for disabled people. She regularly travels to the nearest town centre, and sometimes goes to London for days out with her extended family. Occasionally she also goes on holiday abroad. We met at her home, before going on a short journey around her local neighbourhood. She hoped to take me to the centre of the nearest town but inclement weather prevented this. Most of the interview was conducted the next morning at her home. Because of time constraints that day, the final section of the interview was conducted several weeks later by Skype.

Peter

Peter lives in North West England and uses a powered wheelchair for mobility. He is in his 50s and is retired after a successful career. Having grown up in the countryside, he enjoys hill-walking, so saved up for a second 'all terrain' power chair which he uses to get out into the countryside again. He described this as being very beneficial to his health and well-being. He also has an assistance dog, which can sometimes complicate access issues as I observed while we travelled together. In his free time, he is involved with campaigning for a charity. We met at a railway station, before travelling around a local town and returning to his home for the interview. Due to time constraints, the final part of the interview was conducted at a later date over Skype.

Jane

Jane is a young woman who has always used a powered wheelchair for mobility. She works full time in an office job in the city centre, commuting there every day by train. She also travels frequently on leisure trips to see friends, as well as occasional work and holiday trips within the UK and abroad. Her job regularly brings her into contact with other disabled people, so she had both a personal and professional interest in taking part in the research. We met at her workplace, and we walked together through the city before catching a commuter train to her local station. As such, the journey we did together was in part her normal commute home. The interview was conducted the following day at her office.

Jessica

Jessica is in her 40s and lives in a large city in Northern England with her family. She began using a manual wheelchair several years earlier, and switched to a powered wheelchair about a year before our interview. Before retiring due to ill-health, she had a career in the public sector. She travels by both private car and public transport, though her confidence in using the latter has been shaken by barriers she had faced in the past, and has gone on long distance trips by public transport to see family elsewhere in the UK. We met at the railway station in the city centre, before taking a train to another town where we had lunch. We then took a bus back to her city, before catching a second bus to her home. The interview took place at her home the following morning.

Anthony

Anthony is a student in Northern England. He has been involved in disability activism and has worked with a range of organisations around disability issues. He therefore has a detailed

knowledge about disability rights, as well as wider socio-economic issues that affect disabled people. I met him at his house, before we walked around his neighbourhood and he showed me the local retail area. His PA then drove us to a nearby city, where we travelled around the city centre. Finally, we conducted the interview in a nearby university where we had been able to secure a quiet meeting room.

Margaret

Margaret is in her 60s and lives on her own in a town in North West England. She formerly had a job that involved considerable travelling but was made redundant following a sudden health problem. She uses a lightweight, collapsible powered wheelchair for outdoor mobility with free-spinning front wheels that were prone to losing grip. We walked to the centre of her town, stopping to do some errands and have lunch before returning to her house where the interview took place.

3.6 Go-along Journeys and Data-led Interviews

3.6.1 Go-along journeys

A key characteristic of the go-along journeys was that they were led by the participants themselves. I asked each participant to take me on a journey of their choice and to show me things they felt were important to their experiences of mobility, rather than restricting the type of experience or environment. This stemmed from my desire to understand powered wheelchair uses' experiences of mobility as broadly as possible. In turn, this meant that the types of journeys participants took me on, as described in the participant profiles above, were diverse and encompassed participants' usual commutes, regular trips to local shops, and specific journeys they chose that they would not have otherwise made. The experiences we had on these journeys are described in more detail in Chapter 4.

I met each participant at a location of their choice, often their home although sometimes a public location such as a café, to review the plan for their participation in the fieldwork and ensure they were comfortable using JourneyCam. In these initial, informal and unrecorded meetings, participants often provided valuable contextual insight into their experiences. They frequently discussed not only their participation and the research project itself, but many also gave unprompted reflections on their wider experiences of accessibility and mobility. An essential part of these meetings was to review the information sheets and consent forms that participants had already been sent, to make certain these were fully

understood and completed, and that the participants were properly consented. This also meant that they were able to ask any final questions before fieldwork commenced.

Once consented, I helped the participant to attach JourneyCam to their wheelchair in the location of their preference, which was usually at the height of their control panel (Figure 2). However, individual preferences and the diversity of wheelchair designs led to JourneyCam sometimes being mounted elsewhere, such as at head or leg height, or even in one case at the level of a participant's footplate. Reflecting prior work exploring users' preferences for 'chairable' technology, participants generally preferred JourneyCam to be mounted such that it did not stick out and the overall form-factor of their wheelchair was maintained, to avoid compromising manoeuvrability (Carrington et al., 2014, p.3110). Their choice of where to locate the device was also often constrained by the limited number of secure mounting points available on their wheelchairs and could be challenging (Carrington et al., 2013; Parent, 2016). A certain stiffness was required in the clamp to ensure JourneyCam remained securely attached to the chair, and this typically meant that I had to attach the device under the guidance of the participant. Such inaccessibility can prevent a disabled person from independently using these kind of mobile video tools (Parent, 2016).

Having secured JourneyCam to their chair, I explained how to operate JourneyCam using the Bluetooth trigger button and let them test it in operation. Once they were comfortable with this, we travelled together on a journey of the participant's choice, which were in some cases several hours long. During these journeys we conversed about a wide range of topics, including current affairs, hobbies, and interests. However, often our conversations related to the specific environments we were travelling through, and to the participant's broader experiences of using a powered wheelchair or being a disabled person. As we encountered particular barriers, participants frequently narrated what was happening to them: they literally 'showed' and told me about their experiences (Carpiano, 2009). These detailed explanations of particular interactions with their environments, and how these related to their experiences of being disabled, were often picked up by JourneyCam as we travelled. This sometimes meant that the comments participants made at the time were then used as the starting point for their detailed reflection later, during the semi-structured interviews.

In addition to conversing with participants as I would with any other person I was travelling with, I also provided them with any support they requested while we were on a journey, such as technical failures or repositioning JourneyCam if it became dislodged. On occasion,

participants also asked me to provide personal assistance in inaccessible environments: one person asked me to put my hand on their back to steady them as they disembarked a train, for example, while another asked me to help push their chair up a few particularly steep dropped kerbs. This allowed me to observe the in situ experiences of the participants as I went along with them, and indeed physically experienced with them (but differently) some of the barriers they faced and the workarounds they had to employ to get around them.

As we travelled, I also made short field notes using a Notes application on my smartphone. This was usually during quieter moments of the journeys, such as a lull in the conversation, or in the case of some participants when they were talking to their personal assistant. These notes were by necessity brief. At the end of fieldwork session, I spellchecked and expanded these, and combined them with reflective notes to form more comprehensive field notes.

Once the journeys with the participants were completed, we returned to an appropriate place, which was most often the participant's home or their choice of a quiet public location such as a café, to download and process the video and sensor data onto my password-protected laptop. In some cases, participants had several sets of journey data, for example where we had paused fieldwork for a lunch or coffee break

The opportunity was also taken at this point to briefly discuss the journey we had taken together, and debrief the participants on this section of the research. Wherever possible, the semi-structured interview was planned for the subsequent day. This was settled upon for the comfort of both participants and myself, as the experience of working with the first two participants demonstrated that conducting a full accompanied journey and subsequent interview took a very considerable time. Sometimes, however, this was not possible due to scheduling conflicts and participant availability, in which case interviews were conducted immediately following the journey.

3.6.2 Data-led, semi-structured interviews

Following the accompanied journeys, I conducted semi-structured interviews with each of the participants. The interviews were audio-recorded using a handheld digital recorder, and were framed around the data they had collected on the journey. This was presented via Google Earth as described above in Section 3.4.5 (Figure 3), enabling participants to draw upon different types of data (video, GPS, and accelerometer) as prompts for reflection and discussion. With the GPS track opened inside Google Earth, showing an aerial view of the route we travelled together and the video clips strung along this route, we talked through

the journey we had together, playing each video clip and discussing it in turn. While playing each clip, I invited the participant to explain what was going on and what had prompted them to capture that particular clip. This provided a chronological structure to this section of the interview, from the start to the end of the journey. This also permitted a discussion about how the data might be collated, visualised, reviewed and potentially shared with others. The structure of the interview guide (Appendix H: Interview guide) was such that our discussion began with the data the participant had collected, and the experience of using JourneyCam, before discussing their wider experiences. In the first two interviews, with Matthew and David, I had started with their broader experiences before focusing in on the data. However, I chose to reverse this for all remaining participants, as I found that the conversation flowed more naturally when we started from their specific experiences during our journey together as reflected by the data they had captured, before broadening out to talk about their wider experiences.

This procedure was well understood and adopted by participants, who typically narrated the clips as they were played back. Starting from the data was highly productive: participants usually expanded on their initial description of what was going on in a clip without further prompting on my part. They frequently gave details about their bodily experiences, their feelings about that particular situation, and how typical (or indeed atypical) this experience was in their everyday lives. In these ways, the clips helped them to scaffold their discussion with me, and to discuss issues and concerns beyond just those that were visible within the clips that they had captured. Moreover, such reflections frequently went deeper than simple comparisons with similar situations the participants had previously experienced; instead, participants described issues such as why they felt that certain barriers existed and prevailing societal attitudes towards disabled people. The video clips had a capacity to help stimulate a collaborative process of discussion and reflection that formed the starting point for new knowledge about participants' experiences of mobility (Sumartojo & Pink, 2017).

Because this part of the interview involved playing each clip through, and usually prompted such detailed reflections from participants, it often took a considerable time particularly when working with participants who had captured many clips. As noted earlier, participants had often narrated incidents as were on journeys together, and sometimes these comments were picked up in the videos they recorded. At times, this led to an interplay between their in-the-moment responses to particular situations as captured on the clip, and their later

reflections on these situations in the interviews when they were not caught up whatever was going on. These recorded comments thus informed their post-journey reflection during the interview, as participants revisited not only the clip itself but also what they had been saying at the time.

After we had gone through the journey data together, the next questions asked participants to discuss their experiences and perceptions of JourneyCam as a tool and how they found it in use. They identified aspects that they particularly liked and disliked, suggested potential improvements, and provided ideas for developing it further. In addition, however, some participants also provided feedback which indicated the deeper level of reflection prompted by the tool, such as discussing the qualities of the video clips and how these related to their own feelings and experiences. For example, the shakiness of the footage that they captured as their chair and the camera bumped over rough surfaces was described as being reflective of how participants experienced these environments. The position and field of view of the camera was variously described as providing 'their' or 'their wheelchair's' point of view, but both were considered important and worthwhile. In this way, participants' comments on the tool and the data it produced were valuable in providing additional depth to the various experiences they had already discussed, and considering how and why JourneyCam might be used in capturing and conveying aspects of these experiences to others.

Finally, the interviews finished with more general questions about participants' experiences of accessibility and mobility, which frequently included discussions about being a disabled person in society more broadly. Often, the latter marked a return of our conversation to a theme that had been brought up earlier in the interview, as participants had reflected on the data they had collected.

Interviews varied in overall length between 55 and 265 minutes (4 hours and 25 minutes), although the majority took between 90 and 150 minutes (1.5-2.5 hours). With a substantial amount of time in each interview devoted going through the videos in detail, interviews where participants had captured more video in total generally took longer to complete. In planning the interviews, I had underestimated the time this would take, especially in light of the rich descriptions that participants provided of their experiences. On several occasions, in fact, we ran out of time to conclude the interviews in person and so the final part of the interview was conducted at a later date by Skype.

While the journey and interview process described above was adopted for the majority of participants, there were exceptions to this preferred structure. Two participants, Geoff and Ravi, did not undertake journeys for health reasons and instead took part in semi-structured interviews without having used JourneyCam. In these cases, I omitted the data-led section of the interview. In addition, it was uncertain whether a journey would be possible with James, so I initially interviewed him via Skype about his general experiences of being a powered wheelchair user. We were, however, able to go on journey together at a later date and I conducted the data-led part of the interview subsequent to that. This also led to a second discussion of some of his broader experiences.

3.7 Data and Analysis

The data collected during this phase of fieldwork included the 15 audio recordings of the interviews, field notes I had taken during fieldwork, and JourneyCam data. The latter consisted of time-stamped video clips, GPS tracks, and graphed accelerometer and elevation data in Google Earth. All interviews were transcribed: 11 by me, and four by an external transcription company, having first sought the permission of those four participants to do this. This resulted in a total corpus of approximately 320,000 words of interview data. In addition, the field notes that I had taken before, during and after the accompanied Journeys totalled 26 pages.

I began transcription and analysis of the interviews after the first two interviews took place in early January. I transcribed the interviews using ExpressScribe for Mac, which enables the insertion of timestamps with a keystroke. Data analysis began in parallel with transcription, and I conducted a thematic analysis of the interview corpus (Silverman, 2017). Thematic analysis is a flexible method that can be used with a range of theoretical frameworks that allows "identifying, analysing and reporting patterns (themes) within data… [that] minimally organises and describes [the] data set in rich detail" (Braun & Clarke, 2006, p.79). This flexibility allowed an analysis of the data to understand both the material reality of disabled people's experiences of mobility and how it is experienced by them, as well as how these experiences come to be socially constructed. I aimed to provide a rich description of the overall interview data set, obtained inductively from the data themselves rather than from an a priori coding frame (Braun & Clarke, 2006, pp.83–84). I coded the interviews at the sentence and paragraph level, in order to identify both semantic and latent meaning. In this process, I was informed by the field notes that I had taken, and issues identified in previous

research about disabled people's experiences of access and mobility. Some example codes are provided in Table 2.

Accessibility not taken seriously	Actively choosing accessible places
Understanding chair attributes or capabilities	Given up on complaining
Acceptance or dealing with it	Lack of staff training
Accessibility as built in	Back door treatment
Progress and improvement	Accessibility as freedom
Maintenance	Signage and information provision

Table 2: Examples of codes from coding process

Even while this process was ongoing, this enabled me to identify associations and patterns in the data. For example, many codes related to either particular aspects of the material environment, such as lifts, dropped kerbs, buses, trains, and rough surfaces. Others related to the choices that disabled people make about their mobility, such as being on enforced detours, actively choosing accessible places, or taking risks. After seven interviews had been coded, I felt confident enough to develop tentative themes by clustering these related codes, and identifying areas of comparison and contrast.

This led to an initial organisation of data across of 8 primary themes, which enabled me to gain a general overview of the data (Figure 4). The full initial coding framework is provided in Appendix I: Initial coding framework.

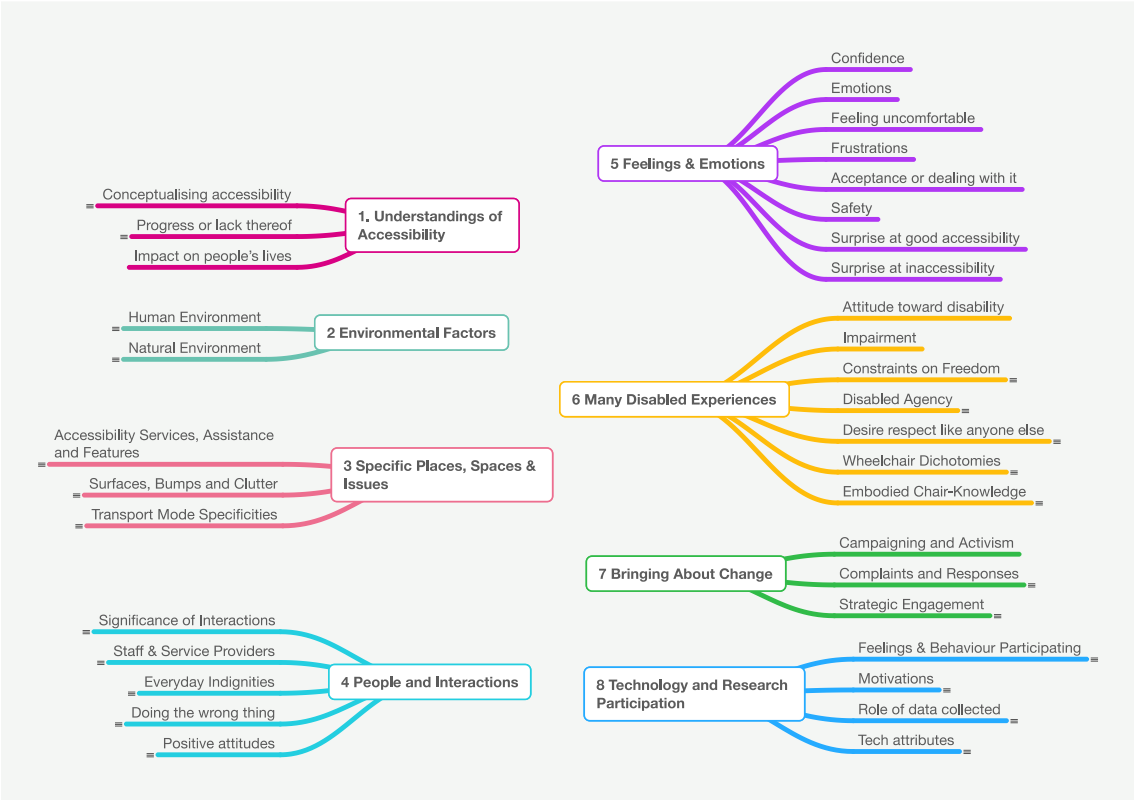

Figure 4: Tentative themes identified from initial clustering of codes

However following discussion with my supervisors, I realised that although these tentative themes were useful in helping me to gain a 'handle' on the data, they were insufficiently analytical to serve as the basis for thesis chapters. In addition, there were too many themes and sub-themes, and they were insufficiently delineated from each other. Finally, as the remaining fieldwork took place, and additional interviews were transcribed, I realised that I was missing certain aspects of the data.

An iterative process of re-working of the codes and themes therefore followed, which led to the following structure focused around four broad areas: JourneyCam itself, enablers and disablers of mobility; effects and impacts of barriers; and disabled people's responses to such situations (Figure 5). The full revised coding framework is provided in Appendix J: Final coding framework.

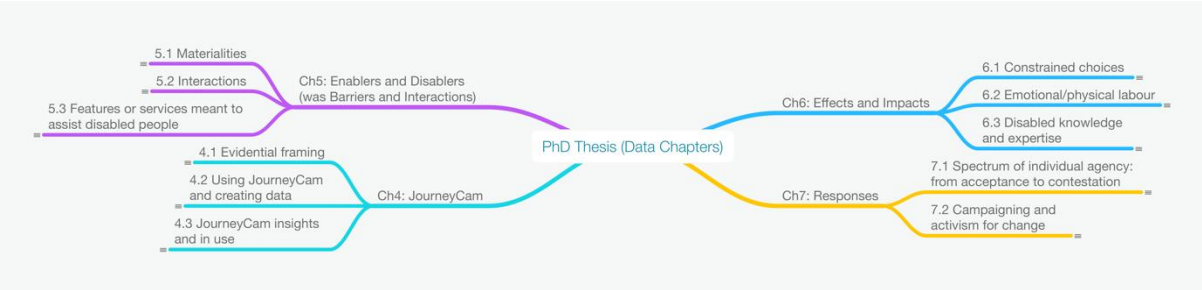

Figure 5: Revised themes following reworking

As I began to write out these themes into early chapter drafts, and revisited the interview transcripts, I realised that the data I initially thought would form a chapter on JourneyCam would be better woven into the other chapters. As data from the group Skype workshops directly engaged with individual and collective responses including activism, I reframed the final chapter around these. This iterative process led to the current structure of the thesis.

3.8 Ethics and Positionality

3.8.1 Institutional and societal assumptions of disabled vulnerability

At this point I feel it is important to challenge assumptions, written into formal university ethics processes, about the nature of disabled people's 'vulnerability'. These processes require additional oversight and caution in any research undertaken with children or other groups considered vulnerable as defined by Section 59 of the Safeguarding Vulnerable Groups Act 2006, a definition which includes anyone with "any form of disability", alongside several other categories such as being in sheltered accommodation or residential housing (*Safeguarding Vulnerable Groups Act*, 2006). While safeguards are very important to try to prevent exploitative research given the social position of a researcher vis-à-vis participant, the definition in the Act frames all disabled people as automatically vulnerable in line with a medicalised understanding of disability. In light of my experiences working with powered wheelchair users in this research, I feel that this reflects broader ableist assumptions about disabled people, and in particularly the ascription of 'global epistemic incapacity' to those with an impairment (Scully, 2018). The framing given by many participants for their experiences accorded with a social model understanding of disability, as something that is imposed on top of their impairment as a form of societal oppression. These are undoubtedly complex issues: some participants described how they felt more vulnerable in certain situations as a wheelchair user, and some mentioned impairment as a factor in this. However, there are many situations where non-disabled research participants might feel vulnerable. In addition, as described below when I discuss my own positionality, it is worth noting that the power relationship between researcher and participant is not always or necessarily unidirectional. The ethics process thus reinforces problematic medicalised understandings of disability, and an ableist implication that this equates to vulnerability.

3.8.2 Ethical challenges during fieldwork

On several occasions during fieldwork, situations arose which posed ethical challenges. As described in Section 3.5.1, one challenge with doing outdoor fieldwork is that posed by inclement weather. This was particularly the case because in this case fieldwork began

during winter. For some of my participants, who lived with chronic health conditions, taking part in bad weather would pose a risk to their health. Even for those without this consideration, undertaking fieldwork in heavy rain or snow would have been very unpleasant. Given these considerations I therefore emphasised my willingness to be very flexible in relation to the timing and format of the fieldwork, both during pre-fieldwork conversations and on the day itself. I emphasised that they could stop participating at any time, and that if needed we could cancel or rearrange the fieldwork at short notice. In some cases this happened, and fieldwork was adjusted (for example, Anne explained that she had shown me a different journey to the one she had initially planned). In other cases, this led to the postponement or cancellation of fieldwork.

I also tried to ensure that participants were compensated fairly for their time and expertise, and in a way that reflected the considerable amount of time that they spent working with me, offering shopping vouchers to the value of £10 per hour or part hour they spent working with me. One ethical issue that I had not anticipated was that two participants turned down this offer, explaining that they had wanted to take part in order to do their bit to help bring about more accessible environments. I responded to this in two ways: firstly, as I did more generally, I explained that while I hoped the research would contribute towards this goal, I was not able to promise them that their participation would lead to this, which they recognised. Secondly, I reiterated that I very much appreciated their participation in the research and emphasised that they were very welcome to the vouchers as a token of appreciation in case they had changed their minds.

3.8.3 Reflections on positionality

A particular ethical issue in this research was my own position as a non-disabled person doing research around disability. Given a history of research conducted by non-disabled 'experts' that disempowered disabled people, reinforced an individual understanding of disability, and did not serve disabled people's needs (Oliver, 1992), I was particularly conscious of the need to be especially sensitive to my own positionality as a non-disabled researcher and how this influenced my conduct of this research.

I tried to address this firstly by grounding my work in a social model of understanding of disability, in particular adopting the social model of disablement as a core epistemological framing (Stone & Priestley, 1996). I recognised disabled people as knowledgeable experts, seeking to highlight their particular expertise and understanding of structural barriers. I have

focused throughout the project on identifying ways in which their knowledge and expertise might be used to challenge and remove these barriers. Building on work by feminist disability scholars, I tried to ensure that participants were able to tell their own narratives about their experiences by affording them practical control over many aspects of the fieldwork. I asked participants to take me on journeys of their choice, and to show me the things that mattered to them in their experiences of mobility, rather than imposing any constraints on the type of journeys they might take me on. When I was asked in pre-journey telephone calls by some participants what I wanted to see, I deferred back to them and emphasised I was interested in their experiences as broadly as possible. As described earlier in the chapter, I also did my best to ensure that I accommodated participants' preferences about the scheduling and locations of our work together, even when this meant that I travelled considerable distances in short periods of time to work with participants in different parts of the country. JourneyCam itself was designed to enable purposive and selective data capture, so participants retained control of what aspects of their journeys were recorded. In all of these ways I tried to ensure that participants had as much control over the process of participating in the research as possible, and that their contribution was recognised.

More broadly, I recognised that within a PhD my research was unlikely to have the kind of impact that would remove barriers in participants' everyday lives. I was therefore open about my hopes for the research – that it would contribute to a better understanding of their experiences – while not over-promising that their participation would directly bring about systemic change. I was also open with the participants about the practical issues of doing this research within the time-bound context of a PhD. I initially hoped to work with organisations such as transport providers, bringing disabled people's situated knowledge into dialogue with service providers through joint workshops. However, when I explained the project to my participants and also when I talked about the next steps after the journeys and interviews, I emphasised that it might not be possible within the PhD. Finally, I gave participants the opportunity to validate or contest my understanding of data from the first phase of fieldwork in group workshops where I shared my tentative analysis with them and invited them to critique it. This process, which formed part of the second phase of fieldwork, is discussed in Chapter 6. It aimed to recognise the commonality of disablement not only through my own analysis of data but also through the research design itself, helping to collectivise both personal experiences of disablement as well as the process of research

production (Stone & Priestley, 1996, p.711). Indeed, these workshops became sites of collective knowledge-sharing, an aspect explored in more detail in Chapter 6.

A related issue that stemmed from my positioning was that of my own politics as a non-disabled researcher. On several occasions during the course of the project, participants asked questions that probed my understanding of disability and in particular whether I had adopted a social model understanding. For example, it was very clear in my initial phone call with Anthony that he was 'testing' my commitment to social model principles, and this was repeated when we met for the journey and interview. He later acknowledged this, reflecting in the interview on our interaction when I was explaining how to operate JourneyCam:

> *"I felt I was in command of the observations throughout the day. If I'm honest with you, I was actually testing it this morning where I said to you, 'Do you want to take the [Bluetooth button] and just click it when I tell you to click it?' and you said, 'Well no, I think if you can do it, it should be better if you do it'.*
>
> *… I just wanted to see if you were trying to transfer as much power to me as possible or whether you were wanting to have any input in that relationship. But it felt very much that you built the whole research project on the basis that the individual should have as much power as possible throughout the experience and within the parameters of what you've set, which is obviously logistically what happens when you do research, you set the parameters… But within that you've given me as much power as possible"*
> *(Anthony, post-journey interview)*

While Anthony's comments suggest that my attempts to afford participants as much control over participating in the fieldwork as possible were at least somewhat successful, they do raise the issue of my positionality as a researcher. I had been checked out, to see whether I had the 'right' kind of politics – specifically, adopting the social model of disability – and had 'passed' the test. While other participants were not as explicit about this, it came through in some of our interactions, such as when the issue of impairment came up in the workshops. In that context, I explained my uncertainty about how best to include it in my analysis, as some participants had explicitly mentioned it while others had not. I explained that I was interested in what they thought, and it became a topic of debate and discussion within the workshops. Nonetheless, I still felt compelled to explain that my approach to the research was rooted in a social understanding of disablement, and that my interpretation of what

they had said to me so far was that impairment formed a far less significant part of their experiences than societal barriers.

This experience partly reflects a dilemma of what a researcher should do when confronted by diverging opinions amongst disabled participants, especially if they are distanced from the disabled people's movement: Stone and Priestly (1996, p.711) ask if a researcher ought to ever politicise the unpoliticised or advocate for a social model of disablement. They suggest that, in such a situation, a researcher's own theoretical and political standpoint should be their guide. To take an initial decision to adopt the social model of disablement is itself, they argue, a key step in demonstrating commitment to the disability movement. This is a form of ethical responsiveness, necessary in order to be answerable to my participants: the process of building a trustful and respectful relationship with participants involves a form of political positioning in relation to them (Durrant & Kirk, 2018). I feel answerable to the participants with whom I worked, and for the reasons discussed earlier in this chapter this meant that I framed my work within a social model understanding of disablement. That this granted me access to participants who might otherwise have refused to work with me reflects the ethics of working on a sensitive political issue and of being accountable to them.

3.9 Discussion

This chapter has outlined the methods adopted in this research, beginning with an overview of my epistemological and methodological approach. Building on feminist epistemologies, I emphasised the importance of recognising powered wheelchair users' situated knowledge. I have framed my work within the social model of disablement, explicitly acknowledging the role of disabling structural barriers in disabled people's lives. This epistemological framing led to the adoption of a go along method, where I accompanied powered wheelchair users on journeys of their choice and provided them with a custom smartphone tool enabling them to capture video and data about our journeys together. These was followed by semi-structured interviews, which drew upon the data they had gathered, enabling them to reflect on their journeys and to co-create new knowledge about their experiences of mobility with me during the interviews. The following chapters outline the findings of this work: Chapter 4 describes enablers and disablers to disabled people's mobility; Chapter 5 explores the value of their situated knowledge and the costs associated with its acquisition; and Chapter 6 looks at how this knowledge might be brought into dialogue with others.

Chapter 4. Enablers and Disablers of Powered Wheelchair Users' Mobility

4.1 Introduction

This chapter explores the things that participants identified as significant as either enabling or disabling their mobility. In both the journeys and post-journey interviews, all participants described vividly and in detail how they encounter social and material barriers in their everyday lives. These barriers created what have been described as 'ableist geographies', that is 'lived environments which incorporate and perpetuate physical and social barriers to the participation of disabled persons in everyday life… [such barriers] challenge [disabled people's] right to be and, in particular, to be in abled-bodied spaces' (Chouinard, 1997, p.380). They are by their nature exclusionary: spatial barriers serve to materially exclude disabled people from public space, thereby keeping disabled people 'in their place', while social barriers reinforce this spatial marginalisation (Kitchin, 1998). Improving the access of disabled people to public space therefore requires improving both the physical and social environment (Butler & Bowlby, 1997), and any attempt to bring about more inclusive spaces must understand disabled people's experiences of both social and material factors as well as the complex interplay between them. These factors can serve as barriers or facilitators of disabled people's mobility.

This chapter therefore explores some of the most significant material and social concerns as expressed by participants during the journeys and in the semi-structured interviews. Often, I witnessed the issues they described, and participants captured many of them in their video clips. These social and material concerns were often characterised as disabling, hindering participants' mobility, and thereby constraining access to public spaces and participation in society. These 'disablers' were often contrasted with what I term 'enablers': environments or factors that participants described as aiding their mobility. The chapter then examines how some measures that are intended to reduce barriers faced by disabled people, which I describe as 'accessibility features', can in some cases perpetuate disabling practices. Finally, the chapter draws together some unifying themes from across these diverse experiences, underlying the socio-material nature of both enablers and disablers, highlighting gaps between formalised and experiential understandings of accessibility, and exploring the contingent nature of disabling environments.

4.2 Material Concerns

Participants discussed a wide range of issues about the material environment, explaining how these could create different kinds of disabling barriers. These material concerns related to both the built and the natural environment, and were most often physical barriers which impeded the free movement of powered wheelchair users. They frequently related either to the poor quality of surfaces, which gave an unpleasant and uncomfortable ride, or to routes which were rendered impassable by the presence of permanent features such as steps or temporary blockages like scaffolding. Participants often had to take much longer routes than non-disabled travellers to get around these barriers, resulting in additional effort and time spent on their journeys. Their overall experiences of material barriers reflect those widely documented in previous literature on the geographies of disability (Gleeson, 1999b; Imrie, 1996b, 2000a; Imrie & Edwards, 2007; Imrie & Kumar, 1998; Matthews & Vujakovic, 1995). Some participants also mentioned how certain aspects of the natural environment, such as access to 'natural' outdoor spaces and activities, or light levels and the weather, could also pose challenges to mobility for disabled people. Such factors have also been identified in prior work (Corazon et al., 2019; Lindsay & Yantzi, 2014; Ripat et al., 2015; Williams et al., 2004). It was notable that many of the material barriers described by participants could be addressed through programmes of barrier removal, although not all natural barriers are well-suited to such strategies (Shakespeare, 2006, pp.45–46). The most significant material issues participants raised, and their implications, are discussed in more detail below.

4.2.1 Qualities of surfaces

Rough or uneven surfaces were the most common physical barrier discussed by participants. All talked at length about the enabling and disabling qualities of the surfaces on which they travelled, and about the effect of these surfaces on both themselves and their wheelchairs. These comments were frequently made during the journeys themselves, typically while going over uneven surfaces or traversing steep inclines, but participants also discussed them retrospectively while reviewing video clips and describing their experiences during the interviews. David, for example, described viscerally how bumps caused by these surfaces were a source of discomfort as well as of potential damage to his wheelchair:

> *"rough surfaces are horrible, really really horrible… they're not good for the power chair, they rattle it… and damage it and… make things come loose… cobbles… trees coming under pavements, and pavements disintegrating. Stuff like that, it's really horrible" (David, post-journey interview).*

Participants expressed a clear preference for certain surfaces over others, with a hierarchy emerging in which smooth tarmac or large well-laid paving slabs were perceived as most pleasant and therefore desirable to travel over. Yet even the latter could be problematic for participants if they had been unevenly laid or had suffered damage over time, as Anne explained:

> *"you get quite a jolt every time you go from one [paving slab] to another. Bricks are even worse, cobbles are the worst" (Anne, post-journey interview).*

Another participant, Jessica, described the old, worn down stone flags near to her home as her *"worst nightmare"* and compared them unfavourably to railway station concourses or indoor shopping centres (Figure 6).

Figure 6: Worn paving slabs described by Jessica as her "worst nightmare" (author's photographs)

This preference for travelling on smooth surfaces led participants to alter their patterns of movements in their wheelchair. When travelling with them, I noticed how they would frequently adjust their position as they travelled, seeking out smoother routes on footpaths and roads to avoid bumps or cracks rather than necessarily taking the most direct route. When interviewed, one person described the need to be vigilant:

> *"[I have] to watch out for cobbles, and bumps… it's just kind of an obstacle course. So I feel like I'm driving a car" (Ravi, interview).*

Another participant described in detail how their experience of negotiating a bumpy path differed from that of her personal assistant (PA):

> *"my cup of tea was going everywhere. And hers… it didn't even spill… I was saying to her, 'do you feel all the bumps', and she said 'no', and I said 'do you concentrate on the footpath' and she said… she looks at it, but she's not concentrating on it … I'm literally, sort of, doing a radar like, y'know, back and forth, back and forth,*

should I go that way, should I go this way, is that bump, is that twig gonna make me jump this way, should I avoid it, should I not" (Anne, post-journey interview).

Anne's explanation highlights just how different her experience as a powered wheelchair user was to that of a non-disabled person travelling on the same path. Despite knowing the path well, she had to be constantly vigilant in a way that her walking companion did not. This vigilance helped her to avoid bumps which could disturb her planned path or cause her discomfort. Yet despite the additional effort she expended to do this, she was unable to prevent her drink from spilling: vibrations transmitted through the chair were sufficient to upset the cup of tea she held in her lap. The negative experience caused by a bumpy surface therefore went beyond discomfort, and caused danger due to the risk of her spilling her tea.

It was also clear from conversations with participants that some found bumpy surfaces to be more difficult to deal with than others. Those living with impairments that cause heightened sensitivity to pain, for example, described how poor-quality surfaces were more than an inconvenience but could cause injury and severely restrict their activities. Likewise, those whose impairments led to limited strength explained how bumps could jerk them out of position in their seat, leaving them in an uncomfortable position or even causing them to lose control of their wheelchair. For some, it would require the assistance of another person such as a PA to position themselves again, reducing their independence by imposing an unwelcome and otherwise unnecessary reliance on others to assist them (Scully, 2010, 2014). These psycho-emotional costs and associated labour imposed by disabling material barriers will be discussed in Chapter 5.

Most participants also discussed how the steepness of inclines, such as slopes or ramps to and from vehicles, often posed particular challenges. Those with experience of manual or 'powered hub' wheelchairs described the challenge of propelling themselves up or controlling their descent down such slopes. There was also a widespread concern around the potential for accidents, and several explained that they felt nervous of tipping out of their chair when traversing steep inclines. Jessica had twice previously ended up in Accident and Emergency after falling out of her chair, and explained how steep slopes made her feel:

"awful. Absolutely awful… my heart is in the back of my throat, because I feel that there's the potential for me to backwards and have another nasty accident" (Jessica, post-journey interview).

These kinds of psycho-emotional impacts of material barriers will be discussed further in Chapter 5. As with driving on rough surfaces, participants often changed their behaviour when faced with such barriers. Many avoided steep slopes entirely, incurring additional time and effort as they sought other routes. Several asked for my assistance as they traversed steep inclines, for example by asking me to put my arm out and steady them in their chair.

These examples highlight how the design of particular features of the built environment, in particular poor-quality surfaces and steep ramps, had the effect of disabling wheelchair users and forcing them to change their behaviours. Disabled people's needs are not well considered in the UK planning system (Imrie, 2000b; Imrie & Wells, 1993), and the examples described by these participants show how specific configurations of built space can exclude disabled people. These exclusionary spaces have been widely documented in the literature on the geographies of disability, for example in relation to shared space (Imrie, 2012a) and the provision of accessible toilets (Kitchin & Law, 2001). Yet these participants' experiences show that even mundane aspects of the material environment, such as pavement surfaces, can have a considerable effect on disabled people. Furthermore, not only do exclusionary environments have a physical impact on disabled people and cause them to act differently, they can also make them feel less valued than non-disabled people (Imrie & Kumar, 1998), another aspect of psycho-emotional disablism that will be discussed in the next chapter. The long-standing nature of many of these barriers reinforced participants' perceptions that disabled people's experiences of the built environment are not prioritised by local councils or society as a whole.

Some experiences described above also hint at the ways that the built environment is not stable and constant, but rather exists in a state of variability and inconsistency. Certain aspects of the built environment will inevitably degrade with time, for example as paving slabs crack or tree roots work their way under tarmac leading to bumpy or uneven surfaces. In turn, these changes can lead to environments becoming less hospitable for disabled people over time, underlining the critical importance of actively maintaining accessible places and routes. This will be discussed in more detail later in this chapter. However, participants also explained how short-term changes and variability could also lead to disablement and exclusion through the imposition of 'temporary' obstructions and barriers to their mobility. These are further discussed below.

4.2.2 Circumventing temporary obstructions and blockages

Participants often described how temporary obstructions were especially problematic, as they could impede the only accessible route from one place to another, and were very difficult to anticipate and plan around. I encountered or observed such obstacles on almost every journey I undertook with participants. Most often these were things which obstructed the pavement, including advertising boards, building works, wheelie bins, and parked cars. These were often difficult or impossible for wheelchair users to circumvent without having to travel in the road, though even this was not always possible due to a lack of dropped kerbs (a factor discussed in more detail in Section 4.4.1).

A particular bugbear explicitly mentioned by several participants were display boards or 'A-boards'. These were often encountered immediately outside hospitality venues and, along with the presence of other permanent or temporary street clutter like bollards, bins, or parked cars, could entirely obstruct the pavement for a wheelchair user (Figure 7). A typical comment was that A-boards posed *"a great nuisance, especially on smaller streets"* (David, post-journey interview), though similar sentiments were widely expressed by participants about other things that frequently blocked pavements such as parked cars.

Figure 7: (L) Footpath in residential neighbourhood made impassable by the presence of a parked car (R) A wide footpath in the entertainment district of a large city substantially blocked by a variety of street furniture (author's photographs)

Another issue raised by several participants was shop displays that protruded into aisles, or advertising boards or other display units that were frequently placed in the entrance to shops. One participant explained how businesses that were otherwise unproblematic for her to enter as a wheelchair user became inaccessible in these situations:

> *"[they are] my pet hate. They're just always in the way… they're everywhere, they're everywhere, they're everywhere, they're even– all the jewellery shops right,*

so you got, an entrance that might be two metres wide, they put a great big A board right in the middle. So whoever's going in, has to take a detour, and squeeze down the sides… I can't, so I just push it. And then I tell them, but that's already got me stressed" (Anne, post-journey interview).

Anne's description not only identifies how she faces these barriers regularly but also the psycho-emotional consequences of coming up against them so often, an issue discussed further in Chapter 5.

As noted above, another experience ubiquitous to all participants was that of parked vehicles blocking the path. We often came across this in residential suburbs or inner cities, where the pavement was rendered impassable for a wheelchair user. These issues were heightened when it was rubbish collection day (Figure 8). As with the other issues in this section, it was often the combination of multiple permanent and temporary blockages that caused particular access barriers. This highlights the significance of contingent and changeable factors in wheelchair users' unpredictable experiences of mobility.

Figure 8: Jessica's JourneyCam footage showing a parked car and wheelie bin obstructing the pavement

Other temporary issues highlighted by participants included road and building works, which led to pavements obstructed by clutter such as open manhole covers and scaffolding. This was particularly well illustrated on a journey with David in central London. He captured clips as he carefully manoeuvred around an open telecommunications manhole (which had to be partly moved by the engineer to allow him passage), before seeing an A-board that partly obstructed the pavement. When we passed that, he found his way blocked by scaffolding erected for building works, but no temporary ramp to allow him to get off the pavement and onto the road, nor any advance signs warning that the pavement was shut (Figure 9).

Figure 9: David's JourneyCam footage: sequence approaching the manhole (top left), then seeing an A-board (top right) before finding our ourselves completely blocked (bottom left), and retracing our path past the open manhole (bottom right)

In the subsequent interview, he explained how it was understandable that for safety reasons we could not pass the building works, but that because there was no temporary plastic ramp provided to bridge the pavement and street levels, wheelchair users are unable to get past this blockage:

> *"they should have put out one of those plastic ramps… plastic yellow things that come off the kerb temporarily… they're fine, they work very well. Most building sites… have those" (David, post-journey interview).*

In the absence of such provision for those who could not traverse a kerb, there was no choice except to retrace our path, and face the 'obstacle course' of pub sign and an open manhole. There was so little clearance between the latter and the engineer's parked van that David's wheelchair clipped the flimsy metal barrier around the manhole:

> *Interviewer: And then we doubled back, and… the BT man had gone off.*
>
> *David: Yep. And we held his… frame.*
>
> *Interviewer: So I… stepped in.*

David: Ah, we should hear a knock now! [klinking noise] Yeh!

(David, post-journey interview).

Faced with these barriers, participants sometimes opted to travel along roads rather than footpaths or pavements, although as described above this was not always possible if no dropped kerb or ramp was provided. Elsewhere, often though not exclusively in rural or semi-rural areas, participants had no alternative but to travel on the road because no pavements were provided. Participants described positive and negative factors associated with travelling on the road. Anne, for example, explained that the camber on the road was less extreme than on the footpath, with the latter also more likely to have tree roots distorting the surface. Another participant described how they preferred travelling on the back lanes of terraced residential areas rather than on the footpaths, as these *"were smoother, quiet and you didn't have the constant jerkiness of the slabs"* (Geoff, interview). For these participants, the road sometimes offered a better experience of mobility.

Yet travelling on the road could be fraught with danger as it brought the wheelchair user, as well as their PA or others accompanying them, into the path of motor vehicles. Participants acknowledged these dangers, but often noted they were less problematic than the pain or discomfort (and in some cases, the danger of falling out of their chair) they experienced on paths. As already noted, in some cases the design of the built environment also left them little choice except to travel on the road in the absence of alternative provision.

One participant captured several videos that graphically illustrate how blocked or absent pavements could force wheelchair users into dangerous situations involving motorised traffic. In the first example, James saw that the footpath ahead was impassable due to the combination of a parked car and overgrown bush, and choose to travel in the road instead with his PA as a lookout. There was no pavement on other side of the road that we could travel on, so had no option but to continue on the road. As it was a quiet residential street, a car that overtook us shortly afterwards was travelling at a relatively low speed (Figure 10).

Figure 10: James's JourneyCam footage (L) as he moves out into the road because the pavement ahead is blocked by a parked car and overgrown bush, and (R) as a car overtakes us while we move along the road

By contrast, later in the same journey, we had to travel for a short distance along a major road which lacked pavements. Despite both James's PA and me 'flanking' him and watching for traffic, this experience felt very unsafe. We returned later that day along the same route in the opposite direction, and were again passed at high speed by vehicles as we travelled along the carriageway (Figure 11). The still images do not fully convey this experience.

Figure 11: James's JourneyCam footage: sequence on a busy main road as we approached an underpass (top left), fast traffic passes us in the opposite direction (top right), overtakes us from behind (bottom left) and finally overtake us into the path of oncoming traffic (bottom right).

James subsequently discussed these experiences in the interview. His response highlights how he negotiated the various material barriers during this portion of the journey with his personal assistant, and how the barriers in the material environment meant he was forced into an unsafe interaction with motorists.

> *James: crossing [the main road] here is a bit… scary… You just make sure it's clear. I could go up the kerb there, but there's no way to get down the other side. Plus it's overgrown anyway.*
>
> *Interviewer: What are you thinking when you're in this situation on a road, and there's traffic going past?*
>
> *James: Emm, a little bit nervous [laughing]. It's just really want to just get off it as quickly as I can. But then again not going too fast, to cause an issue with the other cars. You can see there's a nice paved bit there, that I can't get onto. If they just made a drop kerb there, it'd make it a lot safer.*
>
> *Interviewer: And then you pulled over and stopped underneath the bridge here.*
>
> *James: Yep, that's cause [my PA] mentioned there was a car behind, so I thought it was best… to let them past on this bit. Rather than carrying on. Give them time to get round, and a few other cars to stop. Like this one here stopped to let everybody past me. Which I do think was pretty good.*
> *(James, post-journey interview).*

James's comments also highlight how these unsafe interactions made him feel:

> *Interviewer: What were you feeling here?*
>
> *James: Ehh, a bit nervous… they're quite fast, there's a lot of noise as well, so you can't tell if something's coming up the road. So yeh, it's not the best.*
>
> *Interviewer: … stuff that was going in your direction… did that give you enough space, do you feel?*
>
> *James: Ehm, I felt okay, it wasn't too close. Some go closer than that, so! I think some of them could have waited until the other cars had past… [they] will cut into me, rather than hit the car on the other side of the road. Yeh… particularly here. 'Cause that car on the right's quite close. This next one coming up. Which pulls around there, there's not much room for it to actually do that. It's always nice when a bike crosses the road as well 'cause I know it's safe! Yeh, was definitely a sense of relief when I got on this bit here! 'Cause you're out of the way of big cars.*
> *(James, post-journey interview).*

These comments highlight the close relationship between disabling material environments and the kinds of interactions with others they engender. In this case, the absence of an accessible route (materialised through a lack of footpaths, dropped kerbs, and pedestrian crossings) compelled a wheelchair user to travel on a main road, where they became vulnerable to the behaviour of motor vehicle drivers. Elsewhere during the interview James described the importance of training new personal assistants, and this extract demonstrates how the relationship of trust they had built up with their PA helped them to navigate this unsafe situation. This intertwining of material and interactional aspects of the environment will be further discussed later in this chapter.

4.2.3 Natural environmental factors

In addition to aspects of the built environment discussed above, many participants also identified how the natural environment could be disabling. Several participants described how dirt and muck were problematic for powered wheelchair users, as unlike a pair of shoes one cannot remove the tyres on a wheelchair when entering a house. This was particularly the case for someone who relied on a personal assistant at home, who described what might happen if they got their chair dirty when they were on their own:

> *"I know I've gone over dog shit, or mud. I can either sit here and wait, but I get too frustrated, so I need to move round the house, and then you've just… y'know!" (Anne, post-journey interview).*

Two participants who had experience using both manual and powered wheelchairs drew attention to the fact that propelling a manual chair requires one's hands to be on the rims of the wheels, and as Jessica put it, *"they get filthy"*. Participants also mentioned ambient light and temperature as factors that could significantly affect their experiences, which interacted with other factors such as their wheelchair. Jessica explained how the battery indicator lights on her wheelchair control panel could be blinding in the dark, making it hard to see what she was doing. Light levels were related to perceptions of personal safety, which was raised as a concern by some participants. One noted that in a busy place with lots of cameras, such as the West End, *"the amount of darkness doesn't matter… but my route… [nearer] home is very isolated and it's off the road… [it] has always felt vulnerable"* (David, post-journey interview). This again suggests a complex interaction between specific social, material, and natural factors in his perception of safety in low light conditions. The presence or absence of

CCTV, the isolation of a particular route, and the level of ambient light all affected David's experience of mobility.

Alongside light levels, participants described ways in which the temperature, weather and season could also have disabling effects on them. David explained how low temperatures could impact powered wheelchair users differently to manual wheelchair users:

> *"like a motor–cyclist you're not moving about, and you've got wind rushing past you… it's possible to get really freezing cold in a power chair. It's different in a wheelchair where you're exerting yourself and you can stay warm, but you're absolutely immobile in a power chair" (David, post-journey interview).*

As a user of both manual and powered wheelchairs, he also noted that wet conditions could post him functional challenges in controlling his chair:

> *"if the grip rims on the manual wheelchair are at all moist, I can't grip them. So they slide around and I lose control" (David, post-journey interview).*

He therefore chose to take his powered chair, rather than use his manual chair, if it was raining. Like many other participants, David also described how the weather affected his choice of whether to go out at all. He noted that wintery conditions posed a particular safety issue:

> *"I won't go out in snow and ice. It's impossible. Because… I can't control [the wheelchair] on ice. And that could get really nasty" (David, post-journey interview).*

Jessica also highlighted how she would think twice *"if there was any rain, if there was bad weather, if it was a dark day"* (Jessica, post-journey interview). This was for several linked reasons: the discomfort she would experience in poor weather conditions, her concern about damaging her chair, and concerns about her personal safety such as being clearly visible to car drivers. As described in the Methods chapter, fieldwork with some participants was postponed or interrupted due to inclement weather.

Leaves and pooled water, more common in autumn and winter, could also conceal physical barriers. Anne retrospectively described during her interview why she manoeuvred her chair in a particular way, and explained her thought process at the time of capturing the video:

> *"how deep is it, should I avoid it, should I find another dropped kerb, should I just… risk it, and maybe if the hole's too big I come flying out, or maybe don't risk it, all those things" (Anne, post-journey interview).*

Again, participants' comments often highlight the entangled nature of material and social concerns. Many of these barriers could not be fully addressed by a strategy of barrier removal. For example, although providing covered bus stops might reduce the amount of time a wheelchair user spends waiting for a bus in the rain, it would not remove the problems caused by precipitation for wheelchair users entirely. Likewise, previous studies have highlighted how severe winter weather conditions can cause a range of barriers for wheelchair users (Lindsay & Yantzi, 2014; Ripat et al., 2018, 2015).

However, some weather-related barriers could be at least partially addressed to make environments more accessible. For example, if better drainage ensured water did not pool on drop kerbs, for example, or if pavements were well-gritted during cold weather, participants would face fewer material barriers to their mobility. The fact that these issues do not appear to be regarded as a priority speaks to a broader societal issue: an apparent lack of concern for providing suitable environments to enable the mobility of wheelchair users and other disabled people. Moreover, the ever-changing nature of barriers associated with the natural environment, which were linked to weather conditions, seasons, and light levels, again highlights the impact that unpredictable or transient factors can have on disabled people's experiences.

4.3 Social Issues

I use the term 'social issues' to refer to how participants experienced their interactions with other people, and unsurprisingly such interactions featured prominently in their everyday mobility. Walking, the most widespread form of mobility, has been described as a profoundly social activity wherein social relations are not simply enacted *in situ* but 'paced out along the ground' (Ingold & Vergunst, 2008, p.1). Experiences of mobility amongst wheelchair users are likewise social endeavours, including inevitable interactions with the wide range of other people with whom wheelchair users share space.

Some of these interactions, such as the unpredictable nature of crowds, have 'material' implications, demonstrating the blurring of material and social factors. However, others highlight specific social barriers that are faced by disabled people in their encounters with non-disabled people, such as the attitudes and behaviours of others. These were often related to being visibly different, with their use of a powered wheelchair or (in some cases) their visibly 'different' and 'unusual' body resulting in other people staring at them. Disabled people disrupt non-disabled people's expectations of 'normality', and a stare, the "snagging

of the eye by the novel", is the bodily materialisation of a search for coherent narratives to explain such differences (Garland-Thomson, 2006, pp.173–174).

Participants emphasised the significance of these interactions in their experiences of mobility. They often dwelt in the interviews on how they perceived the attitudes and behaviours of other people towards them. It was particularly notable that these interactions could be every bit as 'enabling' or 'disabling' to disabled people as the material factors already discussed. In some cases, the ways in which these interactions enabled or disabled was due to the direct actions of the other person, whether or not that was consciously intended. For example, a stare or an insensitive comment could make someone feel that they didn't want to go out, whilst the friendliness of a member of staff could make someone feel welcomed. However, it was sometimes indirect actions – that is, individual or collective behaviour that was not directed at the disabled person – which were perceived as disabling. In addition, it was often a combination of these interactional and material factors which was highlighted as particularly significant.

4.3.1 Indirect actions

Most participants expressed discomfort around crowds, both verbally during interviews and through their behaviour while out and about. This was due to the perceived dangers posed by the physical presence and unpredictable behaviour of a crowd, rather than the specific actions of individuals, reflecting prior research on disabled people's commuting experiences (Transport for London, 2010). Participants described going out of their way to avoid busy locations, including planning their routes carefully to consider temporal factors such as rush hour or seasonal variations in the size of crowds that would be present:

> *"At rush hour then I would not go [to that main street]… It's too busy. Everyone's just there. It's like when there was the German Christmas market. I just didn't go, because there's no point. Like there's just too many people, too many like obstacles… Rush hour it'll be really busy. And then probably like lunch time… [and] it's always busy when it's Christmas" (Jane, post-journey interview).*

Crowds not only posed physical obstacles to the mobility of powered wheelchair users. In addition, as discussed in the following chapter, participants were conscious of what they described as their own responsibility to control the movement of their chairs, which were often large and heavy. Some described how interacting with crowds could lead to a risk to

the safety not only of themselves, but to others as well, if the crowd impeded their ability to control their chair:

> *"sometimes when I'm in a crowd, I feel that somebody could quite easily fall on me, fall on [my wheelchair control joystick] and I could injure them… So I don't like crowds, just because my arm's there, my elbow's out, and if anybody knocks my elbow, I'll… I'll… take them out, you know! It's like a tank this chair!"*
>
> *(Anne, post-journey interview).*

The presence of crowds compounded another issue, the issue of safety in the interaction between a powered wheelchair user and others around them:

> *"when it's really really busy, and you have loads of people around you, that can be quite intimidating… you also have to make sure that you're driving your chair responsibly so that you're not putting anybody else at risk"*
>
> *(Jessica, post-journey interview).*

Participants explained how non-disabled people made incorrect assumptions about the capabilities of wheelchairs, which extended to how they interacted with wheelchair users. Several reported that people misjudged how much space they would need to get past or manoeuvre in their chair. One person described how

> *"sometimes you get people jumping back. And… people are very unsure. But they always think you're going a lot faster than you are" (Geoff, interview).*

This uncertainty could result in people behaving unpredictably, which further complicated the interaction between the wheelchair user and the non-disabled person. As David explained,

> *"if they're fifty yards away they'll apologise for being in the way, and they'll jump out the way if I'm twenty yards away as if I'm going to run them over at seventy miles an hour. So it's very strange how people react to wheelchairs" (David, post-journey interview).*

The unpredictable behaviour of others could be dangerous: people risked being run into by the powered wheelchair user if they stopped suddenly in front of them. Given the weight and bulk of powered wheelchairs, participants expressed concern over the potential to injure others, reflecting the 'policing' they had to do of their own movements to negate this possibility. These issues are related to wider notions of disabled people needing to assume particular responsibilities around their bodily self-management and presentation in order to

cater to the expectations and requirements of non-disabled society (Scully, 2010). As such, they also reflect broader hegemonic discourses which assert the supremacy of unimpaired, mobile bodies (Imrie, 2000a). This suggests not only that disabled people must undertake additional work to overcome non-disabled people's prejudices around the bodily (in)competence of disabled people, but also that their formal right of disabled people to access public space is contingent on them exercising what society considers to be 'appropriate' responsibility for their bodily competence and deportment.

Participants' awareness of the potentially unpredictable actions of others was particularly notable at several points during my journeys with them. David's recordings within the cramped confines of a pedestrian tunnel at King's Cross underground station demonstrate how carefully he had to move to negotiate crowds of passengers. On several occasions in under thirty seconds, he was forced to slow down or even stop as his way was blocked by groups or individuals, which he described in the post-journey interview as *"rushing towards"* him (Figure 12).

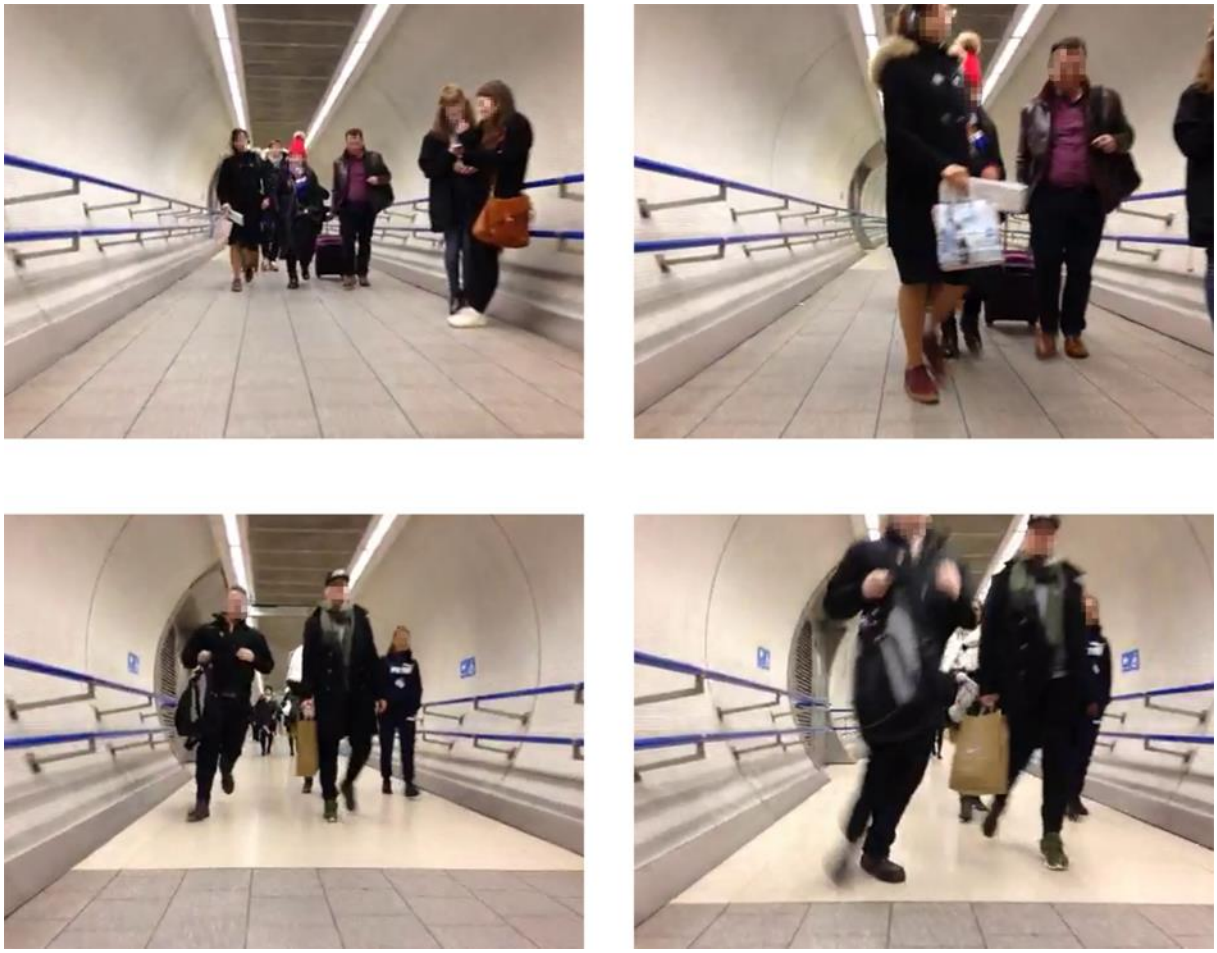

Figure 12: David's JourneyCam footage: sequence in a pedestrian tunnel in a London tube station, as people walking or running in the opposite direction repeatedly blocked his path and forced him to stop moving

In the interview, he made it clear that his caution was related to his perception that he would be blamed for a collision:

> *David: I'm very cautious 'cause I don't want to be one who causes an accident because someone is going to walk into me, I want to be stationary or very slow.*
>
> *Interviewer: Does that caution… can you tell me about that caution? Is it a defence thing? Or–*
>
> *David: Yeh, it's… so that I'm not… held liable if something goes wrong, 'cause I'm the one with the heavy machinery and I would be seen as the more dangerous of the two people crashing.*
>
> *Interviewer: Even if it's someone else running into you?*
>
> *David: Yes. I don't know whether that's how it would be seen, but I don't want it to be risked.*
> *(David, post-journey interview).*

Despite several other participants noting the danger their chair could pose to others, not all participants described their behaviours around crowds as manifesting in caution. Geoff compared the experience of being a wheelchair user in a crowd to being a pebble in water, where the 'gap' behind you was filled immediately. He explained how, when he was a wheelchair user, he *"tend[ed] to go through crowds quite firmly"*, which worked for him but didn't account for the presence of his PA:

> *"[in] Trafalgar Square… people parted for us. But [my PA] was behind, and they were completely hit! 'Cause what people would do is they would walk around, and then immediately walk behind the chair and the PA just got hit by this torrent of people coming at them because they didn't keep the space. Although the PA was immediately behind, people didn't think that person was with us, and… basically the space that was in front of the PA, between them and my chair, was filled by people coming the other way" (Geoff, interview).*

In this example, the interactional dynamics between a powered wheelchair user and the public had changed because of the presence of a personal assistant walking behind him. It again demonstrates how disabled people have to 'manage' their movement and that of people around them as they pass through busy public spaces.

As well as crowds, some participants described other 'indirect' behaviours of non-disabled people as problematic and disabling. Jane, for example, described the barriers posed to her by the behaviours of smokers:

> *"cigarettes do my head in, because they're right in my face level, say if someone's walking along with a cigarette I will dodge them, because it's right in my face. So you've got the smoke, you've got… [feeling] like… am I gonna be burnt, things like that. Like I've heard a story of someone being burnt on the face with a cigarette, because obviously it's that level!… So I will dodge. I hate it. That is like a pet peeve" (Jane, post-journey interview).*

When asked about their thoughts on smoking, several subsequent interviewees also talked about the same issue faced by Jane.

The examples above demonstrate how the everyday, unintentional, and even subconscious behaviours of other members of the public could have disabling effects.

4.3.2 Direct actions

As well as the indirect interactions described above, participants discussed at length the more 'purposeful' or direct interactions they had with non-disabled people. These were described as highly variable, and were most often characterised as being at one of two extremes, either 'positive' or 'negative'. The characteristics of especially positive or negative actions shed light on behaviours and attitudes that participants found particularly enabling or disabling. Participants highlighted how these interactions could make or break a journey:

> *"The people will make the whole experience worth it or not. Bumps, uneven footpath, even if you can't move… it's the fact, that's that. But people's attitude can either… completely erase all that, or can make it worse" (Anne, post-journey interview).*

Similar perspectives on the significance of other people's attitudes were expressed by a majority of participants, though the suggestion that positive interactions could make up for physical barriers was not widely expressed. A different perspective was provided by Ravi:

> *"if the environment isn't disabled-friendly, then even if people… treat you nicely, you're still going to have a problem, because people being friendly and treating you right isn't gonna get you up a flight of stairs" (Ravi, interview).*

Many described having had mostly positive interactions with others. David explained, for example, how *"more than 99% of people are very keen to be helpful"* and will *"bend over*

backwards" to move things or make room for him in confined spaces. Jessica concurred, explaining how other people could be 'incredibly helpful':

> *"Yesterday, when I parked the car to go to the station, three different people asked me if I wanted help when I was getting my wheelchair out of the car. That was really nice" (Jessica, post-journey interview).*

Another said that other commuters on her train simply asked whether she had a ramp organised at her destination. She felt that this was a good thing:

> *"[it's] nice, it's straight to the point and it's not sort of beating around the bush or anything, which I quite like because… y'know, especially on the way to work I've not got time to stop" (Jane, post-journey interview).*

In her interview, Jane noted that awareness of her needs as a powered wheelchair user was something that non-disabled people could develop over time, describing how her friends had come to recognise disabling barriers when they travelled with her, and now proactively sought out accessible venues to ensure she was able to participate in group activities.

What was common to these positive interactions was that participants felt they had been treated with respect and dignity by others. However, as well as providing examples of interactions that were positive, participants also described negative interactions with others. While offers of assistance were generally received positively by participants, they also discussed how other people sometimes made unhelpful assumptions about their needs as wheelchair users. In these cases, offers of assistance could be deeply unhelpful. Several described interactions where their wishes were ignored by other people claiming to be 'helpful'. Moreover, it is worth noting that disabled people sometimes feel compelled to show gratitude for any assistance they are offered (to the extent of 'performing' a disabled role) if this is the only way to get the assistance to which they are legally entitled (Scully, 2010).

In addition to offering unhelpful assistance, participants described non-disabled people doing 'the wrong thing', which manifested in several ways. Some were intrusive, asking inappropriate questions about the nature of the participant's impairment. Others stared at them because they were in a wheelchair (Garland-Thomson, 2006, 2009). Jessica explained that staring was widespread:

> *"you see a lot of kids staring at you. And you see their parents sort of tug them or say 'stop staring' [laughs]. And you see a lot of… adults that should know better*

staring at you like there's something's wrong with you" (Jessica, post-journey interview).

These interactions had the effect of 'othering' the disabled person, and as Jessica explained, of making them feel somehow 'less' or inferior. Jane explained how, as a younger woman who used a wheelchair, she attracted particular attention:

"[p]eople stare a lot at you, I'm so over it, I've dealt with it for–how long… I don't want to be like stared at and things" (Jane, post-journey interview).

She went on to say that she was *"immune"* to it, and wasn't bothered as she felt it was usually curiosity, except that she wished that if people had any questions they would simply ask her. However, other disabled people might find such questions intrusive. The acts of being stared at or questioned in this manner are forms of everyday ableism, as non-disabled onlookers attempt to know and classify – in individualised, medicalised terms – those who look different to themselves (Calder-Dawe et al., 2020). More generally, such actions demonstrate a lack of awareness amongst non-disabled people about disabled people's lives and experiences, and suggest that non-disabled people do not respect appropriate boundaries in their interactions with disabled people.

In some cases, participants described how these interactions could sometimes involve non-disabled people making offensive or patronising assumptions. One participant explained how the disabled parking bay at her GP was being used by someone who did not have a blue badge, and on asking if she could park there, received verbal abuse. She described how the other driver:

"started having a go at me and she said that disability… was a life choice… [and then] she started shouting at me" (Jessica, post-journey interview).

Jane described being accosted by Jehovah's Witnesses on her way to work:

"[they] stopped me for ten minutes to say I was suffering. Which I just thought was really rude!" (Jane, post-journey interview).

She also described an incident where an older woman had commented to no-one in particular, on seeing her on the bus, that it was the *"invalid's day out"*. Although she said to the woman *"you can't say that, that's not acceptable"*, she explained how she was annoyed because *"no–one else on the bus said anything"* at the time, although several did so after the older woman had left (Jane, post-journey interview).

Assumptions made by non-disabled people about participants' lives, and how these did not align with participants' own identities, experiences or needs, were widely reported. Many participants felt that these attitudes stemmed from non-disabled people's ignorance about disability. When asked whether non-disabled people understood the challenges wheelchair users faced, Ravi's response highlights how technological solutionism to issues of access would not solve the barriers faced by disabled people:

> *"no, I don't think people would know, they assume that the problems would be a ramp, or if there's… automatic doors then that that sorts the problem… they wouldn't realise the issues that are really affecting disabled people. They kind of try and guess, but… they kind of sometimes may get the wrong end… of the stick" (Ravi, interview).*

Many of the interactions described above were due to the ways in which other members of the public behaved towards and around wheelchair users. However, participants also explicitly highlighted ways in which their interactions with members of staff affected their experiences of mobility. This was due to the central and often authoritative role that staff play in helping to facilitate disabled people's mobility, discussed in the next section.

4.3.3 The pivotal role of staff interactions

Participants drew particular attention to the interactions they had with staff, who are figures of 'everyday' or 'street level' authority. Whether these are public sector 'street level bureaucrats' as per Lipsky's (1983) formulation of the concept, or public-facing workers in the private sector, is less relevant than the fact that public-facing staff of service providers exercise considerable discretion in carrying out their duties and thereby hold power over disabled people who might require their assistance. For this reason, many participants described how interactions with staff of bus or train operators could have a significant effect on a powered wheelchair user's journey.

These interactions were thus critically important to their experiences of mobility. Anne explained how, as a wheelchair user waiting for a bus, she anticipated the different ways in which an interaction with a bus driver might unfold:

> *"you can see the driver's face as they're coming. And you can feel it… they come up and then the door opens, and there's a gap that big, and [if they asked to move the bus closer] their attitude will either be, 'I haven't got time… you have to wait for the next one'… or 'yeh, alright love, give me a moment, I'll just reverse and come back'. Completely different" (Anne, post-journey interview).*

Participants felt that public-facing staff had little or no immediate supervision and had a large degree of day-to-day autonomy in their work, and that these factors meant that poor behaviour went unmonitored. Although in some locations this may not actually be the case, with previous research identifying how remote monitoring influences the work practices and personal interactions of London bus drivers (Pritchard et al., 2014, 2015), these staff held considerable power over the experiences of wheelchair users. Participants highlighted the negative impact on them when such power is abused. For example, David characterised bus drivers as

> *"loose cannons [who] they can do as they please, they can be as rude as they please, they can be as unhelpful as they please, nobody is there to spot it. And there's no incentive for them to behave well… unless they're reported" (David, post-journey interview).*

Having travelled with him on a bus, I observed this kind of interaction first hand. Despite using the 'disabled' button to request the ramp be deployed at two consecutive stops, the driver drove off on both occasions. When David called out loudly to the driver after the second incident to alert him to the fact the button had been pressed, the driver aggressively accused him of not having pressed the button at all.

Yet working with other participants (Figure 13), I observed how interactions with these staff could be much more positive. Prompted by a video she had taken on a bus, Jessica gave a detailed description of how interactions with the driver could make or break a journey.

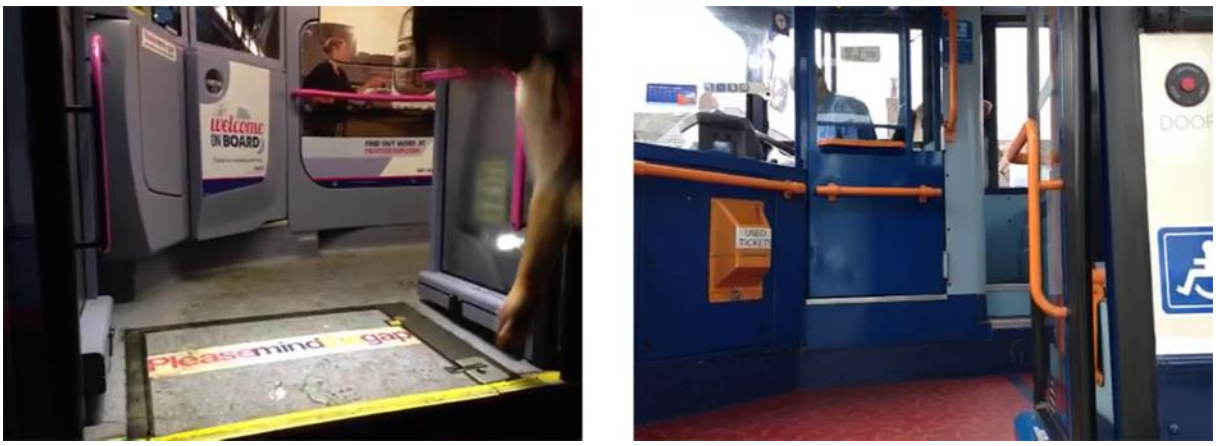

Figure 13: Jessica's (L) and Melissa's (R) JourneyCam footage of interactions with drivers as they boarded buses with manually deployed ramps

She first described previous situations where a bus driver's actions had negatively affected her journey, to the extent of risking her safety:

"the bus driver's not really interacted… not really bothered where I am [positioned]… I've been in the aisle before and I've had to wait until [the bus] stops again before I've gone into the correct place… [or] there's been a pram that's attempted to move, but only sort of moved towards the wall, so there's still not space for me to get in. I've been on a bus where… [the driver wasn't] bothered whether I've been facing forwards, backwards, sideways!" (Jessica, post-journey interview).

She highlights the lack of care shown to her drivers who did not ensure she was safely positioned in the wheelchair space before moving off, and draws attention to the difficulties associated with interactions with other members of the public who aren't willing to move to assist this. She went on to describe, in contrast, a far more positive interaction with a bus driver who not only was attentive to her needs in accessing the wheelchair space in a confined bus, but who also set her at ease through friendly engagement and humour:

"the bus driver was really lovely… he came with me to help me manoeuvre into the place… [it was] very very tight so it was a hundred point turn [laughing]… he had… me as well as all the other passengers on the bus… laughing and everything… he was like a real comedian… [but] he's actually made a very awkward situation so much nicer by having a laugh about it. And saying things which were just funny, you know, and helped the situation, eased the situation… That was a potentially awful experience – but actually it wasn't because of him, because of that driver."

"He understood the situation I was in, and I think he read me very well… all the humour… it was me and him, me and him, me and him… he was talking to me like I was human, and… he was helping me get to where I needed to be, in a very tight space, that took me quite some time, but there was no pressure… it was 'take your time, don't worry about it, don't need to be anywhere', 'only finished three hours ago', y'know, that sort of thing, it was just all really light humour… when I got off the bus I actually said, 'can I say from the bottom of my heart, thank you so much because you've been so lovely', he said 'oh, don't be daft, it's just part of my job', but actually it wasn't… his part of the job was to get me on the bus safely, but he went above and beyond… [it was] another example of an individual working for an organisation making the best of quite a difficult situation because that was the tightest bus I think I've ever been on… had he not been like that, that would have been a very negative experience for me"
(Jessica, post-journey interview).

Although this example was unusual in making such a positive impression, it is worth noting that positive staff interactions fairly commonplace in participants' experiences. Most felt that the vast majority staff were positive and did at least try their best to be helpful. One explained how staff on a regional transport network *"were so friendly that they would… walk you to the lift, press the lift button for you, and see you onto the lift"* which he described as *"way above and beyond the call of duty"* and as *"generat[ing] a wonderfully warm feeling of being taken care of and respected"* (David, post-journey interview).

If participants travelled on certain routes regularly, and encountered the same staff repeatedly, this sometimes fostered relationships that brought about positive interactions. I witnessed this on my journey with Jane, who when I asked about the interaction I observed with a guard on their train, exclaimed *"he's great, I see him all the time there!"* and commented that that *"the same people work… the train, that route. So I do sort of know them… I don't know them, but… they know of me, sort of thing"* (Jane, post-journey interview).

The existence of at least a passing relationship with responsive and helpful staff can have a significant positive impact on people's journeys, and this may suggest ways of improving the experiences of wheelchair users. Rostering patterns that enable particular staff to have consistent shifts, for example, might foster this kind of relationship with regular travellers. However, it is worth noting that this could work in reverse: if a staff member's attitude is negative towards a wheelchair user, they would be exposed to this more often. While on a journey through his town, Anthony described how one particular staff member at a local station took his time when providing assistance and was over-familiar towards him in a way he found inappropriate. Where participants had poor experiences, they often described staff as being unaware of how best to interact with a disabled person or accommodate their needs. This might imply that disability awareness training was either lacking or ineffectual. Some participants, however, expressed the belief that it was about more than simply training, and came down to the kind of person they interacted with.

As with material factors, it is worth noting that the interactional issues described above also highlighted the sheer unpredictability of disabled people's experiences. Such variability applied to interactions with staff and with others on their journey: a helpful member of staff or passer-by could be an enabler, whilst a rude person could disable. Yet social interactions were highly contingent on a range of factors: the individuals involved, their attitude or

mood, whether they were in a rush or otherwise under pressure, and so on. Staff dealing with major disruption on the railways, for example, might be unusually curt or otherwise unhelpful. For a disabled person reliant on that staff member to assist them in their journey, this negative interaction might have a significant disabling effect. Even where environments or services have been adapted to make them more accessible, and in some cases reduce disabled people's reliance on others for access, 'enablers' could sometimes themselves cause disablement. Such situations are examined in the following section.

4.4 Enablers as Disabling

This section discusses how certain features or services that are intended to improve access for disabled people can sometimes have the opposite effect. These 'enablers' are often material features such as dropped kerbs, or exist at the nexus of material and interactional factors. An example of the latter is the provision of ramp assistance for trains, which relies on both material enablers (ramps) and on interactions with train company representatives before and during the journey in order to deliver a co-ordinated service. What unites the enablers in this section is that they offer the promise of a more accessible environment or mode of transport that is not always reflected in reality. As such, despite being intended to improve the experience of disabled people they can in fact become 'disablers'. As with other barriers, they often require in the expenditure of significant effort and time to work around.

There are two broad ways in which accessibility features can function as disablers: through their absence, or through being unfit for their intended purpose. In the former, it is the lack of these accessibility features where they might reasonably have been expected which participants found problematic. In the latter, where accessibility features did exist, they were often perceived to be inadequate for various reasons. Yet the mere presence of these features – however poorly designed or badly implemented – implied that an environment was 'accessible', wrongly giving the impression that disabled people's needs had been addressed. As discussed below, this was not necessarily the case, pointing to a gap between a 'tick box' understanding of accessibility and the reality of disabled people's experiences. The following section describes how inadequate provision of key accessibility features can serve to disable, drawing out some of the material and social issues described above. Although this section focuses on particular 'enablers as disabling', the examples given are illustrative of the wider links between social and material factors, and certain themes such as the failure of maintenance or the fragility of service provision are common across them.

4.4.1 Dropped kerbs

An almost ubiquitous aspect of the urban environment, discussed by all participants, are the 'dropped' kerbs which are provided to enable wheelchair users (and others with mobility impairments) a smooth transition between the pavement and the road. These are typically provided at junctions, pedestrian crossings, and entrances to driveways. However, travelling with participants demonstrated how in many places where one might reasonably expect dropped kerbs, such as at road junctions in popular and highly trafficked areas of Central London, they were conspicuous by their absence. One person commented how:

> *"in somewhere like London you wouldn't expect to find no dropped kerb. But today, with you, on the way here, we encountered… a couple of pavements with no dropped kerb" (Matthew, post-journey interview).*

Our journey had taken us along Oxford Street and the surrounding area, which are very heavily frequented by tourists and Londoners alike. In this case, Matthew was incredulous that these areas lacked dropped kerbs, and were therefore remarkably inaccessible for wheelchair users. The inaccessibility of this area of central London was, in fact, mentioned by several participants. David took me on a journey through nearby Soho, where not only were there few dropped kerbs even at junctions or where driveways crossed the pavement (Figure 14), but the kerbs themselves were also unusually high.

Figure 14: A pavement without a dropped kerb in a busy part of central London, preventing powered wheelchair users from crossing the building's service entrance and continuing along the pavement (author's photograph)

We had to retrace our route on several occasions as we reached junctions that he could not cross in his chair, adding considerable time and frustration to our journey. One example was when we were blocked by scaffolding and building works, discussed earlier in this chapter, though similar things happened several times because of the scarcity of dropped kerbs. They explained how this was a particular problem within that local government area:

> *"[i]n Westminster they're absolutely terrible, especially around Soho. But all over Westminster, it's a particularly terrible borough" (David, post-journey interview).*

His comment highlights how the provision of dropped kerbs, probably the most common accessibility feature in the built environment, is ultimately the responsibility of local councils, and could therefore be quite different in different geographies. This likely reflects the devolved nature of access policies and practices, which vary significantly between local government areas (Imrie, 2000b).

However, even where dropped kerbs were provided, participants regularly found them problematic. I frequently observed how their wheelchairs bumped visibly over the edges of dropped kerbs, and how participants had to slow down and alter how they drove their chair in navigating them. This was often because the residual 'upstand' of the dropped kerb was still impassable or the incline was too steep. There is complex guidance around the installation of particular forms of paving, such as tactile paving and dropped kerbs, relating to their proposed use and location (Department for Transport, 2005; Department of the Environment, Transport and the Regions, 1998) aimed to ensure accessibility. In theory all paving should be built and maintained to these standards. Yet participants' perceptions of these features was that they were not adequate: Jane's explanation that a particular kerb *"isn't a proper dropped kerb"* was a common sentiment.

Sometimes, this was because a kerb did not meet the appropriate regulations. Jessica noted how her local council had acknowledged that the dropped kerbs in her neighbourhood were not compliant with guidance:

> *"there are so called dropped kerbs, but there's still quite a big gap to get on them… the council acknowledged that when they came round, that they… weren't flat… and they couldn't be considered as a dropped kerb" (Jessica, post-journey interview).*

Despite this, the issue had still not been resolved at the time of our journey and interview, many months later. Not only does this demonstrate how the adequacy of the provision of an accessibility feature is dependent on the implementation by local councils, but it also raises questions about the priority afforded to enabling a disabled resident to access their local area.

However, at other times, participants felt that the provision of an accessibility feature such as a dropped kerb was inadequate, even if it complied with formal specifications. This points

to a gap between the understandings of accessibility, as codified in standards documents or formal specifications for accessible environments, and disabled people's lived experiences of what it meant for something to be accessible.

4.4.2 Lifts

Most participants mentioned the presence of lifts as an important accessibility feature for wheelchair users, as their absence often renders an entire building or mode of transport inaccessible. Several participants discussed this in relation to the London Underground, much of which is completely inaccessible to wheelchair users (Transport for London, 2021a). A further problem is partial accessibility, due to provision of lifts to only certain parts of a transport system. Some stations only have step-free access to particular lines even if the rest of the station is accessible. In some cases, the inaccessibility of a particular platform may render a line inaccessible in one direction only, adding significant complexity to journey planning. Such a situation can mean that wheelchair users must take entirely different routes or even modes of transport on their outbound and return journeys, as I did with one participant in London.

However, as with many other accessibility features, even when lifts were provided there were many ways in which this provision could be inadequate. In some cases, the distinction between 'non-provision' and 'inadequate provision' of an accessibility feature could be unclear. In particular, maintenance is especially important for mechanical accessibility features such as lifts or retractable bus ramps, as they are prone to failure in ways that fixed environmental features such as ramps are not. Participants often described encountering broken lifts, which they related to issues of inadequate upkeep and proactive maintenance:

> *"I think that people have a responsibility to keep lifts in good working order, and I don't think they do that, I think they deal with lifts reactively, they let them wear out and break down and then they deal with the problem… There's no proactive attempts to keep things going… it can be very unreliable" (David, post-journey interview).*

Dealing with these issues reactively means that following a failure, there will inevitably be a period of time where an inoperable lift (or other feature provided to aid accessibility) poses a barrier to the disabled people who rely on it. This has the effect of disabling a wheelchair user, as if the accessibility feature had not been provided at all. However, such a failure can in fact pose a greater barrier than the lack of the feature in the first place, as by its nature it

is unpredictable and therefore hard to plan for. Participants may have made the reasonable assumption that a route was accessible, only to discover mid-journey that a lift failure had rendered it inaccessible and left them trapped or at best inconvenienced and frustrated.

Yet even when present and functional, lifts could pose problems for accessibility, often due to inadequate design or implementation. For example, the provision of audible announcements in lifts is meant to enable those with visual impairments to know which level they are on, and to provide warnings about opening and closing doors. Yet when travelling with David, the lift announcements at one London Underground station were simultaneously so muffled as to be barely comprehensible, and so loud as to be painful. He compared these unfavourably to the clarify of the announcements at a major railway station that we had passed through earlier on our journey together. Again, this experience suggests that the formal provision of what is intended to create an accessible environment does not necessarily result in something which is in fact accessible to disabled people.

Service providers have a legal duty to anticipate the needs of disabled people and make 'reasonable adjustments' to accommodate them (HM Government, 2010). This might include measures such as fitting a lift or ramp, or replacing an inaccessible vehicle by a specific date. However, what is 'reasonable' is contingent on the organisation and its resources, as well as the nature of the service that it provides. Moreover, it is clear that there is a gap between formal understandings of accessible environments and participants' experiences. It is clear from their comments on the frequency of equipment failures, and the impact these have on their lives, that their expectations of what organisations ought to provide and maintain is not matched by the reality of service provision.

4.4.3 Lowered counters

Another feature aimed at improving access for disabled people is the provision of lowered counters at places where wheelchair users interact with staff, such as at station ticket offices. Yet as with lifts, the mere provision of such counters does not necessarily ensure accessibility. As we passed through a major railway station in a large city, Jessica highlighted that the single lowered counter was closed (Figure 15).

Figure 15: Jessica's JourneyCam footage of the only lowered counter at a major railway station, which was closed

At a different station later in our journey, she pointed out the total absence of lowered counters, and in the subsequent interview explained how this impacted on her interactions with railway staff:

> *"There were no [lowered] counters… And that happens a lot, in a lot of places I go… one thing that I am very particular about, and I don't think it's a particularly big ask, is that when I'm talking to people I can see their face… [Sometimes] I've had to say 'please can you stand up so I can see your face when I'm talking to you'… I've had mixed receptions to that in the past… At that particular counter I'd have been able to see them, but… they'd have probably only been able to see the top part of my face, and I'd have had to reach up to use the card machine… you just get used to it. But… I would much prefer to go to a lower counter" (Jessica, post-journey interview).*

Indeed, when I returned to the first station the following day, the lowered counter was again closed, supporting the participant's suggestion that this was a common occurrence. The closed or absent lowered counter not only meant that this participant had to use a less accessible counter, but also exposed them to the possibility of more difficult interactions with staff. Throughout the fieldwork, material and interactional aspects of accessibility were linked in a similar manner. As will be discussed in the following chapter, disabled people already incur hidden labour in the process of managing their interactions with non-disabled people (Scully, 2010). Additional barriers, such as those imposed by the non-provision of accessible counters, can compound the challenges associated with disabled-nondisabled interactions.

4.4.4 Accessible toilets

Many participants raised accessible toilets as example of a very important accessibility feature which they often found problematic. As with other accessibility features, this was often due to their absence, although problems were also discussed which related to poorly designed or implemented accessible facilities, or the misuse of such toilets for other purposes such as storage. All of these issues have been identified in prior research, with Kitchin and Law (2001) noting how the paucity of accessible toilets constrains disabled people's participation in public space. There is historical precedent for the segregation of bodies that society considers abnormal, in the incarceration of those considered 'incapable' in hospitals, workhouses and asylums (Gleeson, 1999b) and the prohibition of 'unacceptable' bodily forms from public spaces through "Ugly Laws" in the United States (Imrie, 2014, p.17)

Several participants talked about how they had to plan their trips around the locations of known accessible toilets in particular locations, which had the effect of restricting their movements around towns and cities. In addition to highlighting the widespread absence of accessible toilets, participants explained that where they did exist the provision they offered was often unsuitable or compromised. One person explained how on quite a few occasions they had come across situations where shops *"just use [accessible toilets] as storage for extra… chairs and things"* (Matthew, post-journey interview). Others, such as Jessica, highlighted how accessible toilets were often poorly design, with heavy entrance doors or awkwardly laid out cubicles. This made them very difficult to use for powered wheelchair users. Several explained how the emergency alarm cord was often tied up out the way, rather than hanging loose as it is designed to, which would prevent it being used and mean a disabled person was unable to summon help. To my astonishment, while waiting for a participant in one modern office building, I came across an accessible toilet located behind a step (Figure 16).

Figure 16: 'Accessible' toilet located behind a step in the foyer of a modern office building

Participants' experiences highlight several issues relating to the provision of accessible toilets as a form of 'enabler'. The widespread inadequacy of provision – the paucity of accessible toilets, their poor design, their frequent misuse, and the spatial exclusion and political disenfranchisement that these lead to – have been recognised in prior work (Kitchin & Law, 2001). More recently, perceived limitations of even supposedly 'accessible' toilets have led to campaigns such Changing Places, which seeks to provide publicly accessible toilets with more comprehensive facilities, such as hoists, for disabled people (Changing Places, 2018). However, despite clear standards for the provision of accessible toilets in Part M of the 2010 Building Regulations (HM Government, 2015) participants related that many buildings they encountered in their day to day lives still lacked accessible toilets that were fit for purpose. This data suggests critical differences between formalised understandings of what constitutes an accessible space, and how such standards are enacted and experienced by disabled people in everyday life. It also highlights that the provision of accessible facilities is not simply a material concern that is addressed once they are built, but rather is an

ongoing issue that is contingent on short term fluctuations and temporal issues such as whether the toilets are being misused as storage on a given day.

4.4.5 Accessibility features on public transport

Participants identified a range of issues in which accessibility features of public transport could be disabling, many of which exist at the intersection of material and social factors. Prior research has documented how disabled people are disadvantaged by inaccessible public transport, which denies them the freedom travel where and when they like, constrains participation in employment and social activities, and thereby reinforces socio-economic disadvantage (Gleeson, 1999b, p.138; Kitchin, 1998). Participants discussed their experiences of accessible public transport in their interviews, and most emphasised its value and importance to them with many also taking me on a bus and/or train journeys. Although they described improvements in public transport accessibility over time, they also discussed how the features which support this improved provision for disabled travellers were often fragile and could be problematic. These features, and their effects on accessibility as experienced by the participants, are discussed below.

Most participants described their experience of buses, likely due to their relative ubiquity as a mode of transport: unlike trains, trams, or metro systems, buses are commonplace across the country. In major cities, where the fitting of bus ramps is widespread, they therefore often formed a key mode of accessible transport for participants. This is in spite of falling patronage and reductions in services outside London in recent years (Department for Transport, 2019). Even in places where alternative modes of transport such as the London Underground are available, these are may not always be fully accessible to wheelchair users as previously discussed. Buses therefore offer a means of mobility with a broad reach for a variety of journeys in comparison to other modes of transport, as David explained:

> *"the tube system is virtually useless, almost useless to me. For most journeys, so I end up going by bus which takes twice as long" (David, post-journey interview).*

Although many participants used buses, they were not uncritical of their limitations. As above, this was sometimes to do with the service quality: buses are considerably slower than the London Underground. In other cases, it was in relation to the physical aspects of the design of buses, such as the lack of space in which to turn around. However, comments on these material aspects often exposed other concerns of a social or interactional nature:

> *"I don't really like using the buses, as sometimes I can't manage to get up the ramp by myself and need someone to help me" (Matthew, post-journey interview).*

As someone who used powered hubs on a manual wheelchair, Matthew found bus ramps too steep to manage alone, and therefore had to ask for help from bystanders or the driver. In this way, a disabling aspect of the physical environment necessitated an interaction, which they would have rather avoided in terms of maintaining their independence. As already noted, such links between social and material factors were very common.

Railway travel was discussed in detail by several participants. Much of the UK railway network is not step-free and so poses an accessibility challenge to wheelchair users: many stations date from the Victorian era and platforms have varying heights and curvatures, while some trains that do not comply with the 1995 Disability Discrimination Act were granted Ministerial 'derogation' to remain in service beyond their intended withdrawal deadline of January 2020. Due to the widespread use of high floor rolling stock and the variability of station platforms, even trains which are compliant with the 1995 Act are largely inaccessible except through the use of 'ramp assistance'. This is a service by which wheelchair users can contact the train operator in advance of travel, and be met by staff members who will deploy manual ramps to enable step-free access from platform to train.

However, participants discussed various ways in which ramp assistance as an 'enabling' feature was problematic. Perhaps the most serious of these were the times when, despite being pre-booked, ramp assistance simply did not turn up for them to board their train. Some participants also explained how they had been carried off to an unintended destination, because ramp assistance had not been provided at the intermediate station where they wished to disembark. From participants' descriptions, these were relatively common experiences. Matthew explained:

> *"I've come into Paddington before, and nobody's been there with the ramp… [on another occasion] I was assured there was a guard on the train and he was going to get the ramp for me. The guard didn't come… I ended up having to get another passenger to shout up to the driver of the train, and… that delayed the train for… a few minutes" (Matthew, post-journey interview).*

The non-provision of the ramp in this case needlessly delayed the wheelchair user, as well as all the other passengers on the train. But it also forced them to ask for help from other

passengers, making them dependent on the goodwill of strangers, as well as inflicting on them emotional labour as they were concerned about being left behind (Scully, 2010).

The non-provision of ramp assistance was more than a mere inconvenience for participants: it could potentially be very serious. David explained how on one occasion he was left behind on a train at a major railway terminus with no means of alerting anyone:

> *"[the] ramp assistance didn't come in good time, the driver closed the train down, shut the doors, and switched off the electrics so I couldn't open the door. So from my point of view I was completely imprisoned in the train. And could easily have been whisked away to the sidings or to the… depot, and could have been on the train for hours, potentially" (David, post-journey interview).*

The frequent failure of ramp assistance to be provided, despite pre-booking, was clearly a source of severe annoyance to many participants. It was also a failure that they found bewildering, with several asking how what they perceived as a relatively simple system could go so wrong. Even when it was available, several participants explained that the staff providing ramp assistance did not always do so safely. Participants described how some staff would not secure the ramp properly, posing a danger to them if they were to travel over it. Again, these issues point to a lack of understanding amongst non-disabled people as to the needs of disabled people. As participants perceived it, it also suggested that there was an absence of appropriate training to address this issue.

Participants also criticised the way in which ramp assistance had to be pre-booked by ringing up the train company at least 24 hours in advance of travel. This forced them to anticipate in advance whether or not they would need to make a journey, something which was not always possible. It also constrained their journeys to specific services at particular times, reducing the flexibility that non-wheelchair users take for granted when using public transport. As Amber explained, pre-booking made it impossible to be spontaneous, which in turn could lead to further problems:

> *"you can't just decide to go somewhere… we can't just decide, it's a nice sunny day [and] we'll go to the beach. I can't just wake up and take my child [there]. [And then] there's always an element of 'oh we have to leave, we have to leave'… It's really constraining. It's really really frustrating" (Amber, post-journey interview).*

This issue, of being compelled to pre-plan their mobility in a way that non-disabled people did not, was something mentioned with great frustration by almost all participants. Disabling

environments meant that trips had to be carefully organised in advance, often in great detail and with 'back up plans'. If they did not do this, participants risked being unable to get to their destination, or worse, ending up stranded. Participants contrasted their own pre-planned, constrained mobility with the freedom enjoyed by non-disabled people, highlighting the inequality they experienced due to being wheelchair users.

Participants also explained how, once they boarded a train, other accessibility issues came to the fore. This included the lack of a dedicated wheelchair-accessible spaces on older vehicles, which meant that wheelchair users being forced to travel in the doorway areas. I spent a lengthy journey with Matthew in the doorway area of one train, which caused both material and interactional issues with other travellers. When he boarded, a cyclist who was stood in the doorway had to move out of the way, and as the participant later recounted:

> *"if this was a wheelchair accessible carriage I'd just go in, and wouldn't have to worry about that man there and he wouldn't have to worry about me" (Matthew, post-journey interview).*

Over the course of the journey, the train became busier as it picked up passengers at intermediate stops. These crowds left Matthew cramped into the corner of the door area, with little room to move (Figure 17).

Figure 17: Matthew travelling in the doorway area of the train (L) and repeatedly having to move around other passengers as they boarded, which left him eventually cramped into one side of the doorway area (author's photographs)

I experienced a similar situation on a busy rush hour train with Jane, who in her interview described the problems posed by crowds as partly due to us having been boarded on to the 'wrong' carriage (one without a dedicated wheelchair space):

> *"it's so busy, and… there's nowhere to go. The disabled [carriage] has space, [because] it's got no seats in it" (Jane, post-journey interview).*

In both cases, participants noted how the cramped confines of the trains in which we travelled together hindered their accessibility, contrasted them to the spaciousness of more accessible alternatives, and noted that this caused interactional issues with other people. Several participants mentioned the London Overground as an example of a modern system which had been designed with the needs of wheelchair users and other disabled passengers in mind. However, such modern and more accessible alternative modes of transport were not widely available.

4.4.6 Information about accessibility

A common complaint amongst participants was that information relating to the accessibility of a given space or service was not widely available or up to date, and that where it was provided it was either inaccurate or insufficiently detailed. Even when they specifically sought out accessibility information it was not forthcoming. They explained how non-disabled people often made incorrect assumptions about what would be 'accessible' when asked to provided information about the accessibility of particular environments. A linked issue was that what they provided was either totally incorrect, or not the information the disabled person needed to make an accurate judgement about the accessibility of the environment.

These issues were particularly common in relation to commercial premises, where different venues could have significantly different accessibility. Several people described having rung ahead and been assured a restaurant was accessible, only to find out it was not once they arrived. Anne described being reassured by staff that a 'themed' restaurant was accessible before taking their young relatives there for a special meal. However, on arrival they discovered that their table was located on different floor, without many of the themed attractions they had specifically taken the children to see. To make matters worse, they were the only people on that floor. As this person explained, it was the lack of information provision that they found difficult to accept:

> *"I understand listed buildings, and I understand I can't get everywhere, but then you've got to tell the person exactly what the situation is… have the respect to tell me that if I make all that effort to get there, you will be on another floor, and if we're not fully booked you might be on your own there" (Anne, post-journey interview).*

Many participants described similar experiences, where they expended additional effort to determine the accessibility of a route or place in advance only to find that the information they received was incorrect or inadequate. One person explained how a 6" high step was assumed to be smooth and therefore 'wheelchair accessible'. This again demonstrates the additional labour that disabled people must undertake to gain access to particular spaces beyond that of non-disabled people, and that even this effort can be wasted when the information is inaccurate.

A related concern expressed by many participants was the belief that information provision and signage for wheelchair users could be significantly improved. On board one train in the north of England, one participant struggled to position their wheelchair safely, later explaining how that there were no clear signs or directions that they could see to indicate where they should be. Another participant and I spent several minutes trying to leave a platform at a major London Underground station, as neither of us could see the sign marking the lift on the platform. This was despite the participant praising the generally good signage and wayfinding on the London Underground network.

Many participants emphasised the inadequacy of signage and information provision about operational problems or technical issues. These contingent or changeable factors could significantly affect the accessibility of environments and therefore their mobility as wheelchair users. Improvements to the accessibility of historic buildings like railway stations were typically made many decades after their initial construction, and cost or engineering constraints can restrict the scope of these modifications. Lifts or ramps may therefore be located some distance away from the most direct route, forcing wheelchair users to travel a considerable extra distance to get to them. In turn, this often meant that they had begun a journey, or gone a long way down a particular route, before they encountered an access barrier such as a faulty lift. As David explained, this led to wasted time and effort:

> *"sometimes there's no signage to tell you the lift is out of order until you've got to the lift. So you waste more time getting back from the lift and then re-planning your journey" (David, post-journey interview).*

I experienced this alongside another participant at King's Cross St Pancras Underground station, where we made it through the gateline and past several members of staff on our way to the lift only to discover it was out of service. As the participant said to me at the time, it would have been helpful if those staff had warned us of this, as it ought to have been

evident to them that the wheelchair user going through the gateline would be unable to access the platform behind it.

All in all, what became clear through participants' descriptions and my journeys with them was an apparent lack of understanding or forethought amongst non-disabled people that if an accessibility feature was non-operational, environments once again became disabling. As such, the absence of adequate temporal and physical warning that an accessible route is blocked by a temporary barrier, such as a faulty lift, leads to significant inconvenience for wheelchair users. Not only does this needlessly waste time as wheelchair users are forced on longer journeys only to have to retrace their route, but it can also pose the risk of them being trapped in an inaccessible environment (for example, if they disembarked at a station where the lift was out of service).

4.5 Discussion: the Contingency and Complexity of Accessibility

This chapter has documented how a wide range of both material and social factors affect the experiences of powered wheelchair users, and can serve as both enablers and disablers in their experiences of mobility. The chapter has also examined how societal efforts to improve access for disabled people, through the provision of 'accessibility' features or services, sometimes fail to achieve this goal and can in fact perpetuate exclusion. Many of the material and social barriers participants identified, and the experiences they described, reflect long-standing issues that run through literature on the geographies of disability. Three common threads run through many aspects discussed in this chapter: the socio-material nature of enabling and disabling environments; gaps between formalised and experiential understandings of accessibility; and the contingent and changeable nature of disabling environments. Each is discussed in turn below.

First, the examples provided here have highlighted the entwined nature of the social and material factors that contribute to disabled people's mobility. These call into question the extent to which these factors may be strictly divided into either 'social' or 'material', suggesting instead that many exist on a continuum of socio-material influences on disabled people's experiences. Any response aimed at addressing disabling environments and making them more hospitable to disabled people must therefore be holistic: organisations should not assume, for example, that improving material environments alone will resolve the disabling barriers that constrain powered wheelchair users' mobility. Likewise an approach to addressing barriers that focuses only on social or interactional issues will fall short of

creating truly enabling environments if it does not also address the material environment and the complex interplay between social and material.

Second, many of the socio-material issues highlighted by participants revealed a significant gap between 'formal' and 'experiential' understandings of accessibility. The former, official understandings of what makes an accessible environment as codified in documents such as building regulations, were often at odds with the experiences of disabled people themselves in such environments and their knowledge of what would make them truly accessible. This gap was perceived by participants as being due to a lack of understanding amongst non-disabled people about disabled people's needs. Whether manifested in formal specifications that failed to account for diversity amongst disabled people, poorly implemented services, or unhelpful staff interactions, this lack of understanding led to disabling barriers. There is therefore an urgent need to pay attention to how disabled people experience accessibility, rather than treating it as a tick-box exercise. This includes engaging with the expertise and knowledge possessed by disabled people.

Finally, participants' experiences clearly highlighted how their mobility is affected by the variable and changing nature of disabling environments, and only some of these contingent factors are amenable to intervention. The accessibility of environments can change, and in some cases be undermined, by socio-material fluctuations. The material environment decays over time, while temporary blockages or weather conditions can block particular routes. Social interactions can enhance or detract from accessibility, especially when those interactions are with figures of everyday authority. The interplay between these socio-material factors further increases the variability experienced by disabled people, and even services intended to improve accessibility can be points of failure which can undermine their intended benefit. Participants' testimonies make it very clear that short-notice changes can be particularly disabling, as they undermine pre-planned efforts to ensure an accessible trip. In particular, the unexpected failure of a service designed to enable accessibility poses a greater barrier than a permanently inaccessible environment. Moreover, when things do go wrong, current service provision for disabled people is brittle and unreliable. The rigid inflexibility of 'accessibility' services provides another example the ways in which the needs of the non-impaired are prioritised under the hegemony of the mobile body (Imrie, 2000a).

The issues described above suggest that disabled people's experiences are not afforded sufficient importance by society at large, with many participants describing the provision of

accessible environments as an ‘afterthought’. Judging by their experiences, this is at least in part a reflection of how little the knowledge and expertise of disabled people themselves – in particular, their lived understanding of what enables and disables them – is brought into the design and provision of accessible environments. To take just one example, disabled people’s views are typically not incorporated into mapping processes, with the result that their particular ‘ways of seeing’ and knowing the urban environment are not incorporated into the maps which represent it (Matthews & Vujakovic, 1995), a shortcoming which an approach such as participatory mapping could begin to address (Kitchin, 2002). Most participants expressed the belief that their experiences and knowledge could be a useful resource from which non-disabled people could learn, which will be discussed further in Chapter 6. The data in the present chapter demonstrates the richness and depth of this knowledge possessed by disabled people about their mobility and the environments which enable it, and suggests that better engagement with these experiences might help to bring about more inclusive and accessible environments.

Chapter 5. The Value and Costs of Powered Wheelchair Users' Situated Knowledge

5.1 Introduction

This chapter explores how the participants in the research possessed situated knowledge which they had developed in response the enabling and disabling factors discussed in the previous chapter. Like Chapter 4, this chapter draws on data from the accompanied journeys and semi-structured interviews. It begins by considering how powered wheelchair users' experiences provide them with particular forms of situated knowledge and expertise, which assist them in making their way in a world built by and for the non-disabled majority. This knowledge, built up over time, relates to how they experience the world as powered wheelchair users at the intersection of three factors: the specific environments that enable or disable them, the technologies they use to aid their mobility, and their individual bodies. This enables powered wheelchair users to acquire skills and expertise in navigating around the disabling barriers they face in their everyday lives. Rooted in their situated knowledge, participants had a wide range of practical proficiencies, such as knowing the capabilities of their wheelchair in given conditions or how to best navigate particular disabling situations. But their situated knowledge also gave them a broader understanding of the experience of being a disabled person in contemporary Britain, with insights into processes of disablement at different scales (from specific material and interactional barriers to wider structural factors) that non-disabled people may not share. However, because of the situated nature of powered wheelchair users' knowledge, it is challenging to convey to other people and in particular to non-disabled decision-makers who play a critical role in the creation of enabling or disabling environments.

The second section of this chapter explores how, although their situated knowledge was frequently beneficial to participants in enabling them to exert agency in the face of disabling barriers, it was acquired at a significant cost as the social and material situations that generate it often have negative aspects. Powered wheelchair users do not conform to non-disabled norms of mobility, and like many other disabled people are forced to undertake additional labour in order to 'get by' in a non-disabled world that is hostile to their needs. Although not the only group upon whom such work is imposed, the sheer pervasiveness of environments that exclude powered wheelchair users means that they undertake such labour on a daily basis. The psycho-emotional aspects of this labour, which are imposed on

disabled people in addition to structural barriers discussed in the previous chapter, can have a significant effect on powered wheelchair users' mobility.

An under-recognised aspect of this psycho-emotional disablism is that, though participants felt that their situated knowledge could serve as a resource to create a more accessible society, they were often funnelled through formalised processes of complaint which they typically found frustrating, time-consuming, and inadequate. Rather than a constructive process in which their expertise was valued and used to inform the design of inclusive places or services, their engagements with service providers were through complaints processes which had the effect of individualising the barriers they faced. Participants found this very problematic: not only did these processes impose additional psycho-emotional labour on them, but the individualisation inherent to the complaints process meant that the systemic nature of these barriers was not acknowledged, and the structural or collective action that would be required to address them was not undertaken. They recognised their knowledge, while enabling them to exert agency and 'get by' in disabling environments, was insufficient to bring about wider systemic change via complaints processes alone. In Chapter 6, I describe working with participants to explore the ways in which they felt their situated knowledge might be used more effectively to bring about structural change. Here, I describe how they recognised their own knowledge and the agency it grants them, the costs associated with acquiring it, and how current ways of engaging with policymakers via complaints processes constrain its utility and value.

5.2 Situated Knowledge and Expertise

As discussed in Chapter 3, this thesis draws on insights from feminist researchers, and in particular the value of engaging with what Haraway describes as "situated and embodied knowledges" (Haraway 1988: 583). The situated knowledge of marginalised groups, such as disabled people in a non-disabled society, not only provide an insight into the experiences of those groups but into society as a whole. This section firsts explores the ways in which participants perceived themselves as having particular knowledge – as users of powered wheelchairs and disabled people – that is distinct from that of the non-disabled majority, before discussing how the nature of this knowledge poses challenges when they try to convey it to non-disabled people.

5.2.1 Situated knowledge as an asset for powered wheelchair users

Participants frequently discussed the distinctive nature of the knowledge they possessed as users of powered wheelchairs. Perhaps the most literal aspect of this knowledge, which was mentioned by most participants, was that they have a physically different view of the world compared to non-wheelchair users. As Ravi explained, *"we're lower down, and [have] different perspectives than people… that are ambulant" (Ravi).* Behind this literal meaning was a broader implication: that as wheelchair users they had a distinctive perspective on, and knowledge about the world. This was most often emphasised in the context of talking about the video clips they had captured, as Jane explained when she described the 'point of view' from which the clip was taken: *"it's not what disability [someone has] got, it's how they see the world" (Jane).* Participants expressed that these perspectives had particular value that they considered to be distinct from the perspective of non-wheelchair users, and which provided them with situated knowledge about the world.

This situated knowledge stemmed from their prior experiences of the complex interactions between the technologies they used for access, such as powered or manual wheelchairs, the environments they sought to travel through, and their individual bodies. It was built up over time, existing at the nexus or intersection of these factors, and participants used it in a range of different ways. On one level, situated knowledge allowed them to make choices about mobility: in the previous chapter I discussed how they would carefully consider their choice of route when planning a trip, or even whether they should go out at all. Such plans were influenced by factors including their previous experiences of particular barriers, the weather conditions, and how they felt at that moment in time. The latter might depend on how tired they were, and how much time they had available (as discussed in the previous chapter, accessible routes could often be more time consuming or unpredictable in duration than non-accessible routes).

However, at another level participants' situated knowledge went beyond mobility, being intimately linked to their experiences of being disabled in a non-disabled society. They talked about how non-disabled people typically did not understand many aspects of their lives, such as how they incurred additional costs that were associated with the barriers that they faced. While disabled people's economic circumstances are affected by range of factors (Purdam et al., 2008; Thornton, 2005; Palmer, 2011), major costs are incurred for personal assistance, transport, and adaptations or equipment, on top of many smaller cumulative

costs in their everyday lives (Smith et al., 2004). These are often associated with overcoming disabling barriers: participants highlighted how, for example, they are forced to take taxis if public transport is inaccessible. Several recounted that they were charged more for a wheelchair-accessible taxi, as much as double that of a non-disabled person. Anne explained how one company attempted to justify this:

> *"when I asked them [why], they… would justify it by saying 'oh it takes longer 'cause we have to help you in and out'." (Anne, post-journey interview)*

Although charging disabled people more than non-disabled people for a taxi was outlawed in April 2017 (Department for Transport, 2017), during the fieldwork for this study, these discriminatory practices have continued (BBC News, 2018). Participants also explained how they faced other costs associated with their mobility as disabled people that were less explicitly discriminatory. Again, their awareness of these costs was rooted in their situated knowledge. Peter, for example, was prompted by a video of an accessible shop to talk about the wider costs he faced due to inaccessible retailers:

> *"sometimes you've got to pay more because [that shop] is the only one you can get into... It's probably just pennies sometimes but it's another one of those issues that people don't understand, that being disabled sometimes costs you money… little things like that… all add up and you don't have the choice that other people do because you can't get into certain shops." (Peter, post-journey interview)*

One of the most significant costs associated with being a powered wheelchair user was the wheelchair itself: *"a lot of disability equipment is ridiculously expensive"* (Ravi, interview). As Ravi further explained, their £19,000 wheelchair was almost five times more than a family member's first car. 'Advanced' features such as suspension to reduce the impact of bumpy surfaces on the user contributed to additional costs, despite often being essential for people to be able to use their chair effectively in their daily lives. Again, this highlights the situated nature of the knowledge that disabled people have relating to and beyond their own mobility: they know the cost of a *given* chair, to meet their *individual* mobility needs within their *specific* social and environmental context, in light of the *particular* resources they are able to draw upon.

Participants' situated knowledge also came into play constantly while we were out and about on journeys together: they knew the attributes and capabilities of their wheelchair-and-body in specific environments and would make decisions about their movements

accordingly. Quite often, they would zig-zag or take what appeared to be otherwise indirect paths in an environment. Most often, this was because they had perceived obstacles to their progress that I was not aware of as a non-wheelchair user, despite accompanying them: particularly troublesome cracks in the pavement, for example, or other surfaces or barriers that they found difficult to traverse.

One participant's comments, and the experience of accompanying her, especially highlight how powered wheelchair users' situated knowledge exists at the nexus of an individual body, the technology they use for mobility, and the wider environment. Reflecting on bumpy surfaces in their local neighbourhood during the post-journey interview, Anne described the physical impact of being at this intersection:

> *"a crack in the tarmac, or the concrete or whatever, it just really jolts you… [it] used to be alright, when I was younger, my body was stronger, as I'm getting older, all these little bumps, pull my skin off… if I don't take a bump straight on… my skin's so sensitive that it can tear at times." (Anne, post-journey interview)*

These comments indicate the embodied nature of her situated knowledge: environmental factors that had not been a barrier to her younger self now were obstacles that could cause harm. Conscious of her own ageing, she had to be mindful of how experiencing a given environmental barrier, using her particular wheelchair technology, might cause her body to react at this point in time. As such, her situated knowledge led her to modify how she used her wheelchair in this specific context, approaching bumps straight-on. She went on to explain how her impairment meant she could not counteract the forces that knocked her out of position in her chair, such as those caused by a bumpy surface or kerb camber. Although using an air cushion helped to protect her from the worst bumps, it also made it harder for her to reposition herself in her chair, demonstrating that technology does not necessarily mitigate the disabling aspects of an inhospitable environment.

While all people have situated knowledge stemming from their distinct social positioning, those whose mobility does not conform to dominant norms have specific knowledge of how particular environments may be disabling or enabling to particular people who happen to use particular, non-normative technologies in their mobility. Inevitably, some aspects of this knowledge are unique to individual disabled people, for it is the specificities of particular material configurations of bodies, technologies, and environments which affect the character of disability and which in turn can permit 'good' or 'bad' passages (Moser & Law,

1999, p.198). As such, the situated knowledge and expertise of the powered wheelchair users in this study exist at specific intersections of individual corporeal forms, technologies, and environments, demonstrating the contextual nature of what Moser and Law describe as 'dis/ability: "specific passages between equally specific arrays of heterogeneous materials… the character of the materials which en/able those passages… [and] the arrays which secure or don't secure them – like absent lifts" (Moser & Law, 1999, p.201).

For Anne, one assembly of material specificities – her body, the particular chair and cushion technologies she used to aid her mobility, and the built environment – combined to make certain 'passages' easier than others. Her situated knowledge influenced how and where she chose to move her chair, in doing so helping her to navigate these passages and express agency. I witnessed her carefully avoiding particular, known cracks in the pavement leading between her home and a local shopping area. This highlights the individuality of such experiences: other wheelchair users may well not have experienced this environmental barrier as disabling in the same way or may not have been aware of how this particular barrier might disable them until they experienced it for themselves. To begin to understand Anne's lived experience of mobility as a powered wheelchair user requires us to attend to these embodied dynamics, and to the situated knowledge and expertise that exists amongst disabled people at the meeting point of technologies, environments, and individuals.

Throughout the fieldwork there were many other examples of participants making choices about their movement that were linked to this body-wheelchair-environment nexus. Some chose to reverse their chair up a steep ramp despite not having a clear view, as they felt it would be less likely to tip forwards than backwards. Others entirely avoided traversing steep inclines, or in some cases asked me or a member of staff for a steadying hand on their shoulder or wheelchair. During the post-journey interviews, some participants talked about their specific experiences and the effects of these in more detail, such as Anne's perception of a ramp in the car park in her local town centre:

> *"[it has] the most horrendous slope… it's so dangerous. To get from the car park down to the lift… I have to go backwards and get somebody to hold the wheelchair, 'cause I'm scared of it tipping back." (Anne, post-journey interview)*

While the psycho-emotional effect of such barriers will be discussed further in Section 5.3, here it should be noted that Anne's experience (and subsequent avoidance of this car park) was due to her situated knowledge of how difficult this barrier was for her. Similarly, Jane

explained how with the agreement of her boss she timed her daily departure from the office so she could get *"the quietest train home"*, as she knew that if she left at the regular time she would have to try to board a very busy service. Some participants described workarounds that they had devised to get around disabling barriers, such as jamming their wheelchair's footplate in the door of a train to prevent it leaving if ramp assistance had not arrived. Others, such as Tom, explicitly ruled this out because of the risks that such workarounds involved:

> *"I always double [check] everything, you always have Plan B. And your Plan C. Basically, it's… station staff, driver, passenger. If none of those are available, emergency button. If that's not available, panic. And what some people do is try to put their wheelchair in the doorway. And stop the door closing. Very dangerous to do that. 'Cause if you misjudge, you'll go off, you'll go out. So I never do that, 'cause it's just too dangerous." (Tom, post-journey interview)*

The workarounds that participants employed were thus rooted in their situated knowledge of what would work for them as individuals, using a specific technology for mobility, trying to circumvent particular barriers.

Furthermore, while the examples above suggest that participants used their situated knowledge in a 'conscious' way, for example in the planning of trips or to explicitly guide the movement of their chair, it is worth noting that this knowledge was sometimes enacted 'subconsciously'. For example, when Jane reflected on a video clip she had captured, she explained the difference between her everyday actions 'in the moment' and what she noticed when she saw this movement played back on video:

> *"On a normal day, I don't think about… it being bumpy, things like that, I sort of subconsciously do it. But when you actually have to concentrate on what you're doing… when you're going, or… dodging something, it does make you realise how much you actually do it." (Jane, post-journey interview)*

I also observed how participants used their situated knowledge in situations where there was the potential for them to be hurt, or for damage to be caused to their chair or the surrounding environment. It is worth emphasising that participants attached significant importance to their chairs, due to their centrality in enabling mobility. They were therefore particularly conscious of situations where their chair might sustain damage, most often when they attempted to circumvent physical barriers in their environment. These situations were not necessarily dramatic: rough surfaces, for example, were described by one

participant as *"not good for the power chair, they rattle it, and, and damage it and make things come loose" (David, post-journey interview)*. As described in the previous chapter, uneven surfaces were common and especially over time could damage the participants' wheelchairs.

Other participants, drawing on their prior experiences, describe particular occasions where they had been hurt or their chairs had been damaged in such environments:

> *"[there was a] magazine rack onto the bus driver's door… I could only get off the bus by ruining… the rubber seal on the corner [of my wheelchair control panel, which] caught on the edge of the magazine rack, but I had no choice 'cause I can't move my controller… I actually scraped all of my fingers, and squashed my fingers, which hurt. And I don't believe that I should have to get off a bus and cause pain to myself in doing that." (Jessica, post-journey interview)*

In light of their importance in enabling mobility, and their as well as their significant cost, participants often described taking particular care of their powered wheelchairs. Anthony described how he was conscious of the potential cost of having to repair his wheelchair:

> *"I go along roads sometimes like this where it's bumpy or even where it's really poor terrain, I'm thinking to myself, 'If I ruin one of my motors on my chair, that's going to cost me'… I've got two motors at the front, one for each wheel and that's £1,600 each." (Anthony, post-journey interview)*

Similarly, Jane commented that *"I think I care more about the chair than… myself, 'cause it costs so much"* (Jane, post-journey interview). The choices that participants made in exercising this care stemmed from their situated knowledge of the importance of the chair to their lives, and its resilience and capabilities in specific environments. This informed decisions such as whether to use one chair or another in particular weather conditions, an issue mentioned by David, or if it would be safe to ask someone to help lift them over an awkward kerb given the weight of the chair with them in it, as described by Matthew.

It was thus clear that participants' situated knowledge and expertise was crucially important to how they used their powered wheelchairs, as well as to their mobility more broadly. It enabled them to exercise agency about how and when they travelled, often permitting them to work around disabling societal barriers. Yet the very experiences that lead to this situated knowledge amongst powered wheelchair users are not shared by non-disabled people, and was difficult to convey to others. The following section explores the challenges the participants recognised in conveying their situated knowledge to others.

5.2.2 The challenge of conveying situated knowledge to non-disabled others

All of the examples described above, including where participants made judgements and decisions about how they would interact with the environment through their chairs, demonstrate the application of their situated knowledge as powered wheelchair users. Yet precisely because it stemmed from their own particular situated experiences, this knowledge was not something that participants believed was easily accessible to non-disabled people. A comment by Rachel was typical, explaining how non-disabled people's knowledge of the barriers they faced, or what was needed to enable access, was at best superficial:

> *"I think most people it doesn't extend much beyond, like, you can't get upstairs. I think that's most people's level of understanding." (Rachel, post-journey interview)*

As discussed in the previous chapter, participants felt that non-disabled people often made inaccurate assumptions about both the capabilities of powered wheelchairs and about disabled people's lives more broadly. In their reflections, it was notable that participants framed the understanding they possessed – and that non-disabled people did not – as relating to their personal experience as powered wheelchair users. For example, Jessica described how becoming a wheelchair user herself was what made her aware of these issues, as she now had personal experience of them:

> *"I don't think people do understand it… if they put more thought into it, they'd understand it better. But I don't know if you could necessarily appreciate it… all the time, unless you absolutely had to… I have to look at the floor in terms of what's that kerb like… what's that dip like, what's… the steepness of that hill like… it makes me much more aware of things that I would never have been aware of before." (Jessica, post-journey interview)*

Such comments were commonplace, with participants' situated knowledge of the factors that made particular environments (in)accessible being rooted in their experiences and lives as powered wheelchair users. Some participants explained that their own experiences as wheelchair users had influenced their family and friends, who had gained an understanding of the barriers faced by disabled people through their personal connection with the participant. They contrasted this with the lack of knowledge of the wider public.

One participant explained how their friends were more attentive to the accessibility of the environments that they would be visiting with the participant, for example when planning a trip to another city for an evening out:

"Even my friends will say, since they've been friends with me, they've noticed steps or things like that more… my friend's already looking at places to go out [in a city we're visiting soon]… she sort of goes 'is it wheelchair friendly' and everyone's like 'I don't have a clue', whereas she said, if she'd been there, she'd notice straight away." (Jane, post-journey interview)

Jane's experience shows how her non-disabled friends had come to understand her access needs as a powered wheelchair user and were incorporating these needs into their plans. Yet it also demonstrates that her friends themselves recognised that they had previously lacked this knowledge, before they got to know her. This was again a common observation amongst participants, who often described how other people only began to understand the barriers faced by disabled people through personal contact and interaction. Jane later described an awareness of this dynamic within her own family:

"[My nan] said "it's only since having you… in the family, and watching you grow up and how you deal with things", that her eyes have opened to different issues [faced by disabled people]." (Jane, post-journey interview)

Similarly, Peter emphasised that although there was widespread ignorance amongst non-disabled people of the barriers disabled people faced, they could come to know these experiences and what would improve them even if they did not have the same situated knowledge:

"I think a lot of it is because they're ignorant of the situation, they don't understand, unless they know somebody who's [disabled]. The number of people who I'm friends with who say, 'Now, we realise what it's like'. Because they're out with me and they see the problems I have." (Peter, post-journey interview)

A lack of understanding was widely perceived by participants to afflict professionals who made decisions or provided services that affected disabled people's lives. For example, Ravi felt that policymakers, lacking personal experience of disability or contact with disabled people, failed to provide services which met disabled people's needs:

"I don't think the policymakers actually understand disability that much… they've not had kind of intimate experiences… they wouldn't have contact with [disabled people]… they may not know a lot of the issues. They just might generalise… they would assume [that] their policies are helping disabled people. But probably some of the things they thought are helpful are probably the worst things you can do really, for disabled people, without realising." (Ravi, interview)

This lack of knowledge amongst non-disabled people, including decision-makers, was something that participants felt could be addressed, though several highlighted that the knowledge a non-disabled person could gain would not be the same as that of a disabled person. Amber described the ways in which people who designed environments could better understand disabled people's needs and (like most participants) particularly emphasised the importance of listening to disabled people. Her comments highlight the situated knowledge of those who came across barriers on a daily basis:

> *"Talk to people. You are never ever going to understand what it is like to use a wheelchair, any kind of wheelchair, because manuals are different from electrics and all electrics are different. So, you are never ever going to understand what it is like unless you do it. I don't mean five minutes when you can get out and go to the loo if you come across a step… Everybody [who uses a wheelchair] comes across similar problems. You need to speak to the people who do it day in, day out because they are the people who actually feel the frustration about what happens when you can't… Walk a route with someone at the very least. Don't do it in the wheelchair because you won't get it… Get some real experience from some people who have really experienced it." (Amber, post-journey interview)*

Similarly, Anne reflected on the value of professionals listening to the situated knowledge of disabled people. She explained how despite not having a visual impairment herself she had come to understand the importance of correctly installed tactile paving by listening to the experiences of those for whom it was essential:

> *"I know how badly they put it down… I think if the people who installed [tactile paving] knew, understood it… They would understand how they cock somebody's life up." (Anne, post-journey interview)*

Later in the interview Amber again highlighted how 'experience' sessions, where non-disabled people use wheelchairs for a short period of time to try to understand disabled people's experiences, were simply no substitute to talking with and listening to disabled people:

> *"having them talk to people that use the service, you know. Informally or formally. I really don't believe in these, stick someone in a wheelchair and push them around a bit to give them a feel for it and things. That's not empathy… It's just not the same as seeing what it's really like for someone who live with it day to day. A talk, I don't know, people switch off at talks. They need to be able to ask questions, which is not a comfortable thing. If people are going to be able to get an*

understanding, needs to be an actual understanding." (Amber, post-journey interview)

Yet participants acknowledged that it was not inevitable that non-disabled people would learn from such conversations about what would make an environment accessible. The experience of Anne, a former access officer at a local council, highlights this issue. Despite being employed in a role with a specific focus on improving access for disabled people, and having the opportunity to learn from her insights, her colleagues paid scant regard to her situated knowledge. She described the difficulties she faced in convincing her colleagues to take her situated knowledge seriously:

> *"I worked very closely with the engineers… and with Planning… I was trying to educate people, and I don't think they liked [it]– these are people that were much older than me, had been engineers for a long long time, certainly didn't want a young girl coming in, telling them how to do something… they would patronise me, go 'oh yeh, alright Annie, we'll think about it'. And it was like… they're not taking me serious[ly]… I think this is, one it's 'cause I was a woman, and one because I was in a wheelchair, it was very easy to [dismiss and patronise me] and I'm like Oh. My. God! You don't understand even what you're doing! You don't understand how you're treating me, that tells me everything about that footpath." (Anne, post-journey interview)*

Although she was not keen on the idea, her bosses suggested that her colleagues do an 'experience' session to travel over the engineering work they had commissioned and built. Such simulations are often regarded as problematic by disabled people due to their individualisation of disability, which ignores the impact of societal barriers, and evidence that they lead to negative perceptions of disabled people's competency rather than bringing about positive attitudinal change (French, 1992). Anne found that although the session initially seemed to have the effect of conveying to her colleagues them the issues at stake, it did not result in a long-lasting change of their attitudes or behaviours:

> *"To get in a wheelchair and feel it, you'll walk out of it half an hour later, and… will it really have an impact? You need to listen to people. [We did] get them all in wheelchairs, going over the work that they've done, like footpaths and dropped kerbs, and– I mean it was a joke, they couldn't do it! They felt [what it was like, but] then… couple of weeks later, they were back into the work… forgetting it." (Anne, post-journey interview)*

The challenges Anne faced in persuading her colleagues to acknowledge and act upon her expertise demonstrate how people who design and implement disabling environments may not engage with situated knowledge even when it is readily available to them. As both Anne and Amber noted, engaging with disabled people's situated knowledge involves far more than just attempting to replicate the experience of being a wheelchair user. It involves listening to disabled people and their accounts of the disabling barriers they experience on a daily basis, both relating to accessible environments and in terms of their wider experience of being a disabled person. It also requires non-disabled people to meaningfully engage with, and seeking to learn from, the situated knowledge that disabled people have built up.

Disabled people's situated knowledge can, therefore, help them to make their way in a world that does not accommodate their access needs, and could at least potentially serve as a resource for conversations that might bring about more enabling environments. This is an aspect that will be further examined in Chapter 6. However, it is important to note that this situated knowledge is acquired at a cost. When they described their experiences of disabling environments, it was very clear that labour was imposed on the participants that was not imposed on non-disabled people. Some of these, such as the physical work associated with having to take longer detour, were discussed in the previous chapter. The next section discusses another form of work that grants disabled people particular forms of situated knowledge, the labour that is associated with psycho-emotional disablement.

5.3 Labour and Psycho-Emotional Disablement

As discussed above, disabled people's situated knowledge enables them to make their way in a disabling society. However, this expertise is acquired at a cost, in the form of the labour they are compelled to undertake as they encounter and work around the material and interactional barriers they face in their everyday life. While the physical costs have been described above and in the previous chapter, this section focuses on the psycho-emotional costs of disablement and how these lead to particular forms of situated knowledge. This section first explores ways in which such additional psycho-emotional labour is imposed, before considering how it was experienced by the powered wheelchair users in this study.

As described in Chapter 2, the world is constructed around the needs of standardised, non-disabled bodies and practices, creating environments in which disabled people often 'misfit' (Garland-Thomson, 2011, p.594). Disabled people are often forced to undertake additional labour, often invisible to the non-disabled majority, to reduce the friction and costs that

occur when they meet standardised technologies or organisations that do not accommodate their particular needs (Star, 1990). As well as the physical costs described earlier, such as the longer journeys or risk of injury or damage to their chair, disabled people experience a range of non-physical costs. They exercise additional surveillance to avoid being caught out by standardised socio-technical environments or processes. Sometimes, they encounter incredulity or even hostility from others who are ignorant of their needs. It is important to note that these costs are still incurred when disabled people successfully navigate inhospitable environments: work is incurred even in 'good passages' (Moser & Law, 1999, p.207). Indeed, it is precisely this work, drawing on their situated knowledge, which can sometimes enable smooth journeys. Again, such hidden work goes beyond physical aspects of mobility. It encompasses psychological aspects such as pre-emptive or on-the-fly journey planning, as well as the feelings engendered by experiences of inaccessibility or discrimination. It also includes emotional work that is related to managing difficult social interactions with others and controlling self-presentation in such interactions, for example to gain support, maintain relationships with others, drive social change, or maintain self-respect (Scully, 2010, pp.29–31).

Such situations can lead to the "socially engendered undermining of [disabled people's] pyscho-emotional wellbeing" (Thomas, 1999, p.60), which has different aspects that may affect particular people differently at different times (Reeve, 2004, p.85). These include the impact of structural disablement on disabled people, such as how being physically excluded from inaccessible places can reinforce a sense of segregation and difference. Psycho-emotional disablement also includes the effect of direct "acts of invalidation" towards disabled people through the hostile looks, words, or actions of others (Reeve, 2014, p.93). Finally, societal prejudices may become internalised by disabled people themselves, affecting their sense of self-worth and potentially influencing the decisions they take about their lives (Reeve, 2006, pp.101–103). All of these aspects are rooted in disabled people's experiences and situated knowledge, and interact in complex ways: someone may know that they have to play the role of a 'grateful disabled person' in order to obtain assistance, be left hurt if their request is rebuffed, and feel angry or embarrassed that an inaccessible environment compels them to ask for help in the first place (Reeve, 2006, p.98). The labour this requires often involves masking their own emotions in order to manage those of others: they may defuse awkward interactions with humour (Cahill & Eggleston, 1994), or feel unable to express their anger at poor treatment due to personal embarrassment, the risk of

retaliation, and societal norms of non-confrontation. They recognise that sometimes, they cannot afford to alienate a non-disabled person whose assistance they require to navigate disabling structural barriers.

The participants in this study undertook many of the forms of psycho-emotional labour described above. In both my observations while travelling with them and in their reflections during the interviews, it was clear that how they dealt with these examples of disablement was intimately linked to their situated knowledge of being a powered wheelchair user. Although structural and psycho-emotional factors are closely linked, participants' accounts frequently referenced situations where they experienced psycho-emotional disablement. In some cases, the psycho-emotional aspect of disablement was readily apparent and explicitly discussed. These included situations in which participants felt insecure, vulnerable, angry, or frustrated. At other times, it was an undertone to their response to disabling environments, such as being forced into a state of constant vigilance to ensure a smooth experience of mobility, or the effect of having to rely on other people for access. How these situations imposed particular forms of psycho-emotional labour, and the impact of this, is discussed in more detail below.

Many participants described being forced to maintain a constant state of vigilance to assess and react to inaccessible environments. Some of the physical aspects of this labour, such as dodging cracks in pavements and taking long diversions in the face of inaccessible routes, have already been discussed in the previous chapter. However, what came through strongly in interviews was the significant cognitive load and emotional labour that was associated with 'misfitting' these environments. Several participants likened how they monitored their immediate environment to technologies such as satellite navigation or radar. Ravi described how he had a *"a sat nav in my brain" (Ravi, interview)*, while Anne's description of watching the ground like a radar to avoid bumps that would cause her to spill her tea (discussed in Chapter 4) show how the vigilance that she exercised was linked to her situated knowledge of how her interactions with the environment were mediated by her powered wheelchair. The concentration that was called upon to enable her smooth 'passage' was not required of her PA, who despite travelling with her regularly was not fully aware of the mental effort Anne exerted in her everyday mobility.

It is worth noting that such vigilance was not always a conscious activity: Jane described, earlier in this chapter, how she only realised the extent of their constant scanning for

obstacles when she later reflected upon it in the interview. But the impact of this vigilance, whether conscious or not at the time, was generally described by participants in terms of the tiredness it caused them. For example, Jessica explained how barriers in her environment meant she always had to be alert while using her chair:

> *"it is very much like, well if you can imagine trying to manoeuvre a car… outside a school when there's loads of kids on the road, or when there's a riot. It feels very similar to that. That you… can't concentrate on the things that maybe you'd like to be concentrating on – and that's why it's quite exhausting as well in a chair, because you can't ever switch off, you have to constantly be aware of where you are and where other people are and what they might do." (Jessica, post-journey interview)*

This form of emotional work is a direct result of what Reeve (2014, p.85) describes as environmental or structural inaccessibility. Jessica's description shows how is not only caused by physical environments but also by interactions with others. Furthermore, the unpredictability of accessible routes, which can depend on contingent factors such as the weather or operational status of lifts as discussed in the previous chapter, imposes further vigilance on disabled people that non-disabled people do not experience in the same way. Jessica's vigilance is rooted in her situated knowledge that her passage may be impeded by particular material and interactional barriers. These structural factors affect how people feel about their journeys and the environments they pass through. Different environments can inspire positive or negative trains of thought and emotion amongst pedestrians, with 'unobtrusive' environments enabling people to focus on issues of importance to them (Calvert et al., 2019). The disabling structural barriers described above, and the in-the-moment vigilance that they impose on powered wheelchair users, have the potential to undermine positive aspects of mobility and movement through the imposition of psychological work.

Psycho-emotional disablement was also apparent in the way that several participants talked about how they sometimes felt unsafe, insecure, or vulnerable. These feelings were usually associated with having previously encountered particular inaccessible environments or ableist attitudes. Again, this stemmed from their situated knowledge, rooted in their prior experiences of identical or similar barriers. One participant who had previously had an accident on a steep incline, for example, described how she felt when having to use a steep ramp to board a train:

"Awful. Absolutely awful. I feel my heart is in the back of my throat… there's the potential for me to [go] backwards and have another nasty accident so I don't feel particularly safe at all. I don't feel safe that there's nothing on the side [of the ramp]… if someone ran off the train… 'cause they were in a mad rush… there is scope for [my wheelchair control] lever to move in a direction that I'm not controlling it in. And that could have quite severe consequences. I'm very conscious of that, going on that ramp" (Jessica, post-journey interview)

Although Jessica did still use trains, her description highlights how structural inaccessibility has clear psycho-emotional consequences (Reeve, 2014, p.85). If the trains were accessible without a ramp, she would have been able to board without the experience reminding her of the accident. For other participants, these kinds of feelings led to them actively avoiding the use of particular modes of transport. Anne, for example, explained how the motion of a bus caused her to slide around in her chair, making her feel unsafe and therefore unwilling to take a bus on her own. James described one previous train journey as *"a nightmare"*, explaining how it had left him with a strong aversion to rail travel:

"The first carriage I managed to get into and in their wheelchair designated space but I couldn't recline my chair at all and it was really tight. The second one… had a nice big open carriage, it was really pretty easy, really comfortable. But then again on the way back, that carriage was full of bikes, so we had to sit in the corridor…[and] the second train on the way back, the carriage door was too narrow, so again we had to sit in between carriages… it's not a pleasant experience using the train at all… I don't, <u>really</u> don't like using the train now." (James, post-journey interview)

Although he said he would not rule out taking the train entirely, this experience had *"really put [him] off"* doing so, and he tended to travel most places by car. Several participants discussed similar experiences of how structural inaccessibility had left similar psycho-emotional impacts. Geoff, for example, described how the wheels of his wheelchair became trapped in a train doorway while travelling with his young son. The driver, unable to see him, attempted to close the doors and a serious accident was only averted by the actions of passers-by. He went on to explain the lasting emotional impact of that incident on his son:

"I would have ended up under that train… the consequence [was] my son refused outright to travel on the [railway system] with us, and we had to use taxis everywhere. And he still remembers that as well. He said it was quite a traumatic experience for him… he was what, three at the time… [A]s a disabled parent you

don't want your experiences of obstacles to have an impact on your children." (Geoff, interview)

This incident provides an example of how structural barriers not only directly impeded the mobility of a disabled person, but also led to psycho-emotional disablement of their family.

Yet such structural barriers also imposed other forms of emotional labour, through how they affected disabled people's interactions with other people. In order to work around such barriers, disabled people are often compelled to ask for assistance from other people. As one participant explained, this not only constrained their freedom and independence – as they were now reliant on the goodwill of others – but also led to them feeling embarrassed and insecure:

> *"[It is] admitting you are vulnerable. If you were saying to someone 'I can't get up that drop kerb', it… has a negative effect, and you feel vulnerable, but you're also telling perfect strangers that you're vulnerable… perhaps [it] isn't the best thing in the world to be doing, but sometimes you've no options, sometimes you do need the help… it's a shame because as an area goes, it's quite a safe, friendly area… I think it's a pity that I can't go out to my doctor's or even to town, without feeling this fear, either of not being able to get up or down a kerb and having to accept help, and therefore telling people I'm vulnerable, or being in a situation [where I am] not sure where my chair was going… or if I was going to be able to stop it before I got into danger." (Margaret, post-journey interview)*

This participant's description highlights these two distinct but interwoven aspects of psycho-emotional disablement: the direct effect of disabling environmental barriers, such as the fear of losing control of their chair; and the indirect effect of being forced to rely on others, and therefore disclosing potential vulnerability. Disclosure in this way also has the potential to undermine the agency that is connected to a disabled person's situated knowledge in otherwise disabling situations. Even the act of conveying their need for a particular form of assistance, a topic which would not typically be discussed outside of their intimate circle, can break norms of conduct in the interaction between a disabled person and non-disabled others (Scully, 2010, p.27). Worse, it may also result in existing societal prejudices about a disabled person's capabilities and agency being mistakenly reinforced via a process of 'ascribed global vulnerability', with non-disabled others inappropriately extrapolating required assistance in one area of a disabled person's life (such as the need to be able to access a train) to all areas of that person's life (Scully, 2014, p.209). Yet unless they disclose

these particular needs, disabled people remain constrained by the disabling effects of non-sustaining environments in which they 'misfit' (Garland-Thomson, 2011, p.594).

Structural barriers that force dependence on others are also problematic because disabled people are then sometimes obliged to accept poor treatment to gain the assistance they require for mobility or access. Anthony described these dynamics in his interactions with one member of staff at his local railway station, where he regularly uses ramp assistance:

> *"He's frustrated and he's fed up with things. He moans… he smokes on the platform while he's waiting to get me off … people say to me, 'Why do you put up with this shit and then you're actually nice to the person who is helping you?' I'm thinking, 'Well even though I'm really fucking pissed off, I don't want to tell them that…and put them in a bad mood because then I've got to rely on them next time', again that issue of power. But this guy, the train will come in and because he knows it's me, he thinks he can take five, ten minutes to slowly get out of his little office and come round to help me because he thinks I'm not going to complain because we're pals. It's like, 'I'm not your pal… I want you to be there with the ramp when I get off the train'. But I know that if I said something horrible to him, he would either be really offended or he'd be really shocked that I'd raised something with him and then what's going to happen next time I come in? It goes back to that issue of dependency… you're navigating all these environments but you're mindful that you have no power in any of this at all." (Anthony, post-journey interview)*

Again, while a structural barrier directly excludes a disabled person, forcing them to rely on ramp assistance, it also imposes subsequent psycho-social disablement: conscious that his reliance on ramp assistance meant he could not afford to alienate the employee, Anthony chose to prioritise maintaining a working relationship with him (Scully, 2010, pp.29–31). As with many other aspects of disabled people's experience described here, such decisions are grounded in their situated knowledge about what is necessary to enable their mobility. Yet in this case, that meant Anthony ignored behaviour he felt was unacceptable and was selective about the issues he complained about (an issue that will be further discussed in Section 5.4).

Several participants described situations where they had been made to feel humiliated or embarrassed. Such situations were generally caused by one of two factors: the measures they were forced to take in response to structural inaccessibility, or the behaviours of other people towards them. The archetypal example of the former was the so-called 'back door

treatment': the widespread issue where the only usable entrance to a nominally accessible building for them as a wheelchair user was 'around the back', segregating them from the entrance used by non-disabled people (Edwards & Imrie, 2003; Imrie, 2000a). This is yet another spatial signifier of difference (Imrie & Kumar, 1998) that demonstrates the inter-related nature of material and social factors in disablement. Jessica described how this could involve being taken through non-public areas such as restaurant kitchens, while her dinner companions waited for her at the table:

> *"[the restaurant staff] took me round to the back of the building… I had to wait for them to move the bins, then they opened the back door to the restaurant, and I had to wait for them to clear a lot of the corridor… there were plates with used cutlery and food… it wasn't a clean environment at all, it was filthy… I then had to go through the kitchen… [and] I thought 'there's a real health issue here'… you know, it's smelly, it wasn't clean, I didn't think it was hygienic… I don't really think that was an acceptable way of letting a wheelchair user into a restaurant… [I wanted] to have a nice evening out… but [ended up] feeling humiliated when there was no need for me to feel humiliated" (Jessica, post-journey interview)*

Although she complimented the restaurant and staff overall, her account highlights how structural disablement can cause psycho-emotional effects. She noted that *"there should have been a better way"* for her to access the restaurant. Her experience demonstrates how a clumsy attempt to promote accessibility did enable wheelchair users to access the venue, yet the experience of that access was so different and inferior to that of a non-disabled person that Jessica felt humiliated as a result. It suggests the restaurant had focused on ticking the 'box' of accessibility and lacked insight into how a disabled person would feel about this experience when it was implemented in practice.

In other cases, however, the hostile actions or 'acts of invalidation' committed by other people towards disabled people were more direct examples of psycho-emotional disablism (Reeve, 2014, p.93). In some contexts, this involved non-disabled people disbelieving or otherwise invalidating the situated knowledge of participants. While travelling with David, I witnessed how the bus driver ignored his use of the blue 'wheelchair ramp' call button twice at subsequent stops. As the bus began to pull away from the second stop, he called out to the driver to alert him that he wanted to get off. In response, the driver shouted back, aggressively accusing him of not having pressed the call button at all. The experience of being forced into a confrontation with the driver, who had publicly accused him of lying,

clearly annoyed and humiliated David. This was on top of him having been inconvenienced by having to alight a stop beyond where he had originally planned.

Similarly, Amber explained how because society as a whole does not consider that disabled people might also be parents, facilities or services aimed at those with small children are often inaccessible. In turn, this can lead to interactions in which their role as a parent is devalued by the attitudes of non-disabled others:

> *"the lack of accessible changing areas for babies… [or] rules [in a soft play area] where a child has to have an able-bodied person in with them… I've had arguments at the front desk about why I should be able to take a carer in with me without them charging the carer… [They state that] I have to be responsible for [my daughter]. I need a physical pair of hands to be responsible for her." (Amber, post-journey interview)*

In this case, structural disablism caused interactions which undermined Amber's psycho-emotional wellbeing by calling into question her ability as a mother. As before, the situated knowledge that disabled people have – in this case about parenthood, and the accessibility adjustments that may be necessary to enable them to fulfil that role – is seemingly not considered by service providers.

However, beyond these incidental acts of invalidation participants also described directly discriminatory forms of psycho-emotional disablism, such as receiving abusive comments from other people. Such 'low level' prejudice and harassment is far more widespread than dominant conceptions that equate disability 'hate crime' with extreme forms of violence, which risks obscuring the prevalence and impact of these kinds of everyday discrimination on their victims (Hall, 2019), and can undermine the perceived safety of everyday spaces that disabled people access (Healy, 2020).

Jessica gave two examples of this kind of low-level prejudice. First, she recounted an interaction with another shopper in the confined environment of a shop, and his reaction when she asked him to make space for her:

> *"it was really busy… the bloke hadn't seen me and I said 'excuse me please' and he didn't move, and I said it again, hadn't moved, so I just tapped him on the back and said 'excuse me please, could I get past'… and he turned around and swore at me and said 'why didn't you just effing tell me in the first place'… I got really upset by that… I didn't say anything and just moved forward, but then I just left the shop and then went home" (Jessica, post-journey interview)*

She went on to explain how her subsequent visits to that area were coloured by this incident, and she described having to make a conscious effort to return in the face of such discrimination. Initially, the incident acted as a constraint on her desire to go into the shop in question, though it later provided an impetus to exercise her right to do so:

> *"the next time I went I thought 'I'm not going in that shop again'. And then the next time I thought, 'yes I am because I'm not gonna let him intimidate me like that, that's wrong." (Jessica, post-journey interview)*

Jessica also described a separate incident when someone who had parked in a disabled parking bay shouted at her that disability was a *"life choice"*. She explained how the psycho-emotional impacts of such horrible interactions could linger:

> *"It's all very well me saying I don't care what people think, 'cause I genuinely don't, but then… there have been some instances where you just think 'that's just so nasty… so unnecessary, and… just cruel'… And that… does get to me… I do feel I've hardened up a lot, being in my chair… normally I'll sort of think 'oh that wasn't very nice' and I just move forward and I don't really think about it… But those two experiences did really intimidate me and… it wasn't very nice." (Jessica, post-journey interview)*

Jessica's experiences demonstrate how 'acts of invalidation' (Reeve, 2014, p.93) could cause psycho-emotional disablement amongst even a 'hardened' wheelchair user, and could have a major impact on a disabled person's wellbeing. It was not only that the encounter itself was disabling, but that the person experienced the longer term 'existential insecurity' of not knowing how the next stranger will react to them (Reeve, 2012, p.80). Experiences like this can lead to some disabled people actively avoiding particular modes of travel in future, and therefore directly constrain their mobility (Wilkin, 2020).

A common theme in many participants' accounts was that their experiences led to a form of 'anticipatory tension': the emotional labour that was associated with the anticipation, or even expectation, that things might going wrong on their journey. Such expectations were rooted in their situated knowledge and experiences of things having gone wrong in the past, in some cases on many occasions. It is important to note that although individual incidents of (direct or indirect) psycho-emotional disablism may seem harmless or one-offs, Reeve notes that these are often experienced on a daily basis and so can have a cumulative effect on their self-esteem and self-confidence (Reeve, 2012, p.82). David's testimony summed up this cumulative impact on his psycho-emotional wellbeing:

"certain things have gone wrong so many times in the past that when you try and do them again, you get a very tight stomach, knowing that… this could go horribly wrong, this could be upsetting, someone could be rude. I may not be able to make this journey. There could be some aggression. I could be accused of lying… that [feeling is] … even before I've set off, while I'm waiting at the bus stop, before I've actually started… anything involving transport." (David, post-journey interview)

Although David didn't let it stop him travelling, several other participants talked about how this anticipatory tension affected their travel behaviours, such as explaining how they would not go to places they had not been to before or would not use new routes. Jane, who commuted by train on a daily basis to her full-time job, explained how she *"wouldn't go on my own [to a new development in city centre]… just in case I get stuck" (Jane*, post-journey interview*)*. Instead she said she would travel with a friend, personal assistant, or family member until she was confident about the accessibility of that environment. Previous experiences of structural inaccessibility thus led, in this particular instance to a specific form of psycho-emotional disablement for someone who was otherwise very independent: the restriction of certain activities, and an enforced reliance on other people. When participants described this kind of anticipatory tension, and their lack of confidence that a journey would go well, they often drew upon past negative experiences to explain their low expectations, or to highlight how and why they had changed their behaviour.

It is worth noting that this form of emotional labour was not only influenced by participants' own direct experiences, but also by those of their friends and acquaintances. In this context, shared social networks provided a means by which experiences were shared and discussed. Ravi highlighted how hearing about the negative experiences of his friends had discouraged him from using public transport himself:

"I might not feel fully confident to… go on a bus. Especially hearing quite a lot of the stories from my friends… I'm just scared of… the negative things that would happen, because… I don't really know how I'd cope in that situation. Because I [would] feel quite vulnerable… people being rude. Or um, being threatening. So the psychological kind of aspects I'd be more scared of rather than there's no ramp, or there's (a) step or something. People's kind of behaviour, I'd find worrying… I've not really faced a lot of the discrimination that… a lot of my other friends have experienced, and… it's quite shocking to think people can act in the ways that I've heard." (Ravi, interview)

The fact that Ravi particularly highlighted the 'psychological' aspects of potential negative interactions with others as being a greater concern than physical inaccessibility, despite him acknowledging that he had not faced much discrimination himself, demonstrates how 'acts of invalidation' (Reeve, 2014, p.93) against a single disabled person can impact upon many others. Any individual act of psycho-emotional disablement can affect the broader disabled community, whose shared experience of disablement and discrimination forms the basis of common aspects to their situated knowledge.

In light of this anticipatory tension, many participants described their sense of disbelief or even joy when their journeys went better than they had expected. Amber explained how, despite having had good experiences in the past, she still felt a physical sense of relief when things went well on a journey. She related this to the sense of uncertainty she felt every time she embarked on a trip, and the unease she felt not knowing how it would go:

> *"Yesterday's journey wasn't horrendous, especially that bus driver. I saw him, I asked, he smiled, jumped down, pulled the ramp out and I went. Great. What I find quite sad is that I breathe a sigh of relief once I'm on the bus if they've been like that because I never know what the outcome's going to be. It is a real relief when the bus driver's like that." (Amber, post-journey interview)*

As with the vigilance described earlier, the anticipatory tension discussed by many participants highlights an underlying issue relating to the psycho-emotional labour that is experienced by disabled people. Facilities such as bus ramps, which aim to reduce disabling barriers, are associated with a high degree of uncertainty, unreliability, or 'brittleness'. When they go wrong – if compromised by poor maintenance, the hostile acts of another person, or a process which is inflexible to the lived needs of the people they are supposed to assist – they impose further emotional and physical labour on disabled people. Psycho-emotional existential insecurity (Reeve, 2012, p.80) relates not only to disable people's uncertainty about how others might act towards them, but also to unease about the very features and services which ought to reassure them of the accessibility of environments.

The vulnerability of these accessible services and facilities to failure also risks undermining the situated knowledge that disabled people have accrued of workarounds that enable their access. Amber's comment that she found it sad that she felt relief in this context demonstrates her recognition that she ought not to feel relief for such a fundamental thing to her mobility as being able to access a bus.

Feelings of anger, irritation, annoyance and frustration in the face of disabling barriers came through very clearly in some interviews, as well as being a recurrent underlying theme amongst most participants. As with the anticipatory tension discussed above, they were a response to experiences of structural disablement (Reeve, 2004, p.85). Given the frequency of these incidents, some participants described how this imposed a recurrent form of psycho-emotional labour on them:

> *"Oh! All the time, I'm constantly… stressed might not be the right word, [but] angry." (Anne, post-journey interview)*

For most participants, such feelings typically related to occasions where things went wrong unexpectedly, such that their plans were thrown into disarray. For example, David explained how it was the unanticipated things that caused him the most annoyance: that *"unexpected things make me angry. Exasperated. Make me swear"* (David, post-journey interview). While accompanying him in central London, I observed this for myself. A car had parked across a dropped kerb, and David was forced to drive his wheelchair along the road for a considerable distance before being able to remount the pavement at the next dropped kerb. Reflecting on this incident during the interview, as he watched the video footage he had captured, he asked *"is this the one where I say 'fuck fuck fuck'?"*. While he could laugh about the situation in retrospect, noting *"feel free to keep it [the swearing] in, I'm not worried about it"*, it was clear that the situation had caused him genuine annoyance at the time. As he explained in the interview, these incidents had a real impact on his life which lasted beyond the moment itself:

> *"the anger about something going wrong, or the tension about it… not going right beforehand, doesn't evaporate within moments… it's a very sour, tense, angry unhappy feeling… I find it stressful altogether." (David, post-journey interview)*

Similar frustrations and emotions were expressed by several participants. These negative experiences and the emotional cost they imposed formed an integral part of the situated knowledge that they possessed about the experience of being powered wheelchair users, including the disabling barriers they faced compared to non-disabled people. These aspects of psycho-emotional disablism were also closely related to other aspects of the emotional and physical labour they were forced to undertake to overcome these barriers: the constant vigilance necessary to exercise their mobility; the needlessly disabling environments and interactions; and their feelings of being on edge and tense that all of these situations

prompted. Anger and frustration were thus responses to everyday experiences of disablement. Some participants also framed these emotions in relation to their legal rights, expressing their anger that they were prevented from full participation in society because of disabling barriers.

It is worth briefly noting that disabled people may experience psycho-emotional disablism in different ways and with different intensities, and some may not experience it at all (Reeve, 2004, p.85). Other aspects of their identities, such as gender, age, and parenthood status, also influence individual experiences of psycho-social disablement (Valentine, 2007; Sawchuk, 2012; Murray et al., 2016). Such variations were reflected in some aspects of participants' accounts. For example, Jane recalled how a taxi driver once refused to drive her and a friend home after a night out until another woman intervened:

> *"you look in [the taxi] and they've got a ramp, and they're like 'no we don't have a ramp'… we were gonna have to walk home… a 45 minute walk, after night out in the early hours of the morning. Until this woman got in a taxi, saw that it had a ramp, and basically refused to let him leave without taking us… I just didn't think it was very safe, you could tell we weren't from Nottingham… we were literally saying we don't know how to get home… we had the money, everything like that." (Jane, post-journey interview)*

For two young women who were in their late teens at the time of the incident, a long walk home in the middle of the night in an unfamiliar city raised questions of personal safety that may not have been perceived as so significant by someone of a different age or gender. Jane felt that this situation happened because the taxi driver would have had to exert more effort to carry a wheelchair user than a non-disabled passenger: they would have been required to get out of the car, deploy the ramp, and secure the wheelchair properly. An issue of structural inaccessibility was compounded by the direct psycho-emotional disablism of the taxi driver, which in turn was a particularly significant factor for two young women's safety and wellbeing. However, this incident also highlights how a non-disabled passer-by's actions mitigated some of the negative aspects of this experience, suggesting ways in which structural and psycho-social disablement may be addressed through individual and societal actions.

The characteristics of psycho-emotional disablement experienced by participants are both complex and deeply intertwined with their experiences of structural disablement. The sheer variability of environmental factors such as unreliable lifts or the attitudes of staff lead to

unpredictability, heightening the psycho-emotional labour imposed on powered wheelchair users. These aspects are closely linked to disabled people's situated knowledge of enabling and disabling environments, and the workarounds rooted in that knowledge that they have developed. As described in Section 5.2, participants faced challenges when conveying their situated knowledge and expertise to non-disabled people, who did not share at least some similar experiences of disablement and working around barriers. This is even more the case given the complex relationship between structural and psycho-emotional disablement and the invisible nature of the latter. Moreover, an additional challenge is posed by the primary way in which disabled people can convey their situated knowledge to service providers: by making a complaint when things go wrong. As the following section explores, not only is this ineffective in bringing about systematic change, but it typically imposes further physical and psycho-emotional labour on disabled people which compounds the structural and psycho-emotional disablement they already experience. As such, despite complaints often being the only way for disabled people to feed back about issues, they are a poor way of conveying situated knowledge about their experiences of structural or psycho-emotional disablement.

5.4 Complaints: an Ineffective, Individualised Way of Conveying Situated Knowledge

As described above, during the journeys and interviews many participants talked about how their knowledge was a valuable resource that could be used to improve access for disabled people. Although this applied to a wide range of issues, the dominant role of inaccessible environments in participants' everyday lives meant that they frequently described engaging with service providers relating to concerns about access. However, they often felt frustrated in their attempts raise awareness amongst service providers about the barriers they faced, and in their efforts to bring about meaningful change through such engagements. These frustrations were linked to both the processes of engagement with service providers, and the outcomes of these processes.

Participants described being funnelled through particular sets of formal processes, most often complaints procedures, which were not necessarily appropriate to the issue at hand. This was regardless of whether or not they actually wanted to complain, or simply wanted to feed back to improve service provision for the future. Anne described how, when she asked why the power-assist on the front door of a local shop was so frequently turned off, staff assumed she wanted to complain to the manager. She described her frustration with this attitude:

"I don't want to see the manager again, I've seen the manager, it's just. Just do it. You've got the [accessibility] equipment, just do it." (Anne, post-journey interview)

Even when participants were truly motivated to submit a formal complaint, they often perceived the organisation's response to be indifferent or inadequate. David found that the repeated incidents he raised with his local transport authority were handled as isolated customer satisfaction issues, rather than systemic failings that ought to be addressed:

"[it is seen] as a customer service issue. About pleasant journeys, but… it's more than that… I've raised [many] complaints, serious, non–trivial… non–vexatious complaints… and I get back a template letter, almost all of them the same… regretting what had happened, apologising, saying that the person will be interviewed, and well– nice words, but blah blah blah, we have a policy that everyone should have the right to travel. I'm not sure that anything behind the scenes actually happens to improve matters." (David, post-journey interview)

David's emphasis on the "non-trivial" and "non-vexatious" nature of the issues that he raised with the operator highlights another challenge of making complaints: the risk of being treated as a serial complainer, rather than someone raising a genuine problem.

Yet even when they complained about a specific one-off incident, participants felt that the responses were dismissive. Peter described complaining to a train operator about an issue, only to receive a dissatisfactory response that failed to offer any reassurance that the organisation would prevent the issue from happening again:

"I just got a letter back saying, 'Sorry, we'll talk to the train guard.' And then that was it, nothing else. Which I find quite difficult to swallow, really, because I [would] like to know what they're going to do about it to improve and will it happen again." (Peter, post-journey interview)

These examples were typical of the experiences of complaint that participants described to me. They often expressed the belief that complaints they raised with service providers as individual disabled people were usually handled in isolation (if they were handled at all), rather than being taken as potentially indicative of systemic issues that could be addressed. In some cases, complaints were entirely ignored, or lip-service was paid to the complaint but the underlying issue which gave rise to it was ignored. Melissa distinguished between responses from individual members of staff, who were sometimes empathetic and helpful, from that of the organisation as a whole:

"The individuals who pick up the phone are different from the reactions of the body itself… you often get a good reaction from the person who picks up the phone, but then it doesn't go any further with the body, the body doesn't do anything to try and make anything better." (Melissa, post-journey interview)

In such interactions, it was left to individual members of staff to express empathy, but the underlying concern that was being raised by the disabled person was not dealt with at an organisational level. Indeed, some organisational responses to disabled people's complaints explicitly called into question their account of what had happened. David recounted how his testimony was contested by staff, and without any way of corroborating his account, he felt that he was being accused of dishonesty by the organisation he had complained to. Rachel described how, although organisations would not be so explicit as to call her a fantasist, that was the underlying implication of their response:

"I am a woman who writes a lot of complaint letters. Most of them come back with this didn't happen, you are imagining it. They don't say that, but what they say is, 'We spoke to our staff member and they say that this happened [instead].'" (Rachel, post-journey interview)

Another aspect of this was that many of the issues that participants faced were challenging to express in the form of a written complaint. As Peter explained, this enabled organisations such as local councils to sometimes entirely deny that a problem existed at all:

"it's very hard to convey to somebody who is not sat in front of you and you're just trying to send them an e-mail or a letter to complain… in the past, it's just been a case of, 'Oh, we'll look at it.' And then you get another saying, 'Oh, we think it's fine, there's not a problem.' And that's all you seem to get with [a] local authority" (Peter, post-journey interview)

This speaks to the range of difficulties that disabled people face in conveying inaccessibility and its impacts on their lives to non-disabled people including decision-makers (Rodger et al., 2016). As described earlier in this chapter, conveying psycho-emotional disablement such as the impact of the poor attitude of transport staff can be particularly difficult. Amber explained how people processing a complaint may not recognise that a bus driver's negative attitude would not only be both directly psycho-emotionally disabling but could also make harder for a disabled person to then manage their interactions with other passengers:

"It's very easy to dismiss people and it's very difficult sometimes to explain that huffing and pulling a face actually has more of an effect.

Usually, the people that you're complaining to have a fair amount of privilege and don't understand what huffing and pulling faces can do, especially once you get on the bus and then you can't manage the other people on the bus because you've already been dismissed as a nuisance [by the driver] and everyone gets the idea that they can treat you like trouble and a nuisance and everything is your fault

If I complained to the bus company that he had huffed at me and pulled a face they wouldn't know why I was complaining." (Amber, post-journey interview)

Amber's comments not only reflect the additional work that disabled people have to do to manage interactions with others (Scully, 2010), but also emphasises, as already discussed in Chapter 4, the critical role of staff in facilitating interactions with other travellers and contributing to good or bad journeys.

In light of such responses to their complaints about disabling experiences, participants often talked of not having any faith in complaining. Amber, for instance, went on to explain how she would not have complained about the negative attitude of a bus driver towards her, as it was not clear-cut enough to a non-disabled person as being problematic:

"I would like to complain, but I have no absolutely no faith that anyone would do anything about it because [the disabling interaction] wasn't obvious. He didn't swear at me… He didn't out and out refuse to deploy the ramp, which I have complained about. There are concrete things that you can complain about. Bad attitude is not one of them." (Amber, post-journey interview)

Amber's experience provides an example of an incident where her situated knowledge about what makes an interaction disabling for her would not be taken seriously by an organisation. Moreover, her situated knowledge as a disabled person was such that she knew this to be the case, and therefore would not submit a complaint about the behaviour.

An important common element to all of the above forms of organisational response is that, through their failure to acknowledge that participants' experiences formed part of wider systemic disablement, they individualised the issue that was being complained about. Not only did this mean that systemic problems were not addressed, as described above, but it also reflects a medicalised understanding of disability wherein the 'problem' faced by the disabled person is implicitly located in themselves rather than in the disabling environment or situation. Furthermore, even where organisations acknowledged a problem in response to a complaint, their responses typically also located the problem in an individual – for example, the staff member who had fallen short of expectations. Again, this individualised

framing is problematic, as it fails to account for or address wider systemic issues that need an organisational response such as training. As such they enable the organisation to deflect from their own complicity in the provision of poor service. This is despite the experiences of people such as David, who had repeatedly complained about the same issue across many different journeys, suggesting the need for systemic changes.

It is also worth noting that participants typically framed their comments about feeding back to organisations in terms of how things could be better. None expressed any eagerness to submit complaints, but they sometimes felt it was the only way to get a service provider to engage on an issue. However, complaining leads to a different set of problems, as it involves expending a significant amount of time, effort, and emotion. The act of complaining thus imposes psycho-emotional costs on disabled people, as was evident from Anne's comments:

> *"I was proactively reporting everything back [when I was an Access Officer], because apart from people telling me there… was a problem… I'd just going round on a daily basis, knew the problems, could feel the problems… I would report those back constantly. Now… I do it, but I've found… and I don't want to sound like an old nag, but there are so many areas that are dangerous, or unfair or just really badly made, that I could spend every day moaning about something and that brings me down.*
>
> *So I have to choose, I have to choose my, my little battles, or… where I put my energy… because it's not just writing one letter, you've got to carry it on, usually they say 'can you take me to the site and show me', and this could… take a few weeks.*
>
> *And so also… it does impact on your own morale, if people are saying 'well, nobody else has complained about that, it doesn't look that bad of a problem', and then you're trying to convince them that actually it really affects you… you get more emotionally… drained, by it all. So I do report some things, but I have to choose my little battles really. And how, how full of energy I'm feeling or not." (Anne, post-journey interview)*

Not only does Anne's account highlight direct psycho-emotional costs of complaining, but it also highlights the indirect psycho-emotional costs caused by the organisation's response to her complaint. By claiming that 'nobody else has complained about that', not only does the organisation belittle the significance of their experience to Anne, but also implicitly frames her as the locus of the 'problem'. This closes off the possibility that the organisation could acknowledge that the issue or barrier raised by an individual might affect others or be a

systemic issue in need of collective redress. Anne's comment also highlights how the psycho-emotional costs associated with submitting a complaint had to be balanced against other priorities including her own levels of energy. This point was also picked up by Jessica:

> *"if something really riled me, I would [feed back], if I had the energy. And if I had the ability… it just depends if I could work out the right process… [and] on my energy and how much time had lapsed and how serious it was… when it has been serious enough, and I when I have been well enough I have raised it." (Jessica, post-journey interview)*

To complain about disablement is to take on additional labour, both physical and psycho-emotional, beyond the experience of disablement that prompted the complaint in the first place. The costs and perceived futility of complaining, alongside the sheer ubiquity of barriers that might prompt a complaint, also shaped participants' engagement in practices of complaint. Participants faced a conscious choice of whether or not to complain: they weighed up the costs associated with this, such as having to recount a situation again, and not wanting to risk the consequences of making a complaint. Anthony described the factors that played into his decision, recognising that his efforts would be better spent elsewhere in order to bring about change:

> *"there's countless times you go somewhere and it's inaccessible or you experience discrimination in one way or another and people say, 'You should complain. You should really do something about it,' it's like well I get up in my chair for 7 o'clock, I am in my chair until 10 o'clock at night, I will probably experience twenty examples of discrimination, be it built environment, attitudes, policies or whatever it may be. I could spend my whole life arguing against it but really, it's not really going to change anything. I can tell a bus driver, 'You've given me a really shit service, you've been really disrespectful to me and I'm really affected by that,' it's not going to change anything… Again, that goes back to this wider issue of how you create change." (Anthony, post-journey interview)*

Similarly, Rachel explained how she was selective in the feedback activities she undertook to service providers:

> *"I do tell people things, both in formal complaint letters, quoting the Equality Act at them, and also via just like, feedback forms, or whatever. I'm quite choosy about what I'll put my time into. I could spend my whole life doing that… I would never achieve anything, so I try to be quite choosy about what I do." (Rachel, post-journey interview)*

She went on to explain how *"nicely nicely conversations"* could drag on for years, whereas a more robust approach invoking the Equality Act led to physical improvements from both private and public organisations in a few months, concluding that such an approach was *"highly effective".* As she reflected on relative strategies of complaint, she noted

> *"I guess it depends on what you are trying to achieve. If you want to achieve some kind of catharsis then often I think live journal might be a better route than a complaint form… If you wish to share your musings about what upset your journey, you can fill in a feedback form, but nobody is going to necessarily going to do anything about it." (Rachel, post-journey interview)*

This awareness amongst participants about the relative effectiveness of different strategies of feeding back to service providers and bringing about change will be further discussed in the next chapter. However, it is important to highlight that participants recognised that to file a complaint was typically an ineffective way of addressing access barriers. It often had considerable costs for little meaningful gain and individualised the structural nature of the barriers they were trying to highlight. Furthermore, it was perceived as not conveying their knowledge and expertise as powered wheelchair users. Recognising this, some participants talked about other ways of bringing about change through more meaningful engagement with their situated knowledge, through more formalised or structured processes of engagement with decision makers.

One area discussed by several participants was that of infrastructure planning. This was a domain in which they felt disabled people's situated knowledge about the factors that made environments and service accessible could be constructively applied. They talked about how the early involvement of disabled people in development projects could help to ensure that their needs and requirements were considered at an early stage. As Matthew explained:

> *"I do think that disabled people should have more of a say when things are being planned… For instance, no toilets being on the new Crossrail project… [companies should be] approaching organisations like the [campaigning group] for opinions of disabled people, or other disability pressure groups being consulted before these things are designed and made." (Matthew, post-journey interview)*

Similarly, Anne, the former Access Officer for a local council, noted that retrofitting access later on was more costly and therefore less likely to happen:

> *"It's so difficult to change things that have been installed… going up to the council and saying 'that is not right'… is what I used to do all the time… you have to spend*

ages trying to convince them it's not right. But then they haven't got the money this year, so they'll do it next year, and next year doesn't actually happen because the priority's somewhere else. That's the reality of it." (Anne, post-journey interview)

Such comments emphasise the value of involving disabled people at an early stage when planning infrastructure, in order to effectively utilise their situated knowledge and to influence projects before they were finalised. However, participants described how their knowledge was not drawn upon by planners and policymakers. There was a widespread perception that there was a lack of meaningful engagement by such professionals with disabled people, and where they were involved this was too often tokenistic. One participant explained how consultation typically only occurred after plans had been developed, rather than as an early and ongoing process, and over the course of their interview related this to wider power relations between disabled and non-disabled people:

"when people say, 'we're doing consultations'… where's the power? The power is with the people who have actually decided to do the consultation because they don't have to take any information on board… [we need to go] beyond that kind of consultation approach… how are you building a co-productive approach of having somebody or people with you who will be able to design the development and the delivery phase of this piece of work… how are you being monitored? … there's no point in a town planner coming in with their plans already done… it's saying 'before you even start building a plan, you're working with these people, you're having that dialogue and you're building a plan together'. The problem is, that doesn't happen in reality." (Anthony, post-journey interview)

Participants perceived such engagement as tokenistic, with little power to truly influence outcomes, rather than participatory (Arnstein, 1969) and reflected that it did not draw upon their knowledge and expertise. Their experiences reflect the wider exclusion of disabled voices from technocratic processes of planning and development, which fail to take into account their knowledge and expertise and thus reproduce disabling barriers (Imrie & Hall, 2001a; Bromley et al., 2007; Imrie, 2012a). Disabled people's involvement in redevelopment projects is often constrained by structural barriers (Edwards, 2001, 2002, 2009), and access has long been considered marginal to the work of local authorities with limited resources available for access work and a cautious approach to enforcing access through planning regulations (Imrie & Wells, 1993; Imrie, 1997). Central government funding for local authorities fell by nearly 50% between 2010 and 2018, and council spending on planning

subsequent dropped by 52.8%, the single largest area of local government budget cuts during austerity (National Audit Office, 2018). In this context, councils had few financial resources available to improve accessibility or to do anything but the barest minimum of statutory consultations on schemes. They are unlikely to have the capability, even if they had the desire, to reimagine the power relationships at the heart of the planning process to centre the needs of disabled people, as envisaged by Anthony. In addition, Anne noted how accessibility improvements are often deprioritised due to the cost of implementing them, even when they are legally required:

> *"it's just fascinating… how often disabled access gets left behind because of cost. So even when you got Building Regs that have got to go and check things… they can be left off … not legally, but [they] just don't get done." (Anne, post-journey interview)*

Although councils can refuse planning permission on access grounds, or require Section 106 agreements with developers to enforce adjustments to schemes to improve accessibility, prior work has suggested that this rarely occurs (Imrie, 1997). Meanwhile, disabled people are largely excluded from planning processes due to weak statutory enforcement, as described above, and a planning system that seeks to minimise costs to developers and encourages minimal standards of provision for disabled access (Imrie & Hall, 2001b, pp.57–66). Relying on the private sector in this way seemed futile, as Peter explained:

> *"the councillors say they won't do this pavement because they're waiting for the development to be built. Well, that development's meant to have built for the last ten years but because of various things including finance, it's been going ahead and then it's stopped and it's just actually stopped again. So, that's their excuse, they won't do it because it's not needed and probably they'll get it done as part of the development." (Peter, post-journey interview)*

In this context, disabled people have few opportunities to bring their situated knowledge into the planning of new infrastructure, and thereby are typically unable to influence developments at a sufficiently early stage for significant changes to be made. Even where disabled people had been directly involved in a professional capacity in the planning system in the past, the lessons from their situated knowledge and expertise were not embedded in the institutional memory of the organisations. Anne, the former Access Officer who was still involved in local access issues within her community through an Access Group, reflected on this as a missed opportunity:

"[It is] disappointing, 'cause like 20 years ago, [the] same issues are going on now… what's very obvious is that the people I was working with probably listened to me, because I was there, and I was like… prodding them all the time, 'think of this', and 'let's try this' or whatever. 20 years on, those issues are still there. And… there is a gap between… new planners, new building control people, new builders. And… they're still making the same mistakes. So… things are not being understood, or heard, or registered. And that's disappointing." (Anne, post-journey interview)

Participants' experiences of the planning system, and more broadly how they perceived their lack of influence in the development of new infrastructure, suggest two linked challenges in engaging with disabled people's situated knowledge to bring about more accessible services and environments. The first is that specific individuals, including the planners and engineers who work on these environments, don't understand the issues disabled people face. This is a specific case of non-disabled people not understanding disabled people's lives, as already discussed. In turn, this means that the value of disabled people's situated knowledge is not recognised, nor is it embedded into the planning system or the development of new infrastructure. This leads to a second challenge, as also identified by participants, which is that these systems do not work well for disabled people. How these challenges might be addressed, and in particular how disabled people's situated knowledge might be conveyed to and taken up by decision-makers involved in the provision of infrastructure and services in a more effective way than through complaints processes, is examined in the next chapter.

5.5 Discussion

This chapter has outlined how the participants in this study have situated knowledge both as powered wheelchair users, and of what it means to be disabled in a predominantly non-disabled society. Drawing on this situated knowledge and expertise, disabled people craft workarounds that help them to smooth their passage through hostile environments. As such, their situated knowledge is a valuable asset, for it enables them to exert agency in situations and environments that would otherwise disable them. However, because this knowledge exists at the intersection of individual bodies, environments, and technologies that participants use to aid their mobility, situated knowledge can be difficult to convey to others and is not widely recognised by non-disabled people. In addition, disabled people's situated knowledge comes at a cost because the process of its acquisition imposes both physical and psycho-emotional labour. The socio-material situations that give rise to it can

be fraught: participants learned workarounds because they have few alternatives when they come up against unyielding environments. What is more, the psycho-emotional costs that lead to this situated knowledge are particularly hard to convey to non-disabled people.

As well as helping them navigate a disabling society on a day-to-day basis, disabled people's situated knowledge and expertise holds significant value for creating more accessible and inclusive environments. However, as noted above the existence of this knowledge is not widely recognised by non-disabled people, and the value it holds is therefore not drawn upon. This is particularly the case in technocratic domains, such as infrastructure planning, from which disabled people are systematically excluded. Attempts by disabled people to feed back their experiences to service providers are instead often channelled through formalised processes of complaint. These are deeply problematic: they are not only time-consuming and generally perceived as ineffectual, but they impose additional labour on the disabled people who pursue them. In addition, they perpetuate an individualised framing of the issue of accessibility. This echoes a medicalised understanding of disability, as a 'problem' with an individual, and in doing so excuses organisations and wider society from acknowledging or addressing systemic factors that result in disablement.

Participants recognised that their complaints are being framed in this way, when they discussed the limitations of complaining as a strategy for bringing about change. Moreover, they also recognised that for this to change, these issues need instead to be acknowledged as issues of collective concern. They framed their situated knowledge within a wider context: of non-disabled people not understanding their needs, of being disabled by society, and of the need for societal change. The data presented here therefore suggests that more effective processes are required to enable disabled people to better convey their collective situated knowledge to non-disabled people, in a way that could meaningfully lead to their expertise being brought into the planning and delivery of more accessible services and environments. The following chapter discusses further work undertaken with some of the participants, to explore their views about how to address these challenges.

Chapter 6. Beyond Complaint: Pragmatic Approaches to Collective Political Action

6.1 Introduction

This chapter explores how participants envisaged that their situated knowledge might be effectively conveyed to others to help bring about more accessible environments. It draws upon the second phase of data collection, which involved group Skype workshops with nine of the fifteen participants who had taken part in the first phase of fieldwork. The workshops had two goals: first, to validate my understanding and interpretations of participants' experiences as expressed during the interviews and journeys; and second, to explore with them their ideas about how these experiences might be effectively conveyed to others.

As described in the previous chapter, participants' situated knowledge enables them to make their way in a world built for non-disabled people. As such they are examples of the types of knowledge disabled people have which could be a valuable resource for society in creating more inclusive environments. However, not only was this knowledge acquired at a personal cost, but participants also felt that existing avenues for them to engage with decision-makers or service providers, such as making complaints, were limited and ineffectual in creating meaningful change. The workshops were therefore designed to start from participants' experiences, enabling them to collaboratively discuss their responses to these experiences, and from these to draw out their collective ideas on how best to convey their situated knowledge in order to effect meaningful change.

Exploring my initial analysis with participants was critical to validating my understanding of their accounts of their lives, and in recognising their situated knowledge and expertise. It meant that the workshops' collective discussion of the strategies they adopted in response to disablement was grounded in their experiences, and provided a space for peer validation and mutual learning. These aspects helped to foreground the political nature of the diverse strategies they adopted to disablement, from in-the-moment reactions to more purposeful activism and campaigning. This approach also highlighted how such strategies were typically grounded in participants' situated knowledge of what might be the most effective approach in particular contexts. Yet the workshops also reinforced how their repertoire of possible actions was constrained by factors such as the labour involved when confronting barriers, as well as their access to material, social, and political resources. The ways that the workshops helped to validate findings from the first phase of fieldwork will be briefly discussed below, and this validation helped to frame the findings described in Chapters 4 and 5.

However, this chapter's main focus will be on the ways in which the workshops themselves provided a forum for participants to collectively articulate a form of disability politics that is grounded in the social model. This happened both through the substance of their ideas for bringing about change, and through the very process of discussion itself. The chapter first describes the structure and format of the workshops. It then explores how the workshops helped to validate the findings of the first stage of research, and how participants engaged in processes of knowledge sharing and peer-education about both practical and theoretical issues relating to disablement and disability politics. The chapter then briefly describes the ideas that were suggested by participants, before analysing the common themes that underpinned them that were rooted in a sense of pragmatism and political astuteness. The chapter concludes by highlighting the links between how participants engaged in the workshops and the ongoing relevance of the social model of disability.

The workshops described in this chapter provided a space in which participants linked their individual and collective experiences to those of others, an aspect of 'consciousness raising' about shared injustice – an essential pre-requisite for collective political action (Campbell & Oliver, 1996). They thus supported a form of politics rooted in social model understandings of identifying and tackling societal disablement. In the ideas they put forward, participants made aspirational suggestions for how things could be different, thus using the social model as an 'oppositional device' (Beckett & Campbell, 2015) against which current disabling practices and future alternatives could be measured. The workshops and the pragmatism underpinning participants' ideas therefore provided an example of the social model in action.

6.2 Workshops

6.2.1 Overview

My initial analysis of the first stage of fieldwork consisted of open-coding the transcripts of the interviews that followed the go-along journeys. This was informed by the videos and photos captured by participants themselves in their use of JourneyCam, as well as by my own observations recorded in contemporaneous field notes and reflections, photos, and videos. This process is discussed in detail in Chapter 3.

Having reached this point, I felt it was important to return to the participants to validate my tentative understanding and analysis of the issues they had raised. It is especially important for me as a non-disabled researcher to be accountable to the disabled participants with

whom I worked, as the inherent power relationships between researcher and participant are heightened in the context of wider societal power relationships between non-disabled and disabled people (Stone & Priestley, 1996). In this context, I have sought to foreground participants' knowledge and expertise, rather than adopt an unsustainable epistemological position of detached objectivity (Stone & Priestley, 1996, p.703).

In addition, I wished to explore how participants' individual and collective experiences might serve as a resource for wider systemic change, for example by engaging with decision-makers to improve the accessibility of places and transport. Several participants also mentioned that the possibility of exploring these issues was a motivation for them to take part in the research, even though I explained that for practical reasons taking part might not involve directly engaging with policymakers. Although at the end of each interview I asked participants how they felt their knowledge could help to bring about broader change, there was insufficient time to explore these issues in depth. There therefore remained considerable scope to explore how participants' individual experiences and concerns, as I witnessed and they described to me in the first phase of fieldwork, were part of a wider set of collective experiences amongst powered wheelchair users that might, in turn, form the basis of shared action to engage policymakers. There was also the chance to explore how these common experiences might be brought together through collective dialogue to enable shared sense-making.

These factors led to my desire to bring participants together to discuss their experiences through a group interaction such as a focus group or workshop. A key aspect of focus groups is that they rely on interaction within the group to generate data and insights that would be less accessible without such interaction (Morgan, 1997, p.3). While specific approaches and techniques vary, they are commonly organised group discussions around a specific topic monitored and guided where necessary by the researcher, with their common distinguishing feature being the explicit use of group interaction to produce data (Stewart & Williams, 2005, p.396). In this research, I approached the design of the group sessions as workshops rather than focus groups, drawing on their use in HCI where – as one aspect of user participation in design processes – they are "heavily orientated towards destabilising power structures that might enforce ill-considered technologies on groups who are not typically consulted" (Vines et al., 2013, p.430). In this context, the goals of design workshops include sharing control with participants, sharing expertise, and motivating change (Vines et al.,

2013). In line with my desire to validate my initial understandings and interpretations from the interviews, I was keen to start from some of the data that participants had collected, using it as a prompt for collective discussion. Although I had initially planned to run the workshops in person, because participants were located across England it was logistically very challenging to find a suitable location and date that would have enabled many to take part. I therefore decided to run these workshops online. Careful consideration was given to the best way of doing this, in particular whether they should be run as synchronous interactions (in real-time using an audio- or video-based conferencing tool such as Skype), asynchronous interactions (via an interactive website), or some combination of the two.

There are a range of advantages and disadvantages associated with either approach (Stewart & Shamdasani, 2017). Asynchronous methods, such as 'asynchronous remote communities' (ARC) (MacLeod et al., 2016, 2017) do not require participants to all be online at the same time, making them potentially easier to accommodate alongside other commitments. They typically involve working with geographically dispersed groups, such as those living with rare diseases (MacLeod et al., 2016, 2017) and HIV (Maestre et al., 2018), or those sharing a particular social characteristic such as expectant or new mothers (Prabhakar et al., 2017). They are most often conducted via closed groups on social media platforms such as Facebook, with participants often recruited from existing, public online peer support and community groups on those platforms. While it is possible to create or modify existing digital tools to support online workshop activities, the ARC approach can be used with analogue activities – such as diary studies or personas – suitably modified for an online setting (MacLeod et al., 2017).

However, adapting an existing social media platform in this way has several disadvantages. Unlike the asynchronous communities described in the literature, because I had recruited participants via multiple routes they were not all part of one pre-existing online community such as a Facebook group. I would have had to create such a community specifically for this purpose, in turn requiring all participants to have a Facebook profile and bringing with it the privacy implications of using accounts that are closely tied to their offline identities. In addition to the ethical challenges this posed, I was concerned that many existing platforms were not fully accessible. I therefore did not feel confident that the participants would be able to take part if the online workshops re-appropriated existing social media platforms.

More importantly, I felt that a core strength of the work I had undertaken prior to this point was the immediacy of discussion around particular issues with the participants, which was enabled by the nature of the in-person Journeys and subsequent interview discussions. This was a central reason for wanting to conduct workshops in the first place, as I hoped that participants would respond to and build upon each other's contributions. I felt that an asynchronous method would lack some of the interactional value that might occur during a 'live' workshop. For this reason, I favoured conducting the online workshops in real time, which I felt would be most productive in generating ideas and discussion. Such synchronous workshops most closely resemble in-person focus group or workshop interactions, as the researcher and participants interact simultaneously (Lobe, 2017).

As I did not have the resources to create or modify a website to facilitate synchronous interactions centred around the data participants had captured, and had concerns about accessibility of existing tools regardless, I chose the simplest technical solution I could: using an existing online video conferencing tool to run synchronous online workshops. Multi-person video calls preserve many of the advantages of in-person focus groups or workshops, including the ability to see and hear each other in real time, which supports a level of immediacy and spontaneity in responses and interactions (Tuttas, 2015). However, as with in-person synchronous activities, a synchronous online workshop requires structuring activities to serve as prompts for reflection and discussion and to help guide the conversation. These can be adapted from approaches used for in-person groups, such as questions or visual stimuli (Stewart & Shamdasani, 2017).

I therefore chose to run these workshops synchronously via Skype, and created worksheets that I pre-circulated to participants. These contained individual activities to complete in advance of each Workshop, to enable participants to begin to reflect on their experiences and help structure their thoughts in preparation for the conversations. The worksheets are described in more detail below. I chose Skype to run the workshops due to its maturity as one of the longest-standing video-calling platforms, its wide availability across different devices, its support for both video and audio calling, and the fact it is freely available[9].

As discussed above, a key aim for the workshops was that they would help to validate my understanding and interpretation of participants' experiences. In this respect, they served a

[9] The workshops took place in February 2018, prior to the global COVID-19 pandemic and the widespread adoption of Zoom (https://zoom.com) and similar web-conferencing tools.

function akin to 'member checking', where research data and interpretations are returned to participants who can confirm or reject the credibility of the information and narrative account around it (Creswell & Miller, 2000). Member checking offers the opportunity for negotiating meaning between participant and researcher, and for increasing the level of participation in the research process (Doyle, 2007). Member checking can also provide a reflective tool for participants themselves (Candela, 2019), which would also help to support my second goal for the workshops: to provide a forum for participants to explore both the issues raised by the research and the research itself with each other. Finally, I aimed for the workshops to offer an opportunity for participants to ideate around particular actions or initiatives they felt would be most worthwhile to take forward, and what such 'next steps' might be either within or outside of this research project.

6.2.2 Method

As part of the initial consent process and first phase of fieldwork, I had informed all participants about my intention to run group workshops after the conclusion of the first phase of fieldwork. When it was decided that these would need to be run online rather than in person, all fifteen people who had participated in the first phase of fieldwork were contacted by email and asked if they wished to attend a workshop.

I prepared a series of worksheets to send to participants in advance of the Skype calls. These aimed to structure the discussions to meet the workshops' objectives: firstly, to validate my initial interpretation and analysis of participants' experiences; secondly, to create a forum in which participants could discuss these issues with each other and identify areas of common concern; and finally, to provide an opportunity to consider how these experiences might be used to bring about more accessible interactions and places.

I planned two workshops, to take place one week apart. For ease of facilitation I aimed to have no more than 5 people in each workshop, and to accommodate participant availability I planned to run each workshop twice (Figure 18). Each session consisted of two activities: Workshop A included *Activity 1: thinking about experiences* and *Activity 2: video discussion*; while Workshop B included *Activity 3: ideas for improvements* and *Activity 4: sharing experiences and next steps*. More details on the activities are provided below.

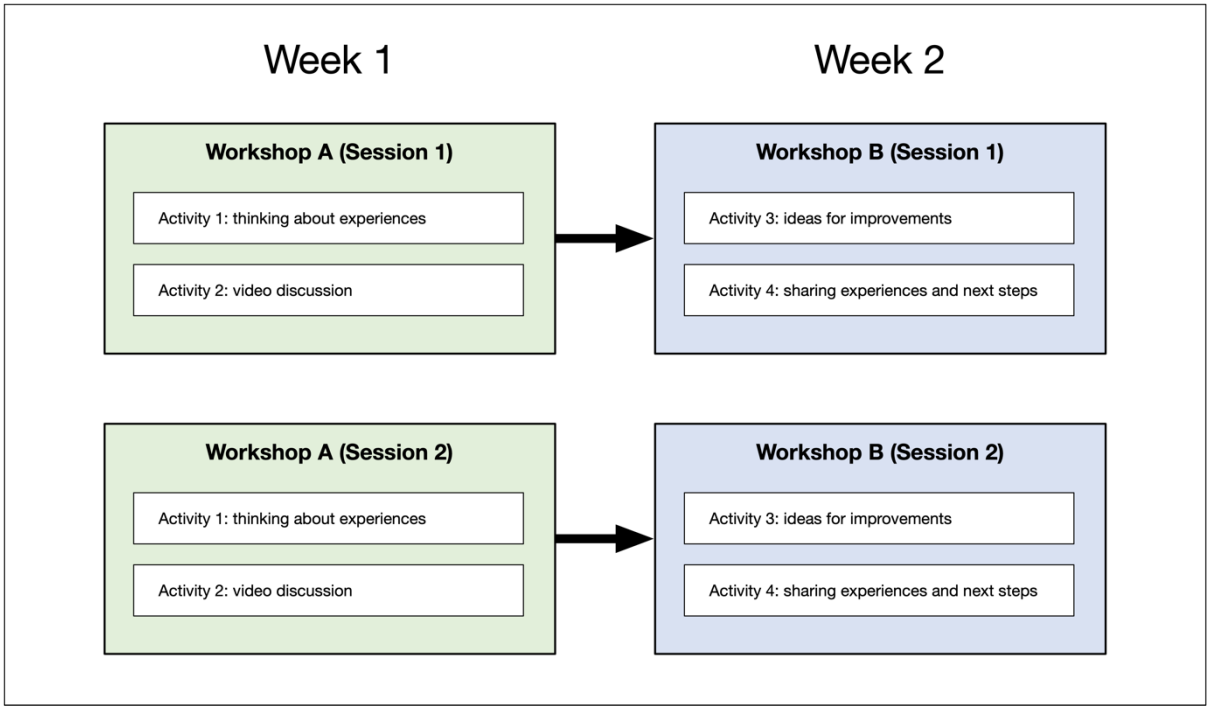

Figure 18: Diagram of planned workshops. Each contained two activities and would happen twice each week to enable as many people as possible to participate. Participants would stay constant in their session each week.

Prior to each workshop, participants were supplied with a worksheet appropriate to that week's activities: Worksheet A contained instructions for Activities 1 and 2, while Worksheet B contained instructions for Activities 3 and 4 (Appendix K: Worksheets A and B). These were designed to structure the discussion and enable participants to begin to think about the issues they would like to discuss in the workshop. They contained tasks to think about and spaces for making notes. These activities were designed to flow logically, so that the outputs of Workshop A informed the discussion in Workshop B. To enable this I collated and summarised the data from that week's discussions and used it to prepare the Worksheet B (see Table 4 for the contents of this summary, which was pre-filled in Activity 3).

All workshops were conducted via Skype video call and audio-recorded. In addition, because I was facilitating the workshops alone, I printed out the worksheets centred on A3 paper and used the blank space to take notes. This enabled me to capture the key contours and points in the discussion, reacting and adjusting the focus of the workshop as it progressed. In the next section, I describe both workshops and their activities in more detail.

6.2.3 Workshop A

Workshop A sought to explore whether my interpretations of the data generated during the first phase of fieldwork accurately reflected participants' experiences through discussing some of the tentative themes that I had identified with them across two activities.

Activity 1: thinking about experiences

The first of these, Activity 1, asked participants to think in general terms about one possible conceptualisation of their experiences: a four-part framework of interlocking factors that seemed important to participants' experiences and how these might influence each other. This was based on factors that I had identified during my initial analysis of data from the first phase of fieldwork.

1. *Restrictions* (things that constrain powered wheelchair users from going where they want, when they want to, and how they want to). These might include physical barriers, interactions with people, or issues to do with impairment.
2. *Sense of control* (ways that powered wheelchair users respond to the problems they face in their day to day lives, that make a difference to their experiences). These might include overcoming obstacles, subverting difficult or awkward procedures, or even simply getting out and about.
3. *Practical experience* (knowledge and expertise that each individual has built up over time about being a powered wheelchair user, which other people simply do not have). This might include knowing the best route for a particular journey, or being familiar with the capabilities of their powered wheelchair.
4. *Feelings* (how people feel about the particular experiences of mobility and accessibility that they encounter). This might include how a good or bad experience affects their emotions, and how these feelings influence their actions.

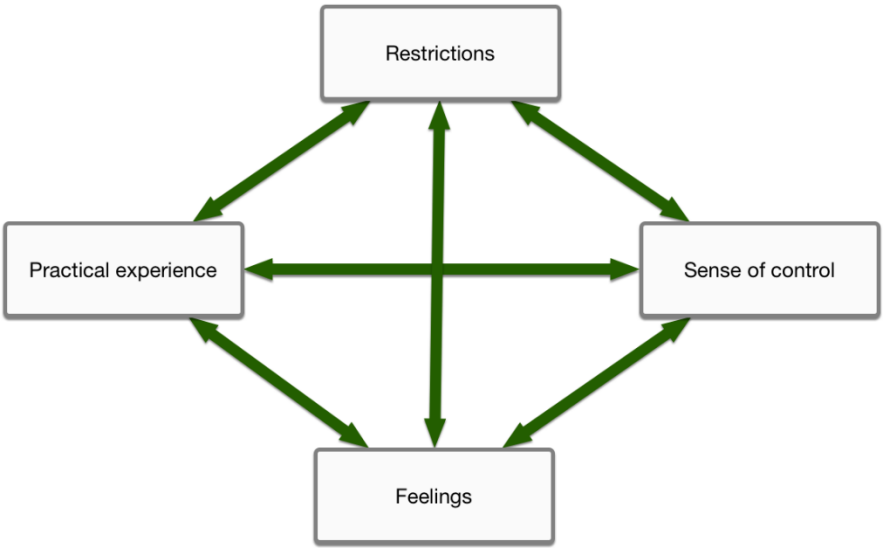

Figure 19: Diagram in Activity 1, showing a model of the relationship between significant factors in participants' experiences

A description of these factors, and a diagram showing how I envisaged them linking to each other, was provided on the worksheet (Figure 19). In preparation for the Workshop, I asked participants to consider whether this framework made sense to them, how it could be improved or adapted, and whether they thought the labels I had chosen for the themes

were appropriate and useful. During Workshop A, Activity 1 was planned as a group round-table discussion about the framework, which I intended to last approximately 20 minutes.

Activity 2: video discussion

Activity 2 was a group discussion structured to enable an exploration of the commonalities between different participants' individual experiences, and to begin a process of thinking about how such experiences could be different in the future. As such, it aimed to both provide additional validation of my initial interpretations of their experiences at both the individual and collective levels, as well as encourage participants to unpick and elucidate exactly what it was about these experiences that would need to change.

To achieve these goals, the second part of Worksheet A contained a table which structured Activity 2, a discussion around the video data captured by participants themselves. This table contained 11 common themes I had identified in my initial thematic analysis, which I organised by the 4 factors from Activity 1. These themes are summarised in Table 3 below.

A: Restrictions	1. Enforced Detours
	2. Lack of choice or spontaneity
	3. Actively choosing accessible places
B: Sense of control	4. Subversion: 'just turning up and going'
	5. Challenging negative situations
	6. Comfort and discomfort
C: Feelings	7. Confidence or lack of confidence
	8. Vigilance and tiredness
	9. Unique perspective
D: Practical experience	10. Unexpected costs
	11. Knowing chair capabilities and limits

Table 3: Eleven common themes organised into the four areas described in Activity 1

Where possible, I identified a video clip that I felt represented each theme (9 of 11 themes). These were uploaded to a secure Microsoft OneDrive folder, and linked from the title of each theme. The table also included the interview comments made by the participant who

captured the clip. Figure 20 shows an example of this for the first two themes; the full table is provided in Appendix K: Worksheets A and B.

	Theme	Notes: what could be done? How would it help?
A: Restrictions	**1. Enforced Detours** *"A-boards are a great nuisance, especially on smaller streets… I'm very happy to fold them up and lay them flat against the building, and leave them like that, if I'm not happy with them… We had a little chat. I can see his point of view, he doesn't want to be liable if someone did drop the scaffolding pole onto us… he wouldn't want to be the one that let me through… They should have put out one of those plastic ramps… that come off the kerb temporarily"*	
	2. Lack of choice or spontaneity *"You see there's just no pavements here at all… crossing here is a bit scary. You just make sure it's clear. I could go up the kerb there, but there's no way to get down the other side. Plus it's overgrown anyway. [I was] a little bit nervous! It's just really want to just get off it as quickly as I can. But then again not going too fast, to cause an issue with the other cars. You can see there's a nice paved bit there, that I can't get onto. If they just made a drop kerb there, it'd make it a lot safer. [My PA] mentioned there was a car behind, so I thought it was best to let them past on this bit. Rather than carrying on. Give them time to get round, and a few other cars to stop. Like this one here stopped to let everybody past me."*	

Figure 20: Section of Worksheet A, Activity 2

In preparation for Workshop A I asked participants to pick four themes of their choice (one from each area), to watch the associated clip for that theme, and to read the quote. The worksheet also asked them to then consider two questions about each clip before the workshop: first, whether there were things that organisations or policymakers could do differently to help in this situation, and second, why those things would help.

Just as during the JourneyCam fieldwork, the video served as a prompt for participants to reflect on the experiences, and in this case the quote from the person who first captured the clip provided additional context for this reflection and discussion amongst participants. The activity was intended both to validate salient themes, as well as try to understand the underlying issues that were associated with each theme and which might serve as the basis for changes that would improve these experiences.

I anticipated that the group discussion might generate very rich data, so allowed an hour for this activity which concluded Workshop A. In hindsight, this was insufficient time as will be discussed below. After the end of the workshop, I collated my notes of participants' responses, and distributed these summaries back to them several days in advance of

Workshop B (Week 2). This enabled the activities in Workshop B to be clearly informed by and developed from the issues discussed in Workshop A.

6.2.4 Workshop B

Workshop B had two aims: in Activity 3, to develop some of the ideas that had been suggested by participants in Workshop A; and in Activity 4 to discuss the issues or challenges that might be associated with sharing personal experiences (such as those that informed the workshops) as well as to seek participants' input into the next steps for the project.

Activity 3: ideas for improvements

The discussions in Activity 2 led to participants identifying underlying issues that they felt ought to be improved, and coming up with 10 distinct ideas for improvement. Participants often came up with multiple suggestions of 'what could be different' and 'how it would help' associated with each idea. I summarised these (Table 4) in Worksheet B, which was supplied to participants before Workshop B.

Idea	**What could be different**	**How it would it help**
1. Raise awareness of disabled people's needs	A change of mindset amongst decision makers Staff on the ground given training & equipment, not just supervisors Allow for flexibility, rather than bureaucracy (e.g. turn up & go) Provide accessible alternatives	Better awareness of what disabled people need More positive interactions with decision makers/people who make places happen, at all levels Enabling disabled people to have more freedom and autonomy. Equality with other people.
2. Identify disabled people's design needs, and actually implement them in standards and practice	Providing things wheelchair users can actually use Account for actual needs, not just the 'specifications' Do the specifications need to be changed to comply with reality? Do specifications provide a 'get out clause'?	Ensure that things are not built 'to spec' but useless for disabled people. Improve the specifications to reflect real world experiences and needs. Ensure specifications aren't a 'tick box' exercise.
3. Improve consultations with disabled people who use space	Involve disabled people all the way through the process of providing of accessible spaces	Include needs early in process before it is too late to change things.
4. Find ways of aligning with other groups	Better alignment with demands made by other users of space (e.g. cyclists).	Avoid pitting different groups against each other. Strength in numbers.
5. Reduce variability and inconsistency between policies	Different councils/companies would be more consistent in provision.	More certainty and reliability of provision for disabled people. Less uncertainty.
6. Reduce disconnect between policies, implementation, and enforcement	Ensure that what policies say is actually implemented; and that if it isn't implemented properly then there was enforcement.	Improve certainty and reduce uncertainty of provision. If policies not implemented, then there is a way to ensure changes are brought about

7. Increase accountability and visibility of access provision	Someone would take ownership of issues around access. Every 'link in the chain' would be aware of its importance, and what their role is in providing it.	Disabled people would know who to contact with issues and would have confidence Those involved in providing services, including subcontractors, would know how to do the right thing.
8. Improved complaints processes	Ways of making complaints no longer hidden away. Less arduous ways for people to complain. Improved accountability of process, so things wouldn't be ignored – feed back to people. A 'charter' for disabled access setting out how people can expect to be treated.	Disabled people would find it easy to make a complaint where needed. Complaints would be taken seriously. People who complained would have meaningful feedback. Systemic improvements could be made, to learn from people's individual complaints.
9. Better processes for highlighting problems	A space to have a dialogue with decision makers and others who can bring about change. Alternatives to just complaining. Organisations would not be able to say that 'everything is fine', but would listen and have process to take things on board.	Different people with different attitudes towards complaining or activism would still be able to help to improve access through their feedback.
10. Improve knowledge sharing amongst disabled people	Ways to surfacing and sharing the knowledge that disabled people have accumulated to help other disabled people in similar situations (e.g. law, access routes/techniques, etc)	A wider community of disabled people would benefit from shared knowledge Knowledge could be highlighted to policymakers to improve their understanding of 'what works' and what doesn't. Would highlight to policymakers the lengths people go to for equality of access

Table 4: Summary of ideas suggested by participants in Workshop A, used for Activity 3

Activity 3 involved participants picking between 3 and 5 of the ideas that they felt were most important or interesting to them in advance of the Workshop, and for each asked them to think about some questions (Table 5):

As a group, we will choose the most important or interesting 3 to 5 ideas to brainstorm.

Have a think about which ones you will choose, and think about the following questions:

What is the actual, 'actionable' change or improvement?

- Is it a change to the physical environment, a process, or people's attitudes? Or both?
- Is it a "best practice" that would help powered wheelchair users?

How could we make this change happen?

- Does it need to be highlighted to a specific organisation or person, and who?
- Is it about campaigning, lobbying, or raising public awareness?
- Is it about sharing knowledge with other powered wheelchair users?

How would your experiences of going on journeys be different if this change happened?

- Imagine what this experience would be like for you, if it was just how you wanted

Table 5: Questions posed as prompts for Activity 3, Workshop B

The worksheet included space for participants to write down their thoughts in response to these prompts. I had planned for 40 minutes for a round-table discussion and brainstorm of the chosen 3-5 ideas, but as with Activity 2 in hindsight this was too ambitious: participants

often picked different ideas, and we ended up discussing many of them. This means that we again overran our time, eating into the allotted time for Activity 4.

Activity 4: sharing experiences and next steps

The final activity aimed to explore participants' thoughts about issues or challenges that might be associated with sharing their personal experiences as a way of bringing about some of the desired changes they had identified in the previous activities. It also sought their input on next possible steps for the Journeying project. Unlike the previous activities, which were based around the data participants had captured, Activity 4 asked open-ended questions about topics, with a few short textual prompts (Table 6):

1. **How could the project data and findings be explained or narrated to other people?**
   - How can 'hidden' issues, or ones which aren't easy to explain, be conveyed?
2. **What are the next steps for Journeying Project?**
   - Should we make some of the data you have captured public? To whom?

     Some examples of things we might consider doing, perhaps in conjunction with other organisations. Some of these are ambitious or could become large projects, so also think about what might be practical, and whether you would like to be involved.
   - A report, like the *MDUK Trailblazer report*.
   - A short documentary film or a website using the video clips you have captured, photos we took, and written or spoken narration/explanations of the issues.
   - An "Ask Me Anything" session with policymakers so they can ask you questions (or you can ask them)! Example: *Chris Hadfield, astronaut*.
   - Think about how we could develop JourneyCam, such as making it available publicly or adapting it into a tool for campaigning.
3. **To make some of the data you have collected public, what issues should we consider?**
   - Under what circumstances should things be made public, and to whom?
   - What forms of data could this involve?
   - How do we balance making a difference in this way, and ensuring your privacy?

Table 6: Questions posed as prompts for Activity 4, Workshop B

These prompt questions aimed to elicit participants' thoughts about how the substantive data and findings of the project might be brought into conversation with policymakers and others, and what they would like to see happen next. As before, space was provided in the worksheet for participants to write down some thoughts in advance of the workshop.

6.2.5 Procedure

As originally planned and as noted above, the workshops were initially intended to run over two weeks, with Workshop A taking place twice during the first week with different groups of participants and Workshop B taking place twice during the second week (Figure 18).

I wanted to ensure that as many people were able to contribute as possible, and so did my best to accommodate participants' preferences for timings. When scheduling Workshop A, however, it became clear that co-ordinating participant availability was very challenging. It ultimately proved impossible to reconcile all availability to fit into two workshops per week. Moreover, the workshops overran their allocated times, resulting in the continuation of the Workshop B sessions into a third week, Workshop C, with available participants. Figure 21 shows the Workshops as they eventually took place, and how participants contributed at each stage (whether in person, written via the worksheets, or freeform comments).

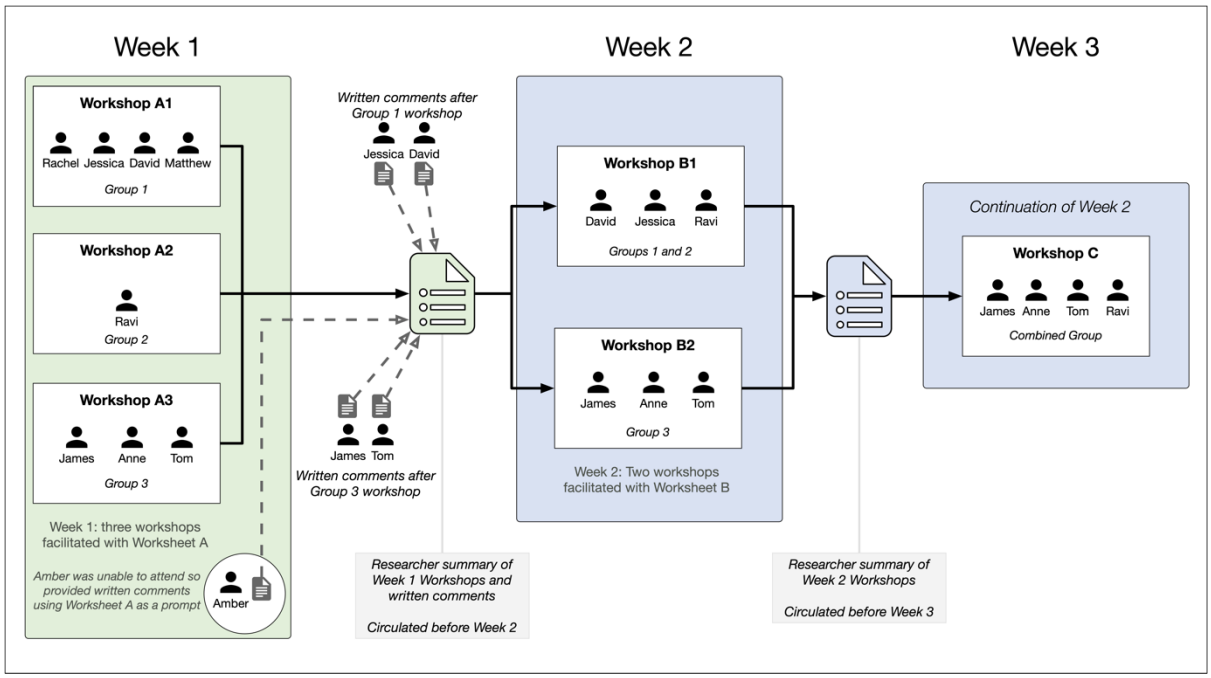

Figure 21: Diagram of workshops as they actually occurred, showing flow of participants and how the content from each workshop and written feedback from participants was collated into summaries in advance of the following week's sessions

Workshop A was repeated three times (A1, A2, and A3) during the first week to accommodate the schedules of different participants, but due to last-minute changes in availability, one session ended up involving only one participant (Ravi). Although I used some of the issues that had been discussed in the previous day's session, which had 4 participants, as prompts in this 'workshop', the intended benefits of a group discussion between multiple participants were not realised. Another participant (Amber) was unable to attend any of the Workshop A sessions, but emailed me her comments on the topics that were discussed using Worksheet A as a guide. Scheduling constraints also meant that not all participants were available the following week to take part in Workshop B. Of the 9 participants who took part in the first week's activity (8 in Skype workshops, 1 providing written comments), only 6

were able to attend Workshop B and two sessions (B1 and B2) were run in accordance with participants' availability.

In addition, and as already discussed, it became apparent even during the first workshop that I had been too ambitious in planning workshop tasks and they would not be completed within the allotted time of 1.5 hours. While the activities did help to focus the discussion, I had underestimated the time needed to work through them, especially given the incredibly rich interactions between participants who engaged in animated discussion and often elaborated on each other's contributions. Despite Workshops A1 and A3 (those with more than one participant) lasting more than 2 hours each[10], we only partially completed Activity 2 within each session. Four of the nine participants in Workshop A provided additional written feedback following the workshop, which was compiled alongside data from the workshops themselves and circulated in the summaries I supplied to participants before the second week's Workshop B sessions. Similarly, both Workshop B sessions ran beyond 2 hours and 15 minutes each, and we did not finish the activities in the available time.

Understanding participants' ideas for the future, including their thoughts on the future direction of the Journeying project and the possible uses for their data, were important aims of the workshops. Because exploring these required completing Activities 3 and 4, I asked participants if they would be willing to return for a third week. Four were available and willing to take part in a single final session, Workshop C, which lasted a further 2 hours. As shown in Figure 21, the pattern of the workshops therefore assumed a pyramid, with the number of participants reducing from 9 to 4 over the three weeks of fieldwork.

All of the above factors speak to the strength of commitment amongst the participants who took part in the workshops. During every workshop, they enthusiastically continued their discussions well beyond the allotted time, despite my emphasising there was no obligation and offering to end the sessions on time. Several took part in the third week's continuation of Workshop B, and others expressed that they would have liked to have done so if they had they not had clashing engagements. Participants' commitment was also shown in the way that more than half took the time to write and send through comments, either when they couldn't attend a workshop (Amber), or to follow up on issues that we ran out of time to discuss in the workshops (James, Jessica, David, Tom). Two people filled in the worksheets, while others provided their notes in plain text. These comments were detailed and lengthy,

[10] Workshop A1 lasted 2 hours, 20 minutes and Workshop A3 lasted 2 hours 5 minutes.

consisting of a total of approximately 8 pages of text. I believe this level of engagement with the workshops was aided by the strong rapport I had built up with these participants during the first phase of fieldwork, an issue which can pose challenges in online-only focus groups and workshops (Tuttas, 2015). It was also reflective of the participants' strong commitment to the research as a whole, which was reflected throughout the fieldwork and has already been discussed in Chapter 3. Their enthusiastic participation in the workshops highlighted their desire not simply to articulate their experiences, as in the first phase of fieldwork, but also to find ways in which their situated knowledge might be used to improve services for disabled people. The dynamics and role of the workshops are explored in more detail below, followed by a summary of the ideas put forward by participants.

6.3 Workshop Dynamics and Role

As I had hoped, the workshops enabled in-depth discussions between participants about the individual and collective issues they faced relating to mobility and accessibility, as well as their wider experiences of being powered wheelchair users and of being disabled in a society designed around the needs of non-disabled people. As well as helping to validate my understandings of the data generated during the first phase of fieldwork, the structure provided by the worksheets helped to frame these conversations in a way that linked participants' experiences to ways that their knowledge and expertise might inform changes and improvements. This section first discusses how the workshops helped validation and contributed to the framing of the two previous chapters. It then explores how the workshops themselves served as a space for mutual validation and recognition of shared experiences of disablement, and provided the participants with a forum for exchanging their situated knowledge and expertise. Finally, it briefly summarises the ideas that were suggested by participants during the workshops.

6.3.1 Validation

The framework outlined in Activity 1 was broadly well-received by participants, who felt that it captured important aspects of their experiences. Participants' reflections about the factors I had identified, what they included, and how they related to each other provided additional layers of understanding around the issues that were discussed. For example, in their conversations about the appropriateness of particular labels, participants engaged in discussions about whether the names I had chosen for each factor aligned with the ideas and experiences that it represented. While there is not space to explore these in detail, it is

worth noting that participants linked their own everyday patterns of encountering barriers to broader issues that echo conceptual and political debates in the social model about the sources of disability. For example, in discussing the factor I had called 'restrictions', some expressed the belief that impairment should be explicitly included in the diagram as one aspect of 'internal' restrictions; others, directly referencing the social model of disability, emphasised that impairment was secondary to the many environmental barriers they faced.

One particular issue raised by several participants was the complexity of the relationship between the four factors I had proposed in Activity 1, as Rachel explained:

> *"I agreed with you that there were these 4 points and that these 4 points were probably good like clusters of information. But I'm not sure that there's a bidirectional relationship between all of them." (Rachel, Workshop A1)*

Jessica noted that the weighting of each factor *"might alter depending on the experiences that you go through"*, and although she felt that the diagram was perhaps *"a little bit too simplistic for me"* she later elaborated that she felt that it showed:

> *"a really good model… these are very complex issues that you've been able to put together in a diagram… I think for me, I just need a little bit more of a description within each box, a little bit more information." (Jessica, Workshop A1)*

Similarly, in the second workshop Anne noted that *"whichever way you take each situation, those are the four things we encounter"* (Anne, Workshop A3), before describing how different aspects of a person's particular experience might align with each factor. These comments during Activity 1 therefore did affirm many aspects of my understanding of the issues that powered wheelchair users faced, while also making me question whether my neat and overly-tidy representation of how these ideas fitted together was appropriate.

One aspect of my initial findings in particular that was validated, however, was my sense that disabled people's knowledge and expertise was an important organising concept. This was reflected in the way that participants conceptualised what I had tentatively described 'practical experience', where they used terms like 'knowledge' and described how it was accumulated over time:

> *"David: I think of practical experiences as a catalogue of knowledge that you build up over time. Detailed knowledge about which bit of the train to get on at [a station] or which detours to take in Westminster to avoid missing kerb drops, which entrance to take into a shop which has the tiniest step, stuff like that and*

you eventually get a whole new part of your brain that bulges with this information

Rachel: Mmhm, yep, that's true!"
(Workshop A1)

"James: …maybe knowledge as well, in there?. 'Cause it's about learning as well as experience, I think.

Anne: I agree… thinking of James's word, knowledge, that says it too, that is… what we know… we know that if that situation arises, this is going to be what happens to us."
(Workshop A3)

The way that the participants discussed this knowledge in the workshops was not simply in terms of how it helped them to navigate barriers but also in terms of how these barriers could be addressed. For example, they emphasised its role in informing policymakers:

"Jessica: And I think in presenting this to policymakers, that bank of knowledge… they need to really appreciate how important that is. Because, if that bank of knowledge can be used in the planning stages, that could make such a difference to a wheelchair user's experience…

… Rachel's absolutely right, I wasn't born as a wheelchair user. I became a wheelchair user as an adult, so I had to learn – as lots of other people – the hard way, through lots of good experiences and lots of bad experiences… it's not because I'm stupid that I didn't know that, it's because I've never been in a wheelchair before so I didn't know that! So although I could have tried to envisage what those obstacles or issues might have been for wheelchair users when I wasn't one, it's actually only being in a wheelchair that you get that… solid bank of knowledge."
(Workshop A1)

The affirmation by participants during the workshops that disabled people have particular insights into disablement and the ways that it could be addressed, and that they recognised the situatedness of this knowledge, helped to frame and structure both the preceding chapters. Chapter 4 explored the complex nature of socio-material disabling barriers, as identified by participants using their situated knowledge, highlighting how poorly-implemented features intended to improve access could have the opposite effect. For example, the ways in which participants described maintenance gives an example of how their comments during the workshops influenced my framing of this issue in Chapter 4. They

highlight not only the contingent nature of what makes an accessible environment, but also how they saw specific barriers as linked to wider social, cultural, and organisational attitudes towards disability and access:

> *"Jessica: it's also about maintenance… we went to Berlin as well, and one of the lifts near our hotel didn't work one morning… coming back that afternoon… the lift was fixed. Whereas in this country you'd be waiting three or four weeks if you were lucky!*
>
> *David: Yes, [the UK operator's] attitude to lift maintenance is an absolute disgrace."*
> *(Workshop A1)*

Following on from this, Chapter 5 examined the characteristics of participants' situated knowledge which gave rise to these insights. As with Chapter 4, the structure and content of Chapter 5 was influenced by insights from the workshops, as participants framed their situated knowledge as an asset while also discussing the costs associated with acquiring it, and the limitations of existing approaches of conveying this knowledge to others to bring about change.

Some aspects of this will be discussed in more detail below, such as how participants framed the importance of being able to provide constructive feedback to organisations rather than solely complain about things going wrong. First, however, it is important to highlight that the workshops themselves fostered the sharing of participants' experience and expertise, through discussing things such as workarounds for barriers or common issues they faced. This aspect of the workshops, and how it might link to disability politics, will be discussed in more detail below.

6.3.2 Knowledge sharing

In providing participants with the opportunity to explore and expand upon their experiences of mobility with each other, the workshops promoted the sharing of their collective situated knowledge. By enabling participants to draw links between and contrast experiences with those of others, they showed how situated knowledge could be similar to or different from that of other disabled people. Often, this enabled richer, complementary understandings to be created through discussion. Not only did these discussions provide an opportunity to validate my understandings as described above, but they also helped to validate and affirm

participants' own experiences of disablement as legitimate, and as something they had in common with other disabled people.

Mutual recognition of the validity of participants' experiences was sometimes implicit in the flow of the conversations, occurring through affirmation of each other's comments during the course of a discussion as they explored points of commonality. For example, in this exchange Tom and Anne not only agreed upon a barrier they both faced resulting from the lack of enforcement of existing rules, but also concurred that it was inappropriate for disabled people to be expected to take the lead in addressing these barriers:

> *"Tom: Things also about enforcement and checking as well [Anne: yeh] there needs to be some enforcement. It's like my personal bugbear is bins on the road [Anne: oh yeh!], on the pavement. That, I'm sure that is against some bylaw. Obstructing the pavement. But it's not enforced [Anne: yeh] nobody checks it.*
>
> *Researcher: And whose job do you feel it is to be enforcing these kind of things?*
>
> *Tom: Local council, traffic wardens, [unclear] really.*
>
> *Researcher: [Someone] in the previous workshop made the comment that enforcement tends to come down to individual disabled people then having to make a complaint.*
>
> *Tom: Yeh. Which is difficult, very difficult, and stressful.*
>
> *Researcher: And we might come back onto that shortly.*
>
> *Anne: Think that happens a lot.*
>
> *Tom: And it shouldn't be our job!*
>
> *Anne: No, absolutely not!"*
> *(Workshop A3)*

This speaks to another important aspect of the mutual validation that took place in the workshops: the acknowledgement of the emotional and physical labour they incurred as disabled people in the process of working around socio-material barriers. In the process of talking with each other, participants recognised the work that they collectively undertook in order to successfully make their way in a world that is hostile to their mobility needs. For example, after one person described the apparent futility of the process of complaining about negative experiences on public transport, three participants reflected on the psycho-emotional impact this had on them:

"David: complaining, there's an energy behind it, and there's an urgency to do it and almost a moral obligation, but there's also a huge pool of despair lying behind it. That actually I needn't bother, and the fifteen minutes I use for each… complaint have wasted parts of my life.

Rachel: Do you escalate them?

David: Yes, yes, I had a meeting with the [senior manager] on Friday, and I didn't feel happy about that. But at least the door's been nudged open, a dialogue.

Jessica: It can be- often, to me, at a huge personal cost. Because energy is quite an issue with me, in terms of I have limited energy, and to complain requires energy [Rachel: yep], and sometimes you can complain, and the response back is horrible [David: yeh]

Rachel: I found that with my [complaint] particularly [Jessica: did you?] yeh.

Jessica: That can live with you for a while [David: yeh]

David: It does, that's exactly the words, it lives with you, it lives in your head and it sort of won't go away, the distress it causes won't go away for a while, a day or two sometimes, or more."
(Workshop A1)

The value of this mutual validation was something that participants themselves recognised during the workshops. For example, discussing a particular material barrier in relation to the design of toilets, Tom and Anne shared a moment of humour as they reflected on how their conversation showed they were not alone in experiencing this issue:

"Tom: My biggest bugbear is the pull handle on the inside [of] a door that doesn't need pulling, that's already on a sprung loaded spring [Anne laughs]. So what happens, I try to get out, the door bar will then catch my joystick arm [Anne: yep!] which is normally that side, and it forces me into the wall, and I can't get out [of] the toilet. Unless I reverse out.

Anne: Yep. That's happened to me too! [laughing] It's not funny, but it's, it's just nice to hear that actually [Tom: Yeh, other people]– [have] these problems"
(Workshop B2)

In addition to the peer validation that took place during the workshops, participants also learned from each other's experiences as they discussed them together. One aspect of this related to practical tips and tricks, which often stemmed from having to work around barriers they had encountered. Despite these experiences of disablement themselves being

negative, in the context of the workshops, participants used them as a resource to help them convey their knowledge to others. For example, Tom explained about how a bus driver had told him that he would be entitled to ask for a taxi, after two failed bus ramps in a row:

> *"Tom: I got more [information] out of the bus drivers, actually… they gave me a couple of tips… if you get three ramps in a row fail on the buses and you're waiting for a bus, then technically you're entitled to ask them to get you a taxi.*
>
> *Anne: Really?!*
>
> *James: Yeh*
>
> *Tom: They said they don't publicise it because obviously it could cost them quite a lot of money, on a bad day or on a bad route, y'know"*
> *(Workshop B2)*

These conversations not only helped to surface and share knowledge about things such as company policies that were not well publicised, but also enabled participants to discuss the benefits and drawbacks of particular workarounds they adopted in certain situations. For example, Rachel explained the tactics she would employ to access ramp assistance without pre-booking at railway stations:

> *"Rachel: this is subversive, but like all subversion lies on a spectrum. And my approach to this would have been to say, not to ask a question, I tend to inform people that I'm getting on trains, rather than ask their permission [laughing]*
>
> *Jessica: [laughing] Oh, I love that!*
>
> *Rachel: Because it is more effective, I mean… they don't necessarily like it, but it works. So I would have driven past her window and said something like 'I need to get the ramp onto that train, I'll be sitting in the doorway', and then I would have put myself so that my footplates were wedged in the door of the train, so the train couldn't move. And just waited until somebody came with the ramp.*
>
> *Jessica: [laughing] Oh, that's amazing!*
>
> *Rachel: This has… once… gone very wrong. And, on many hundreds [of] occasions, worked seamlessly. And I feel that that's a fairly good proportionate payoff."*
> *(Workshop A1)*

After a discussion of the safety of wedging her footplate in a train door, Rachel explained how she would adapt her style of interaction with staff in this situation:

"Rachel: I'm also monstrously polite, if I'm doing that kind of thing, and not like assertive, which really they find very annoying. 'Cause often I'm very assertive, but in that kind of situation I'm like [adopts a sweet tone] 'you know, I just want to get on the train, just like you, y'know, you've probably been late before, if you could just get it for me like you could just walk on now, then y'know, we can all go off in time, just–it'll be quicker if you just get it than we have this conversation'."
(Workshop A1)

She clarified a little later how she would remain firm in her interactions with staff, which in turn would leave them less opportunity to reject her request:

"Rachel: there is quite a difference between 'Please can I have the ramp', and 'I need a ramp on Platform 2'… there's quite a difference between, not being impolite or rude, but like being 'this will happen' and being like 'this is a gentle request that you could say no to', like 'this is not something that you have the option to say no to'.

Jessica: I'm learning lots of good tips."
(Workshop A1)

As Jessica's response acknowledges, the discussion had enabled her to learn practical information that would help her to work around this particular barrier in future. Such sharing of information and know-how occurred throughout the course of the workshops.

However, mutual learning went beyond practical tips and tricks, extending to conceptual ideas such as the social model of disability which was explained during the first session of Workshop A by Rachel. The following interaction demonstrates both the value of the social model for Rachel, but also how the workshop enabled her to convey this to Jessica:

Jessica: I've not seen this social model of disability but I will Google it, that'll be the first thing I do when I, when I come off this call!

Rachel: Genuinely it's the best thing, it transformed my life! Somebody introduced me to it about fifteen years ago and it changed the– like, it changed my future, it's the best!

David: Mmhm!

Jessica: Ok… that's a good recommendation!
(Workshop A1)

This exchange, and Rachel's emphatic recommendation of the social model, has parallels with Liz Crow's description of it as having provided a "proverbial raft in stormy seas… [giving]

an understanding of my life, shared with thousands, even millions, of other people around the world" (Crow, 1996, p.55). In this way the workshops played a role in fostering, at least for some participants, not only an exchange of practical tips but also a form of education about the social model and thereby disability politics. However, it is important to emphasise that the shared experience of disablement that underpins the social model, and the way in which it enabled participants thereby to envision alternative experiences, permeated their interactions during the workshops. This remained the case even when the social model was not explicitly discussed, as it had been during this exchange.

Participants also recognised that their individual situated knowledges, as brought together during the workshops, were of benefit to each other in bringing different perspectives together on common issues.

> *"Anne: Yeh, I mean just listening to Tom and James, I mean there are a lot of things that they've said that we're all sort of agreeing on is a problem, like those horrible little lifts. But lots of other things. But at the same time, they've got a lot of information like you said, about different things in different areas. And we have got a lot of knowledge between us all, that other people could benefit from. It's just… how do we all help each other?*
>
> *Tom: Even just three of us, y'know, thinking about it, just three of us, and we've often highlighted the same or similar problems from different viewpoints y'know*
>
> *James: Some stuff's universal*
>
> *Anne: Yeh"*
> *(Workshop B2)*

As Anne later put it, on the value of disabled people's knowledge, *"there is so much stuff that disabled people can learn from each other. I mean the rest of the world could too"* (Workshop B2). This exchange highlights how participants perceived significant value in the diverse situated knowledges they had collectively as disabled people, and how they felt that these knowledges could be helpful for society as a whole. The knowledge that was shared and mutually built upon by participants is discussed in more detail below, beginning with the ideas that they proposed and continuing with an analysis of the pragmatic nature of their suggestions.

6.3.3 *Ideas suggested by participants*

During Workshop B, participants described how aspects of their everyday experiences of mobility and access might be improved, and often related these to structural issues around societal disablement. In Activities 2 and 3, they made various suggestions for how these might be addressed, while in Activity 4 proposed next steps that could be taken forward by the Journeying project. Given the overlap between these ideas, and the way in which many of the former provided more details about the latter, I have summarised these proposals in a single table (Table 7).

	Suggestion	**Details**
1	Creating a report of the project findings	• Summarise Journeying project in lay-accessible report.
2	Create a documentary or multimedia experience based around powered wheelchair users' experiences	• The video clips and accompanying discussion are very powerful in showing/explaining issues. Can these be built on? • VR-based experience to put non-disabled people in wheelchair users' shows to 'feel' the bumps.
3	Meet with policymakers and work with other organisations	• Engage with high-level decision makers, e.g. Ministers and through Parliament. • Engage with local council planning departments who are involved in highways and building control. • Think about ways for companies and other organisations to help improve the situation, such as tapping into corporate social responsibility (CSR) budgets and initiatives. E.g. local firms sponsor roundabouts, why not 'sponsor a lift'? • Come up with ideas to change societal language and mindset around disability, parallel to the Dementia Friendly campaign.

4	Creating ideal processes for improving the experiences of powered wheelchair users, including better processes for feeding back on things to be improved	• Make a flowchart of processes for improving the experiences of powered wheelchair users, based on the 10 areas in Activity 3.
		• Think about a better system for complaints and feedback: more usable, accessible, and accountable.
		  ○ 'No blame': learn from mistakes, don't hide them.
		  ○ Could something be created to (semi-)automate this, similar to Delay Repay on trains? Increase visibility of failures, e.g. http://www.recenttraintimes.co.uk.

5	Help to train the next generation of planners and other professionals	• Engage with university architecture or planning schools to include disabled people's perspectives in curriculum • Run workshops or training sessions with disabled people engaging directly with designers, planners, etc.

6	Scope out existing rights and charters that apply to disabled people	• Undertake scoping exercise to identify
		  ○ What 'charters' or other rights disabled people have in law, and where these are expressed in particular domains (e.g. transport, buildings)
		  ○ What commitments organisations have already made to make these rights accessible to all, transparent, and with clear processes e.g. comparable to NHS Patient Charter.
		  ○ Differences in policies relating to disabled people's rights and accessibility between different local areas/councils.
		• Develop ideas for specific charter(s) aimed at disabled people across different domains, e.g. that lift faults are repaired within a defined timescale.

		• Scope ways of aligning with other groups who have similar, overlapping, or potentially conflicting needs, such as cyclists, pushchair users (e.g. Mumsnet), visual impairment, etc.
7	Create a website for reporting accessibility barriers	• Create a website for reporting particular accessibility barriers, similar to https://www.fixmystreet.com.
8	Create a website for sharing knowledge	• Create a website to enable disabled people to share their knowledge and experience with each other.
9	Create an expert group of professional wheelchair users	• Create a 'professional body' of wheelchair users, with specific training to engage policy makers.
10	Running an 'ask me anything' session with policymakers	• Convene session(s) in which disabled people and policymakers could ask each other anything as a space for mutual learning.
11	Further developing JourneyCam	• Continue to develop JourneyCam as a tool to help disabled people capture their experiences of mobility and access, making it easier to use and openly available.
12	Continue the workshop discussions	• Take the discussions that were happening in the workshop further, such as through a podcast on accessibility issues.

Table 7: Summary of suggestions developed by participants during Activities 2, 3 and 4

However, I do not intend to discuss these suggestions in depth for two reasons. First, they were initial ideas summarised at the end of the final workshop into 12 broad areas. While aspects of each idea had been discussed in more detail during the course of the workshops, these were not developed beyond the brief initial suggestions outlined in the table above. Second, I am interested in the common themes that underpinned these suggestions, which were grounded in how the participants felt they might best be able to convey their situated knowledge to other people, and what might be the most effective ways of bringing about the changes they sought. In the following section I therefore discuss key themes that linked the participants' ideas, drawing on the data from the workshop conversations to illustrate the theoretical insights that these themes provide about how situated knowledge might be a resource for policymakers and service providers. An overarching theme was the pragmatism and political astuteness which characterised the ideas they suggested, which is discussed in the following section alongside more specific strategies that exemplify this approach.

6.4 Pragmatics and Astuteness

A core commonality to many the suggestions made by workshop participants was a sense of political astuteness and a pragmatic approach to engaging with policymakers. These aspects underpinned more specific strategies (learning from what works, avoiding confrontation or alienating policymakers, and seeking alignment and a collective front) which are discussed

further below. Astuteness in this context refers to participants' awareness of the challenges of bringing about change, the political dynamics of trying to do so, and the policymaking environments in which they were operating. Although different participants had different levels of knowledge, it was clear from their varied contributions to the discussions that they all shared a certain level of savviness about how best to engage with policymakers. This was typically linked to their professional background or prior experience in such processes. They discussed the need to engage a wide range of actors at different levels, including political decision-makers, technocratic policy-makers, and those who implement policies on the ground. They acknowledged that this required adopting tailored approaches and different messages for different audiences. Furthermore, they understood the importance of making a personal connection in order to convey these messages.

Participants wrestled with the challenges thrown up by these requirements. One exchange demonstrates how they realised that top-down instructions from management might not have the desired effect of changing attitudes towards disability, or incentivising behaviours that would make places more accessible. In one workshop, they discussed what would be the most appropriate level at which to influence the design of roads and pavements:

> *"Anne: who actually are we tackling, are we tackling the people who are building it, or the designers, or… how high up do we go?*
>
> *James: I don't think we'll go too high up, because then they'll be being told what to do… you want to make it, them that want to do it, sort of thing.*
>
> *Anne: So what level do you think we go in on?*
>
> *James: Um, probably the design and the engineer phase, not maybe management."*
> *(Workshop B2)*

When asked how they might be able to gain access to these people, they acknowledged that they would, in fact, have to work with management and immediately raised the need for a tailored approach to do so. Drawing on her own experience as a former Access Officer, Anne highlighted some of the challenges of engaging with managers of organisations:

> *"James: Yeh, the management needs something, but– maybe a different tactic for them.*
>
> *Anne: It's difficult that, because again, remembering what I did in the past, none of the managers– they gave me the permission to do it, but none of them actually*

came on the course. So it was all the staff that actually work on the ground that were sent on it. Which is better than nothing but…

James: Yeh, the management needs to be involved a bit! Otherwise it won't happen.

Anne: And they need to believe it to enforce it… it's very difficult, I don't know, I think this is going to be the hardest thing. To aim it at the right level but they need to know the stuff too, y'know, the hierarchy."
(Workshop B2)

In addition to working directly with service providers, participants recognised the need to engage political decision makers to bring about change. Later in the workshop, Anne and James emphasised the importance of disabled perspectives being considered at the political level to ensure that specifications for disabled access were fit for purpose:

"James: it needs to be from our perspective as well, because a lot of the higher ups… think they know what we need. And that's part of the problem. Whether… it's from a help standpoint or medical standpoint, say 'oh, you need so and so'. Whereas that's actually not what we want and not what we need! And I think this kind of needs to be approached higher up, more like politicians… rather than the engineering level

Anne: I think specifications definitely need to be updated. But then I guess that's the government isn't it so that's a completely different group of people"
(Workshop B2)

Closely linked to this political astuteness was a sense of pragmatism: the suggestions that participants made were grounded in an assessment of what they felt might actually work to bring about the changes they sought. This was aided by the structure of Activities 2 and 3, which began from their experiences and prompted them to think about what would need to change for these experiences to be different. However, participants considered their ideas against the criteria of how they might be realised. This sometimes involved qualifying their suggestions by remarking how it might be unrealistic or impractical. But more often, this involved them reframing the discussion in terms of what might be achievable. One exchange, arising from shared concerns about poor lift maintenance, demonstrates this process. Jessica noted that local amenities were sometimes funded by private companies, either through sponsorship or as a condition of planning permission, and suggested this might be a way of funding accessibility features too:

"Jessica: [For] planning consent… the council said 'yes you can build there, but in return you have to… make this extra road and you have to provide these traffic lights and generally improve the local area'… why can't that principle be used in this example… 'yes, you can build there, but you're going to have to have X, Y, and Z, and sort out this lift'…. I dunno, maybe I'm talking rubbish, but the other thing that crossed my mind talking about that was y'know when you drive around and you have roundabouts that said 'this roundabout is sponsored by such and such a company'. Can't you have 'this lift is sponsored by'? Would be great, wouldn't it?

David: Yeh, that would be, yes.

Jessica: … a dream world, there!

David: The McDonalds lift at Goodge Street station!

Jessica: It smells of burgers every time you go in!

David: Oh yep! [all laugh]"
(Workshop B1)

This exchange demonstrates how even unconventional ideas, with certain aspects that were clearly humorous or fantastical, were still framed by participants in relation to a pragmatic assessment of what might be possible. Drawing upon their knowledge of existing practices, they thought about practical ways in which some of the barriers they had discussed during the workshops might be addressed.

As noted above, the astuteness and pragmatism that characterised their suggestions was often rooted in previous experience of engaging with policymakers in either a professional capacity or as a disabled person campaigning for improvements. Three more specific aspects of pragmatism and astuteness were identified in how participants framed their suggestions: learning from what might 'work' to bring about change; avoiding confrontation or alienating policymakers; and seeking alignment and a collective front with others. Each is discussed in turn below.

6.4.1 Learning from 'what works'

Most participants had at least some previous experience of engaging with policymakers, and drew upon their knowledge of what would 'work' in doing so. Some had a professional background in public policymaking or implementation at a local or national level, such as on issues relating to access and disability rights, or in other fields such as health. As well as the former local council Access Officer already mentioned, one person was a former civil servant

who worked closely with national policymakers. Other participants had experience of being involved in efforts to secure disability rights via campaigning or activism. All who took part in the workshops had practical experience as disabled people of trying to bring about change by feeding back or complaining to service providers about particular issues.

When they discussed their ideas to bring about change, they therefore drew upon a range of perspectives of what they felt 'worked' or 'did not work', and gave examples of other initiatives or approaches that could be adopted to improve accessibility. For example, in both interviews and workshops participants made it clear that they felt non-disabled people often didn't understand disabled people's experiences and made inaccurate assumptions about their needs. They suggested the need to improve society's awareness of disabled people and their needs, and Jessica gave the example of the Alzheimer's Society's Dementia Friends programme, which aims to change perceptions of dementia in the United Kingdom (Alzheimer's Society, 2021):

> *"Jessica: The thing that I would draw a comparison with, in relation to raising awareness, is the dementia friendly campaign… a lot of time and money and energy has been invested in raising the profile of dementia and what it's about, and how you can become a dementia friend… I think that's been done in a very tactful and appropriate way. And has been a great success. And now on the top of loads of organisations' letterheads, they're called 'dementia friendly organisations'. And I don't know the specific detail in terms of how that was done… but I do know that it's been a great success."*
> *(Workshop B1)*

She drew parallels between how this scheme had sensitively drawn public and business attention to the particular needs of one specific group, suggesting it could be an appropriate model for a similar effort to raising awareness of disabled people's experiences and needs.

Similarly, Jessica suggested the notion of a 'charter' of disabled people's rights in Workshop A, based on her knowledge of the NHS Patients' Charter which sets out clearly what patients can expect from the health service. She initially framed this as a utopian ideal:

> *"Jessica: [it is] probably dreamland [but] a local council would actually have a charter… saying 'as wheelchair user living in this council area… this is what you can expect'. And that gives power to you as an individual wheelchair user to say 'well look, this is what I can expect, this is what you as a contractor should be fulfilling in these circumstances'. It gives us control, it gives us power, but I'm not*

aware of that existing."
(Workshop A1)

On further discussion, she explained how the Patients' Charter had helped to change the culture of the health service. She expressed the belief that if it could be emulated, disabled people could have clear and consistent expectations of organisations such as councils:

> *"Jessica: [It] set out what patients can expect from their NHS. And that was a real turning point for the NHS in terms of it's not all about doctors and nurses and receptionists, it's actually about patients and what they can expect. And then following on from that… that's now evolved into waiting time standards. Whether they're now met is a different matter [laughs], but… the 18 months for hips, knees and cataracts, the four hour waits in A&Es, none of that would have happened without the beginning of the patients' charter."*
> *(Workshop A1)*

She also highlighted how the existence of a charter helped to enable a set of consistent processes when things go wrong:

> *"Jessica: I know I keep harping on about it, but it's my area of knowledge. There is a formal NHS complaints procedure, and that makes it very clear in terms of what the process is that you should follow, and if it isn't worked out to your satisfaction what the next stage is, and then you've got the health service ombudsman."*
> *(Workshop B1)*

In discussing how such a charter might work in practice, Jessica described the need for a broad consultation mechanism to obtain input from a wide range of disabled people, and a wide reference group, but a smaller and more focused policy group working on the charter itself. Again, these suggestions were built on her professional experience of policy delivery, an example of how participants drew upon their situated knowledge of 'what works' in engaging policymakers. However this situated knowledge had been acquired – through professional experience, as with Jessica, or via campaigning and activism – it provided an insight into potential pathways of action and practical steps that could be taken.

However, the importance of learning from 'what works' was not only discussed in relation to how to engage with policymakers. Participants stressed the importance of doing this in relation to specific socio-material barriers and how they could be addressed. For example, they brought it up in relation to their experiences of accessible environments abroad, drawing unfavourable comparisons to what they perceived as lacklustre efforts in the UK:

Jessica: I went to Germany recently and used their public transport that was very old, and it was fantastic! … why can't it be the same here… it was all very straightforward… And what a different experience that was to when you come back to this country!

Ravi: I think part of that issue is changing people's attitudes, the attitude probably in England is completely different to how they view you in Germany or somewhere else…

David: … when I was in Berlin five years ago, I was startled at how easy it was… we got around really easily, and I think Germany was way ahead. They've made the political and moral decision to invest in lifts for their underground system, which this country doesn't have the courage or the will… It's improving slowly, but at a snail's pace here. It's only a question of money and will, and I see that as a discrimination issue…
(Week 2, Workshop 1)

Their knowledge of 'what worked' in enabling accessibility for powered wheelchair users in other countries was, as this exchange makes clear, another aspect of participants' situated knowledge. Those who had travelled and experienced more accessible environments first-hand compared it to their experience of access in the UK, and related socio-material barriers to wider cultural and societal attitudes. It is worth noting that a sufficient level of material resources was required to have these first-hand experiences, especially as disabled people often incur additional expenses when travelling; powered wheelchair users in particular risk costly damage to their powered wheelchairs when flying (Muscular Dystrophy Campaign, 2012). The ideas that these participants suggested, based on their knowledge of what works elsewhere, are contingent on a certain level of access to economic and social resources. These come together to enable them to build and articulate their knowledge, and advocate for an approach to improving accessibility that balances a political imperative to address barriers with a pragmatic approach to getting things done within the system by avoiding confrontation.

6.4.2 Avoiding confrontation or alienating policymakers

A common perception amongst participants in describing how to engage with policymakers was their belief that they needed to act carefully and professionally to avoid alienating the people they were trying to influence. This reflects an aspect of the challenge for disabled activists identified in prior research of striking the right balance between being too close to

government and being subsumed, and being too far away and ignored (Barnes & Oliver, 1995, p.115).

For example, in Workshop A, participants had discussed the need to change decision-makers' ingrained attitudes. They elaborated on the challenges associated with this in Workshop B, discussing how such an attempt could lead to resentment:

> *Anne: A change of mindset amongst decision-makers. Yeh, that's going to be hard… getting people to change what they believe, or what they know. When they've been probably doing the job many years, is going to be difficult…*
>
> *Tom: …I think that's probably why things aren't happening like they should. Because people are just ticking boxes, rather than actually really thinking about it…why is it that when the disabled toilet gets upgraded, it normally gets upgraded at the point of being unusable. So what's gone wrong there?*
>
> *James: Yeh, I think we need to step carefully with that one, not make them defensive when we go ahead with it.*
> *(Workshop B2)*

This exchange highlights how emotional labour is enforced on disabled people, who have to moderate their own actions or behaviours to accommodate the sensitivities of non-disabled others in pursuit of goals such as better access. As discussed in Chapter 5, there are many reasons why disabled people may be motivated to 'step carefully' and avoid making others defensive, which in turn imposes upon them emotional labour of managing non-disabled people's feelings and emotions. Many of these were brought up in the workshops as well.

For example, participants discussed how raising issues could be emotionally exhausting, particularly when their sheer prevalence meant it was a constant, unending task:

> *Jessica: It does feel like you're constantly a campaigner… you can't just go out and mind your own business… there is a constant campaign that you have to live through, every time you go out.*
>
> *David: Yeh, I agree.*
> *(Workshop A1)*

As previously described, participants' moderation of their own behaviours could also be a strategic behaviour in order to help them meet their specific goals, such as avoiding the risk of losing access to a service they require to overcome a disabling barrier. A similar logic applies in relation to obtaining what they require from an organisation: they may choose not

to raise an issue if they feel it could compromise their influence with an organisation at a later date.

Participants thus highlighted the need for caution, linked to not wishing to be perceived as 'complainers'. This is partly an instrumental concern: their concerns might be disregarded more easily if organisations could write them off as a complainer. Acquiring this reputation could therefore undermine their efforts to bring about change. In this context it is worth noting that several participants, especially those such as Jessica who had professional experience in engaging with policymakers, did not perceive themselves as campaigners or activists. She expressed the belief that campaigning had negative and confrontational implications that would be unhelpful in trying to change policymakers' mindsets about disability, a perspective that Ravi agreed with despite having been involved in campaigning himself:

> *Jessica: I don't like that word campaigning, and I understand why it's used, but to me it has a very negative and confrontational connotation behind it, and if part of this process is to change the mindset to be less confrontational and be more open and transparent, I just wonder if there's another word we could use so we're leading by example. You know, engagement is a very good word.*
>
> *Ravi: Yeh, I think engagement's better. 'Cause what it is that we need, we need this to be in the mainstream, not that something that needs to be fought for, it should already kind of exist when they start designing things, like lifts and pathways and things like that*
> *(Workshop B1)*

This aligned with participants' comments that they would much rather provide constructive feedback than complaints, but that current systems and processes did not afford them that opportunity. It was also linked to the emotional impact of complaining discussed above, as if the only way of feeding back was to complain it forced a mode of interaction that was often very negative for the participants:

> *"Jessica: [Complaints come] at a huge personal cost… I have limited energy, and to complain requires energy… That can live with you for a while…*
>
> *David: It does, that's exactly the words, it lives with you, it lives in your head and it sort of won't go away, the distress it causes won't go away for a while, a day or two sometimes, or more.*

Jessica: I don't want to have to complain! I don't want there to be a reason to complain! … [in one case I tried to give feedback] and they then automatically sent me the complaint procedure…

Rachel: Yeh, I mean ideally, not to complain would be ideal. I mean there will always be some circumstances, they should be a lot less than they currently are. But it would be nice if it felt like it was listened to, and acted upon!"
(Workshop A1)

In Workshop B, when we discussed how these processes might be improved, participants elaborated on how they felt that organisations ought to welcome feedback so that they might improve their services in collaboration with disabled people. They discussed how complaining should be a last resort, rather than the only available route to raise issues:

"Jessica: the complaints procedure should be the last– again it's about this negativity, it should be seen in a positive way… in an ideal world, there should be feedback mechanisms that don't involve compliant that could be very much welcomed, could be invited, and could be very knowledgeable and beneficial to the organisation involved… we've talked about changing the mindset of policymakers and of people… it shouldn't be a 'them and us', it should be we're working together. And where that doesn't happen, that's when a complaint process needs to be available

David: Yes, working together is a big thing. My recent complaints to [an organisation] have come back… in many many cases, the bus driver invents a pack of lies, or the bus company invents a pack of lies, and I know they're lies because they contradict the video I made of the incident… I'm astonished that they think it's okay to lie about something where the video shows that this did or this didn't happen. So that's not a constructive response to a complaint or feedback, that's a real failure.

Jessica: It is, but that could be turned around… they could say "thank you so much for sending us this video footage, we'd like to meet you to discuss it further, this could be a real learning opportunity for us –[David: Yes, that would be perfect, yeh]– to learn and try and change how we do things", and that could be a much more positive outcome for you and for them [David: Yep, absolutely]"
(Workshop B1)

The notion of constructive engagement to bring about change ran through the suggestions that participants made and was contrasted with the complaints procedures that are not able to achieve systemic change. Being perceived as a 'campaigner', for some participants,

threatened to blur the line between constructive engagement and complaint, in addition to the emotional labour it incurred.

However, in addition to these factors, there was another motivation for wanting to engage constructively with policymakers: participants recognised that those involved in the delivery of services and environments that affected disabled people had their own knowledge and expertise that stemmed from their professional competencies. Their situated knowledge as powered wheelchair users was distinct from, and complementary to, the knowledge of the highway engineers or transport managers. The following exchange demonstrates how participants, having first identified the need to change minds, acknowledged the validity of policymakers' experience:

> *James: [The professionals] have got experience, it's just they need to maybe look at that experience differently*
>
> *Anne: Yeh, I think you've got a really good point there, because… [as an access officer] trying to [organise]… disability awareness training… [for] the engineers who actually go out and check and work on the highways… they didn't take it well… [laughing]… I was female and disabled. And then who am I coming up telling them how a dropped kerb should be, when they're the engineers… [I] learned very quickly that you can alienate a lot of people very quickly. So it's got to be done really sensitively, because it would be worse to alienate them and then not get any results at all… like you said, James, they know their stuff, it's just they know different stuff than what we know*
>
> *James: Yep, yep!*
>
> *Anne: We know it from our point of view. And they know it from a different point of view… they'll know the engineering stuff, but they don't know it from our perspective, and… we don't want to patronise them… say you put a little upstand on a dropped kerb, is major for us, for them they can't even see the problem. So we don't want to patronise them, but we need to find a way of tactfully showing them.*
>
> *James: Yeh. We can make it their idea.*
>
> *Anne: Yeh, that would be brilliant. Yeh, that's the ideal scenario.*
>
> *James: Yeh, sort of lead the way, and then they can come to their own conclusion! (Workshop B2)*

During this interaction, participants drew upon their own situated knowledge to emphasise the importance of not alienating those who could bring about change. They identified that to do so would be counter-productive, and collectively identified a potential solution to this: enabling service providers to 'own' the change, rather than it being imposed upon them.

6.4.3 Seeking alignment and a collective front

As suggested by the non-confrontational approach described above, participants discussed ways in which they as powered wheelchair users might seek alignment with other groups who have similar aims. Again, the pragmatic aspects of this concern featured strongly in the discussions between participants: Jessica acknowledged the challenges associated with seeking alignment between different groups:

> *Jessica: I found that there was a lot of politics involved with–not all of the third sector organisations, but a lot of them. And a lot of voices were heard, and a lot of voices weren't heard, and the weight of that didn't necessarily reflect the… it wasn't always equal, shall we say, as it should have been. And that was very difficult to manage.*
> *(Workshop B1)*

However, David highlighted that this was not inevitable, drawing attention to how conflict between groups who might otherwise have competing goals could be avoided:

> *David: An example of avoid pitting different groups against each other is, when Doug Paulley took his case to the, eventually the Supreme Court, and before that the Appeal Court, Mumsnet was very supportive of him, and it– the idea that it was wheelchair users versus buggy owners in some sort of war was avoided by that support and alignment between Mumsnet and his campaign. And that was very encouraging.*
> *(Workshop B1)*

Participants discussed areas of commonality and alignment between the needs of powered wheelchair users and other members of the public. They often framed the changes they sought as being helpful for all: one person described my suggestion of a website to provide feedback on bus services as something that *"wouldn't just be useful to us, it would be useful to everybody"* (James, Workshop B2). Later in the same workshop, participants talked about how if more non-disabled people were aware of the benefits of accessible environments to all users, they might be achieved sooner:

Tom: when our local railway station had a lift [fitted to make it] wheelchair accessible, although it benefitted the wheelchair users greatly, Joe Public, 90% of the people that use it, a lot of people use it for their suitcases, and prams, and pushchairs, walking stick users. And… when the lift goes out it's actually a disaster now! I mean it's interesting that it was put in for wheelchair users, and if everybody else had joined in the pressure group it would have been fitted ten years, fifteen years earlier, it's not until the lift was in everybody realised just what a good idea it was!

James: Yeh, but I think it's the same in most things, most things that benefit us will benefit the public as well.

Anne: Absolutely… [long pause]. It's just such a shame we always seem to be on our own fighting for something that is so, it's our right but we are made to feel that it's a luxury.
(Workshop B2)

Participants therefore recognised that the involvement of non-disabled people would have benefitted their cause, and that despite the benefits of accessible environments to others, that they were too often 'on their own' in such campaigns. Although this suggests that aligning with other groups could be a productive way of bringing about the change they sought, it also highlights the societal devaluation of disabled people's needs and opinions unless they are align with and are strengthened by the voices of non-disabled people.

As well as seeking alignment with non-disabled people, participants saw value in disabled people themselves having a collective voice in order to influence decision makers. As with their desire to avoid confrontation discussed above, the way they framed this during the workshops suggested primarily working within the system of policymaking to get things done.

For example, they proposed the idea of a "professional body" of powered wheelchair users, an organisation that could serve as a focal point for consultation on its members' interests and utilise their expertise. One person drew a comparison with a now-defunct organisation of disabled drivers:

Tom: There used to be an organisation called the Disabled Drivers and Motorists Club… There were people there who knew a lot about vehicles and the problems, and they would get consulted… on things like the Blue Badge, parking and stuff

like that
(Workshop B2)

They felt that an issue taken up by an organisation on behalf of its members would have a greater impact than one pursued by them as individuals. One participant explained how they had asked a user-led organisation to take up the most serious issues on their behalf:

> *David: If something goes very badly wrong with transport for me, I normally– in really bad cases I would get [the charity] to raise the complaint on my behalf because I think that has more clout than coming from an individual. [It is] respected in the transport industry, and listened to. But we can still get really crap responses, even when [the charity] raises them. Some terrible, terrible situations are described by a service provider as a 'misunderstanding'. There's no misunderstanding on either side. So it's difficult to be heard, even with a respected organisation behind you.*
> *(Workshop B1)*

However, as David noted, even with a respected organisation acting on their behalf, there is no guarantee that service providers will respond to issues that are raised by disabled people.

Yet the value of engaging with policymakers as part of a collective should not be understated for individuals and how they feel about the process. Even participants with professional experience of engaging with policymakers found value in portraying themselves as part of a larger group of disabled people, rather than as an individual. When we talked about how to make some of the 'hidden' issues of disablement more visible or convey them to other people, Anne explained that she would talk about these issues as "me and my friends" despite being otherwise outspoken about access. They explained that this was because disclosing certain personal aspects of disablement made her feel vulnerable:

> *"Anne: I've always been quite sort of vocal on access issues, but I kind of put it, about me and my friends. If I say it about myself… I feel more vulnerable. And as I've got older… I've got different ailments going on. A bumpy footpath is agony…"*
> *(Workshop B2)*

She described in some detail how the bumps would cause her pain, dislodging her in her wheelchair. She would then have to sit in a twisted position, inflicting additional pain and risking injury, until her PA returned a couple of hours later. As she went on to explain:

> *"Anne: And all of this because the footpath was a little bit bumpy. Now that would mean nothing, to anybody [else]. But to me it's the difference [between] should I*

go out when there's nobody there, should I try to be independent today, or actually, I'm going to come back home feeling worse, let's leave it… And that's very restricting, and… you can explain to your friends, your family, but actually to them it's probably like having a moan… [so] those things you don't say to people… those personal things… you don't want to have to disclose all the time."
(Workshop B2)

This explanation highlights value of being able to raise issues of disablement collectively, as part of a wider group of disabled people, rather than as an individual. Doing so affords a degree of anonymity to individuals if they need to raise "personal things", such as the interaction between disabling environments and their health or impairment, which might make them feel vulnerable and also expose them to societal prejudices about disability. In turn the latter might reinforce organisations' tendency to individualise responses to disablement, rather than acknowledging them as requiring a systemic response. Collective action offers the potential to overcome the tension between providing enough detail to convey disabled people's individual and collective experiences to others, and ensuring that their privacy is respected. Acting through an organisation to raise these kinds of issues offers the chance to de-personalise some of these issues, as well enabling a focus on the shared experience of disabling barriers amongst disabled people. This also provides the opportunity for alignment of interests, not only amongst disabled people with diverse access needs, but potentially also with other societal groups with whom their needs overlap.

6.5 Ongoing Relevance of the Social Model

The pragmatic nature of the ideas suggested by participants during the workshops highlights how they were both conscious of, and responded to, the challenges they knew would be associated with their situated knowledge being conveyed to and used by service providers. It also demonstrates how they were keen to move beyond being perceived as 'complainers' by those with whom they wanted to engage. As during the interviews, participants in workshops contrasted their desired manner of working with service providers, of constructive engagement, with the ineffectual and challenging process of complaining:

Jessica: if I gave feedback to the council, a much better scenario for me and for the council would be if we could have a friendly constructive discussion about what the issues are, and what could be done to resolve them. As opposed to me saying 'that's not good enough', the council saying 'tough, we haven't got money to deal with it', and then if I want to take it further I have to then go and take legal

[action].
(Workshop A1)

If a disabled person is perceived by a service provider as a 'complainer', it frames them as a problematic individual, a moaner whose concerns could perhaps more easily be ignored or side-lined. However, just as importantly it frames the issue of disablement itself narrowly, as relating to the dynamics of an individual rather than as a structural problem of disabling environments that would require systemic efforts to address. The workshop participants recognised that either of these two framings would impede the changes they sought, and in light of this, emphasised the structural nature of the barriers they faced. This was true even when sharing the individual tips and tricks that helped them work around these barriers: they framed the disablement they experienced as a manifestation of structural inequality that required addressing at a societal level.

This framing aligned with key principles of the social model of disability, even when this was not explicitly mentioned, and was also undertaken by participants who were unfamiliar with the social model. It accords with an understanding of the social model not as an overarching grand theory, but as an aid to understanding that can "provide insights into the disabling tendencies of modern societies in order to generate policies and practices to facilitate their eradication" (Barnes, 2020, p.20). Indeed, participants' framings of the issues in this manner supports the notion that the social model of disability acts as an 'oppositional device', introducing contingency into the present and facilitating disabled people's resistance practices through making visible exclusionary barriers and imagining a different future (Beckett & Campbell, 2015). It helps to form a shared collectivity in the face of injustice, enabling disabled people "to recognise one another as members of the same struggle, with shared values, coming together to dismantle disabling barriers and to build an inclusive and enabling society" (Beckett & Campbell, 2015, p.278).

These aspects of participants' shared identity and struggle were clearly expressed in the workshops, even when the social model itself was not directly referenced or discussed. Moreover, as participants talked about the changes they desired for society to become more inclusive, they used phrases such as *"in an ideal world"* (Jessica, Week 2, Workshop 1). As participants articulated their envisioned future they positioned it as an alternative to the status quo, in turn "opening up a horizon, making visible a different, nondisabling world in the fabric of the present… [which] has a practical important and impact on changing the

present" (Beckett & Campbell, 2015, p.280). Such an opening up of the boundaries of possibility, with the conviction that a better world is possible, is an essential part of the process of bringing about change (Barton, 2001, p.3). For young disabled people, the social model has been found to hold value as an oppositional device, enabling them to envision their preferred future, supporting the creation of resistance practices, and providing a focus on emancipatory goals (Griffiths, 2019). These workshops suggest that this is the case for the participants in this study as well.

It was clear that participants attached significant importance to a social model framing of disablement as a structural process that required concerted political action to address. Yet in spite of this, what stood out in the workshops was also participants' understanding of the need for pragmatism: despite giving examples of confrontational interactions with service providers, they generally sought to avoid these and preferred to avoid being perceived as 'difficult'. They therefore saw the need for approaches to engagement that would balance their underlying political clarity of systematic disablement – that what needs to change is society as a whole – with the real-world realities of seeking change through engaging with service providers and policies. This required a particular form of pragmatic and constructive engagement, recognising the need not to alienate the people they were seeking to influence and to engage at different levels and in different places to achieve particular goals, while remaining true to their values which remain rooted in an understanding of the structural nature of disabling barriers as articulated by the social model. These pragmatic ways of engagement were perceived as important by participants in being able to achieve systemic change, rather than simply being an ineffectual 'complainer' with all of the attendant costs discussed in Chapter 5.

6.6 Discussion

The workshops described in this chapter are a continuation of the process of reflection and sharing of situated knowledge by participants that began in the first phase of the research. They enabled the validation of my tentative analysis of the data from the Journeys and Interviews, but also provided a space for participants to engage in a process of discussion and ideation around their situated knowledge. They offered the opportunity for participants to collectively discuss how they envisaged that their knowledge could be conveyed to others, via processes of engagement with service providers and policymakers, in pursuit of more accessible environments and interactions.

Furthermore, the workshop conversations provided a space in which participants engaged in processes of peer learning, relating both to practical issues such as the sharing of specific workarounds for particular disabling barriers, and to wider consciousness-raising about disability politics such as the existence of the social model. Indeed, both of these aspects were inextricably linked: by sharing workarounds and talking about how they would not be necessary if society addressed the disabling barriers in the first place, the very process of practical knowledge-sharing was in itself a political act in line with the social model.

Whilst core aspects of the social model mattered to many participants, either explicitly or implicitly in how they talked about the systemic nature of disablement, their approach to influencing service providers and policymakers blended this with a nuanced sense of pragmatism. They considered who they would need to talk to and how best to influence them, in order to make the societal changes that were required happen. Participants' pragmatism was influenced by other aspects of their identity and previous experience, such as their professional or personal experience of engaging with decision-makers. Engaging at the right levels, and in the right ways, were perceived as key to bringing about effectual change at a systemic level rather than shouting into the void as a complainer. This lends support to the conception of the social model as a helpful 'oppositional device' for disabled people: it enables them to identify the status quo as both contingent and unacceptable, to envision an alternative future that requires collective action to bring it into being, and to locate this need for structural change at a societal level.

Chapter 7. Conclusion

7.1 Introduction

This chapter draws together the findings and contributions made by this research, reflecting back on the research questions I posed at the beginning of the project, my findings, and the process of conducting this research itself. It also considers the limitations of this project, and makes suggestions for future work that would extend this research.

7.2 Reflections on Research Questions

As discussed in the Introduction and Methods chapters, this research was guided by three research questions. Below, I briefly reflect on each of these.

- **What is the role of digital technologies in supporting powered wheelchair users to capture and articulate their experiences of mobility and accessibility?**

This research has shown that powered wheelchair users' experiences of place and mobility are complex and are influenced by a wide range of socio-material factors and contingencies. Participants used JourneyCam as a digital tool and go along method of engaging with these experiences, and to capture representations of them for subsequent review and discussion. This resulted in a rich set of data and reflections, generated both in situ and post hoc, about the places they had travelled through and the experiences they had. While the JourneyCam data alone provided visual and sensor 'evidence' of particular issues and hinted at people's experiences, it was the process of using the tool as a part of wider reflective practices that enabled individuals to elucidate the detail and meaning of these experiences and why they mattered to them. As such, the JourneyCam technology and how it was used to support conversations around place and mobility provided a resource for participants to articulate their situated knowledge of socio-material disablement and how this might be addressed. This highlights that technologies in this space cannot be regarded in isolation from the wider processes of explanation and exploration that they permit, emphasising the importance of designing them in ways that permit flexibility in using and interpreting the resultant data.

- **What are people's motivations behind sharing their experiences of the built environment, and how might technologies be used to enable such sharing?**

Perhaps unsurprisingly given the framing of the research, participants' primary motivation for taking part in this project was to contribute to bringing about improvements in access for powered wheelchair users, and more broadly to improve understandings of disabled people's experiences of place and mobility. Participants were aware that they had a level of

insight into disabling environments that non-disabled people generally did not share or, in many cases, appreciate. Through sharing their experiences in the context of this project, they demonstrated detailed situated knowledge that was rooted in their experiences as powered wheelchair users. Simply by taking part, therefore, participants helped to highlight the value associated with their situated knowledge in identifying disabling environments and making suggestions for improvements. In considering the video and sensor data they captured, participants especially highlighted the qualities of visual data in helping them to convey their experiences and situated knowledge to others, though as noted above, both the technology and data it generated formed part of wider processes of discussion and reflection. These social processes are an essential part of using technologies for sharing experiences: technologies alone are insufficient in conveying complex experiences without the contextualisation and explanation of the data they generate through processes of discussion and explanation.

- **How can personal experiences of mobility and accessibility be used to inform policy and service provision?**

During the final stage of this project, participants articulated various suggestions for ways in which their knowledge might be taken forward to decision-makers and service providers, and thereby used to improve disabled people's experiences of built environments and mobility. Many of their ideas echo the long-standing call by the disabled people's movement of 'nothing about us without us', which emphasises the critical importance of substantive involvement of disabled people in the societal and political processes that affect their lives. I had hoped to explore how this might be achieved in the context of mobility and the built environment by bringing participants together with decision-makers, but this did not prove practical within the constraints of this project. However, the ways in which participants' situated knowledge informed their contributions throughout the project highlights how important their experiences were in underpinning their insight into the socio-material barriers they encountered and also how these might be addressed. These experiences were also essential to the suggestions they made for working with decision-makers and how they articulated these ideas. This reinforces the notion that it is imperative for decision makers and service providers to involve disabled people meaningfully throughout processes of designing, implementing, and evaluating environments.

7.3 Reflections around Powered Wheelchair Users' Experiences

This research has confirmed that a wide range of closely linked socio-material factors affect the experiences of powered wheelchair users. These can be 'enablers' that aid mobility and access, or serve as barriers or 'disablers'; indeed, this research showed how under some circumstances the same factors can both enable and disable. The material aspects of the barriers identified by participants in this project reflect long-running issues identified in prior work on the geographies of disability. These include physical obstructions to accessing places or modes of transport such as steps, poor quality surfaces, narrow or confined spaces, and steep inclines. Similarly, the social barriers that participants discussed include negative attitudes from staff and other members of the public, again reflecting prior work on disabled people's experiences. This research illuminates several closely linked aspects of these barriers, and these contributions and their implications are briefly discussed below.

The first, noted above, is the intrinsic link between social and material barriers to disabled people's mobility: they are closely intertwined and cannot be fully separated, and many of them are socio-technical systems that bring with them further complexities. For example, the absence of level boarding on much of the railway network means that wheelchair users have to rely on manually deployed ramps to access trains. Yet this introduces a reliance on multiple staff communicating with each other to ensure someone meets the wheelchair user at both their origin and destination with an appropriate ramp in working order. It also relies on staff having the knowledge to deploy the ramp correctly and safely, and on the train, platform, and station being accessible. Finally, it introduces the dynamic of a human interaction between the wheelchair user and member of staff that might go well or badly. This example demonstrates how many barriers are not purely material or purely social, and speaks to the need for a holistic, systems-based approach to improving disabled people's experiences of mobility and access.

Secondly, particular initiatives or features that are intended to reduce the socio-material barriers faced by disabled people, such as lifts in buildings or ramp assistance on trains, can sometimes perpetuate disablement. This is often due to poor design or implementation, making them difficult for disabled people to use. An underappreciated aspect of this is that these features are often brittle and unreliable, with little flexibility for the disabled user or forms of redundancy if things go wrong. For instance, even when ramp assistance is pre-booked for train journeys (which itself was viewed as an unfair, inconvenient, and ableist

imposition that restricted their freedom of action), participants reported frequent failures where it did not turn up. Similarly, the failure of a single lift can render an entire journey or building inaccessible. These examples highlight the critical importance of such accessibility features and services being fit-for-purpose, reliable and well-maintained, and appropriate to ensure access for disabled people with dignity and on similar terms to non-disabled people.

A third aspect of these barriers is that accessible environments can become inaccessible at short notice: many socio-material barriers are variable, not static, which affects powered wheelchair users' mobility. Variability may be caused by natural factors such as inclement weather, technical problems such as mechanical faults with lifts or ramps, or social and interactional issues such as a staff member's absence or negative attitude. Short-notice changes like these are particularly disabling as they undermine the work disabled people have done to ensure an accessible journey, and these contingent factors are considerably harder to work around than unchangingly inaccessible environments. While factors like the weather cannot be fully addressed, measures can be taken to mitigate their effects, such as providing accessible shelter. More importantly, steps can be taken in many cases to address the unpredictable nature of accessibility. Installing multiple lifts in busy places like stations would provide redundancy in case of failure, while proactive maintenance would improve reliability. Swift repairs to faulty lifts would reduce the time that environments are rendered inaccessible. Good information about short-notice accessibility changes would help reduce the labour and frustration of being confronted by a disabling barrier mid-journey.

A final aspect of the enabling and disabling factors highlighted by this research is that there is a considerable gap between disabled people's experiential understandings of accessibility, and that which is formalised in regulations about accessible environments. Participants identified many aspects of their experiences as enabling or disabling that they felt were not reflected in codified descriptions of accessibility, nor recognised by policymakers or the wider public as being relevant to accessibility. Instead, they felt that accessibility was treated as a 'tick box' exercise, rather than being grounded in the experiences of disabled people. They identified this as partly due to inaccurate assumptions made by non-disabled people about disabled people's lives and needs, which influence the interactions they have with disabled people and the ways in which disabled people's needs are not fully considered in the design of environments and services. This highlights a need for decision-makers and society as a whole to better understand disabled people's needs to bridge the gap between

the ‘accessible’ environments and experiences that are currently in place and disabled people’s experiential knowledge of accessibility.

In the above respects, this research highlights the complex, contingent, and interactional nature of the factors that enable and disable access and mobility for powered wheelchair users. What is very clear is that disabling socio-material environments remain significant barriers to the everyday mobility of disabled people more than twenty years after the passage of the Disability Discrimination Act. It remains paramount to identify and remove these barriers, as advocated by the social model of disability. However, in order to do this, it is imperative to engage fully with the complexity of these everyday experiences. This includes engaging with the ways that powered wheelchair users’ situated knowledge exists at the intersection of the particular socio-material environments that they travel through, the technologies that they use for mobility, and their individual corporeality. This indicates a need for the social model, with its focus on identifying and tackling disabling societal barriers, to engage productively with discourses around individual corporeality and embodiment. This is not to return to an individualised, medicalised conception of disability, but to understand why certain socio-material environments are disabling in particular ways to specific disabled people who use particular socio-technical systems for mobility.

Such a focus on these individual experiences permits an engagement with the considerable situated knowledge and expertise demonstrated by the participants in this study, which they had built up over time and was grounded in their experiences as powered wheelchair users. While these experiences were diverse, there were many commonalities in the varied barriers and enablers they experienced. This in turn led to overlapping but distinctive situated knowledges of mobility and access. This research shows how these knowledges help powered wheelchair users to acquire practical skills and expertise in working around the complex socio-material barriers they face. In doing so they enable them to exert agency in situations that would otherwise be disabling. In addition, during this research participants demonstrated how their situated knowledge went beyond the micro-scale of everyday interactions. They had insights into how their everyday experiences reflected broader processes of disablement at different scales, as well as to what it meant to be a disabled person in contemporary Britain. In turn, this situated knowledge enabled them to see not only how their own experiences of mobility and access could be improved, but also how society itself could be more inclusive towards disabled people. Participants thus identified

the need for decision-makers to engage meaningfully with their experiences and situated knowledge, in order to bridge the gap between their experiential understandings of mobility and access as powered wheelchair users, and those of non-disabled people.

Yet because their knowledge is situated in their individual embodied experiences of working around disabling barriers, participants acknowledged that it was hard to convey to others, particularly non-disabled people and decision-makers. This was for two linked reasons: first, that the embodied, experiential nature of this knowledge does not lend itself to being easily conveyed to others without similar experiences. It is particularly ill-suited to being conveyed through the kind of feedback mechanisms most often available to disabled participants, such as complaints processes as will be discussed below. Secondly, and perhaps because of this, they experienced difficulties in getting service providers and decision-makers to listen to these experiences and their situated knowledge. This causes a dilemma, as participants identified the importance of conveying these experiences to others in order that they would better understand disabled people's lives and their needs relating to access and mobility. Furthermore, although situated knowledge helps powered wheelchair users to exert agency in disabling environments, its acquisition comes at a significant cost. The situations which lead to knowledge about how to work around disabling barriers often have negative aspects, in particular the additional physical and emotional labour that is imposed on disabled people on a daily basis as they work to 'get by' in inhospitable environments. The contexts that lead to these effects are an expression of society's material and psycho-emotional disablism. This in itself suggests the need for better ways to convey disabled people's situated knowledge to others. Such ways should be able to convey not only the physical labour involved in working around disabling barriers, but also the psycho-emotional impacts of these barriers, in ways that do not further the disablement that disabled people already experience.

An important and under-recognised aspect of the psycho-emotional disablism mentioned above that is that when disabled people try to use their situated knowledge to confront and improve disabling situations they are frequently thwarted. Attempts to bring about change are not generally welcomed by service providers. Participants often described being forced through formalised complaint processes, which they found frustrating, time-consuming, and ineffective. They felt that complaints about accessibility or discrimination were not taken seriously enough, being seen as a minor customer service issue rather than a legal duty, and often had to be repeatedly chased up and escalated. Even when these resulted in pledges to

improve a service, they frequently found themselves having to engage repeatedly with the complaint processes, as lessons were not learned and the promised improvements never materialised. Participants shared a collective understanding that not only were the results of complaining unsatisfactory, but that the very process of complaint itself imposed on them considerable psycho-emotional labour, which resulted in negative emotions and in some cases dissuaded them from complaining at all. They recognised that complaint processes are ill-suited to sharing their knowledge and expertise, and are not generally a productive way of raising issues of disablement. Because the very process of pursuing a complaint has the effect of individualising structural issues and problems, the systemic factors that lead to socio-material barriers remained unaddressed. Powered wheelchair users' experiences form a rich potential resource for improving the accessibility of environments and services, and the participants in this study felt that current processes of feedback mean it remains largely unused by decision-makers. This highlights the need for better ways of not only engaging with disabled people's situated knowledge, but also ways of bringing it into constructive conversations with service providers.

7.4 Incorporating Disabled People's Experiences in Policy

During this research, and particularly during the workshops, participants made a range of practical suggestions for improving their experiences of mobility and access to the built environment and public transport. In addition, they proposed that these practical ideas, and the situated knowledge they possessed as powered wheelchair users that gave rise to them, might be conveyed to decision-makers and others in a position to implement these ideas in practice. In doing so, they sought to imagine how disabled people's situated knowledge might be incorporated into policymaking processes in order to bring about change. The ideas they suggested were typically rooted in their previous experiences of engaging with decision-makers in either professional or personal capacities.

In this process of imagining revised ways of working with decision-makers, it is worth noting that the workshops themselves provided a forum for participants to collectively articulate a form of disability politics that was grounded in the social model of disability. They discussed how a pragmatic, politically astute approach to working with policymakers was compatible with core tenets of the social model of disability that locate the sources of disablement, and the locus for their potential resolution, in structural factors. Both the pragmatic ideas they suggested, and the processes they discussed for engaging with decision-makers, reflected

this social-model inspired recognition of the importance of structural factors as both crucial to their experiences, and crucial to resolving societal disablement.

Participants drew upon their knowledge of 'what worked' in their suggestions for engaging with policymakers, and in making practical proposals for removing socio-material barriers. They aimed to avoid confrontation, both to avoid being dismissed as a 'complainer' and because they recognised that their own situated knowledge was distinct from – but could complement – the credentialed expertise of professionals such as planners or engineers involved in service delivery. They described the need to seek alignment with other groups who would benefit from the same kind of barrier-removal, aiming to build consensus rather than engage in zero-sum politics, and identified value in raising issues collectively. This, they noted, would have several benefits, including creating a critical mass of affected people that would increase pressure for change, and allowing some anonymity in recounting personal experiences that might otherwise be individualised or medicalised and dismissed.

In addition, the workshop discussions enabled knowledge-sharing and peer education. This enabled participants to consciously link their individual experiences of disablement to those of other powered wheelchair user who took part in the research, as they found elements of commonality between their different experiences. The discussion and sharing of common experiences in this manner can lead to consciousness-raising on issues of shared injustice, an important pre-requisite for collective political action (Campbell & Oliver, 1996). Indeed, it was notable that the workshop discussions provided some participants with an education in disability politics, as others explicitly described the importance of the social model to them. In addition, through their suggestions for how things could be different, participants used the social model of disability as an oppositional device (Beckett & Campbell, 2015). They compared the status quo to an imagined alternative in which their views and experiences informed decision-makers, and led to more accessible and inclusive environments.

This research therefore has several implications for incorporating the situated knowledge of disabled people into efforts to improve their experiences of mobility and access. The first is that knowledge-sharing around these experiences should be considered an ongoing process, rather than a one-off engagement between disabled people and non-disabled others. The workshops continued an in-depth process of knowledge-sharing and reflection that began on journeys and continued during the subsequent interviews. This involved the co-creation of understanding between myself and the participants through detailed discussions of how

they experienced mobility. These conversations and the reflections they prompted took place both 'on the go' as we travelled through environments together but differently, and retrospectively around the data that they had captured. JourneyCam is therefore more than simply a tool that can be used by the powered wheelchair user to generate video and GPS data: an important aspect of its value lies in the process of explaining and learning that the tool and wider go-along and interview method facilitates. This suggests that those who aim to gain a rich understanding of disabled people's experiences need to engage in ways that facilitate these ongoing and in-depth processes of generating understanding. While it may be impractical for decision-makers to replicate the precise methods used in this study, especially on a large scale, it is nonetheless imperative for them to consider ways that disabled people's experiences and situated knowledge might be integrated throughout the processes of planning, design, and delivery of environments and services. This would allow for ongoing learning and feedback that is responsive to disabled people's expertise, with decision-makers able to clarify issues and address problems early on. It would also permit the possibility for ongoing and longer-term organisational learning and consolidation of knowledge about issues affecting disabled people's experiences of mobility and access.

A second implication of this research that was clearly demonstrated during the workshops was the value inherent in disabled people being able to more easily share their situated knowledges with each other. The overlapping nature of these knowledges meant that, while there were many points of commonality, there was still considerable and productive sharing of tips and tricks throughout the workshops. This meant not only that they expanded their individual repertoires of ways of working around disabling barriers, but also that they had the opportunity to collectively build on these ideas or even present contrasting views about them. The workshops also demonstrated the potential for these processes of knowledge-sharing to have a wider political impact through the building of shared consciousness, as demonstrated when some participants introduced others to the social model of disability. It is important to note that despite all participants having been sufficiently interested in issues relating to mobility and accessibility to have given up considerable time to take part in this research, they still co-created new knowledge with each other during the workshops. This speaks to the value of not only engaging with a multiplicity of situated knowledges but also of bringing these knowledges into dialogue with each other (Haraway, 1988; Harding, 1993). This is highlighted by the way that participants themselves saw value in the discussions that the workshops enabled, and suggested ways that these might be continued beyond the end

of the research such as through a podcast that would bring different perspectives together. More broadly, this finding also supports the need for additional, and ongoing, opportunities for disabled people including powered wheelchair users to share their situated knowledges with non-disabled people such as decision-makers. Young (2004) highlights the importance of those in positions of power acknowledging the partiality of their own perspectives that would otherwise remain unquestioned, and notes that the bringing of situated knowledges into dialogue is a way of achieving this. Facilitating ongoing conversations between disabled people with experiential knowledge of disabling barriers, and credentialed experts involved in creating environments and services, would be an important step towards this. It is also a necessary pre-requisite in making these environments and services more inclusive by tackling the disabling barriers that currently exist.

Given the disabling barriers that participants characterised and the value of their situated knowledge, as discussed above, a key implication of this research has been the importance of including disabled people's voices and experiential concerns in processes of creating built environments and transport services. This implies a need for organisations involved in key societal infrastructures, such as the planning system or transport networks, to engage proactively with disabled people to seek out their experiences and situated knowledge.

This would entail a significant rethink of the current reactive system of planning, which is underpinned by weak legislation and little compulsion on developers to prioritise disabled people's experiences. It would involve a considerable re-imagining of power relationships at the heart of planning processes to centre them on disabled people (Luck, 2000; Imrie & Luck, 2014). However, such a development seems unlikely in the context of austerity, during which the ability of local government to drive change has been weakened, and in light of recent proposed reforms to the planning system (Ministry of Housing, Communities and Local Government, 2020). While the latter emphasises the importance of reconnecting with local communities its primary focus is on expediting the approval of developments, in line with a long-term pattern of weak legislative planning frameworks. It is difficult to see how disabled people's situated knowledge would fit into such a system.

Similarly, a proactive engagement with disabled people to utilise their situated knowledge would mean that service providers would begin by focusing on the experiential concerns and perspectives of disabled people who use their services. In turn, for example, this would mean that the railway industry would begin by engaging with disabled people's knowledge

of how the current ramp assistance service is experienced in order to understand how it could be improved. It would mean acknowledging the impact of ramp assist failures on disabled people's experiences of travelling by train, as well as the physical and the psycho-emotional impact these failures have on their lives. It would also mean considering that boarding and disembarking from a train is only one part of the wider transport chain, all of which must be accessible, and which should be considered holistically as an interlinked system (Wilson, 2003). To understand disabled people's experiences of transport therefore implies a consideration of how up-to-date, accurate, and timely information about access can be provided, as well as engaging with other actors such as local authorities to ensure that the wider environs of stations are accessible. The isolated provision of a technical 'solution', such as a ramp, that does not account for the overall experience of travel or the broader socio-technical environment and barriers that disabled people experience, will be doomed to failure.

It is therefore worth reflecting on the role that JourneyCam played in this project as a digital tool that helped support people to articulate their experiences and facilitate conversations around them.

7.5 Reflections on the Project

7.5.1 The success of JourneyCam as tool and method

As noted above, this research used JourneyCam as both a tool and a method for engaging with powered wheelchair users' experiences of mobility. This choice of methodological approach was built on a recognition that in-situ engagement with particular places and environments can lead to the elucidation of rich and different types of understandings about those places than thinking about them away from those places (Kusenbach, 2003; Hein et al., 2008). It also was based on acknowledging that interviews prompted by visual data such as photos enable people to provide rich post-hoc reflections (Harper, 2002), especially when those visual media have been collected or curated by the respondents themselves (Clark, 1999; Van House, 2006), and that 'traces' and videos generated by wearable cameras can be used as a way of generating knowledge through processes of reflection, discussion and understanding (Sumartojo & Pink, 2017).

The value and utility of this approach in exploring the complexity of disabled people's lives and mobility was confirmed by the rich, detailed accounts it offered of powered wheelchair users' experiences. Going along with participants gave me a different perspective on my own

mobility as well as theirs, as they 'showed' me their experiences and I experienced their journeys alongside but differently to them. The slow temporal rhythm of waiting for lifts, the spatial aspect of going much further along a road to access a dropped kerb, and the casual disbelief in certain interactions with staff all highlighted to me our differential experiences of the built environment and public transport. Yet as valuable as the go-alongs were, it was through discussion and explanation around these experiences (both in situ during our journeys together and in subsequent semi-structured interviews prompted by the multimedia data they had collected) that rich explanations were generated about the meanings of these experiences in participants' lives. It was through these discussions that clarifications were sought, and suggestions made about how things might be improved.

An important aspect of this was that the method enabled participants significant flexibility including the choice of journey on which they took me, the mode(s) of transport employed, and what they decided to capture or omit. This enabled them to focus on the issues that mattered most to them and which they felt were most important to discuss, an important aspect of engaging specifically with their situated knowledges as individuals. Moreover, this approach was also compatible with the politics of some participants, affording them as much control as possible rather than me making inaccurate assumptions as a non-disabled researcher about what I felt mattered (c.f. Golledge, 1993 and critiques discussed in Chapter 2). The workshops were also successful in helping to validate my initial understandings of participants' experiences and highlighting areas where my interpretation was simplistic or flawed. In particular, however, they were exceedingly productive at enabling the collective sharing of situated knowledge about the complex experiences of being powered wheelchair users, as well as ideation about how this knowledge might be conveyed to others.

7.5.2 Challenges and considerations for adapting this research

Despite the success of the method in this research, there are certain aspects that proved challenging and which should be considered in any future study adopting such an approach. The first is that this method was exceedingly time-consuming. Undertaking a go-along in which participants use a digital tool such as JourneyCam, and then using the data they capture in subsequent sedentary interviews, is a considerably longer process than either a go-along or an interview in isolation. Even when fieldwork went according to plan, working with a single participant took at least a full day and more commonly two days. The go-alongs themselves involved being outdoors for prolonged periods of time, and were precluded

under certain weather conditions. Moreover, it is imperative to be mindful and sensitive to the needs and individual circumstances of participants: unexpected ill-health or a PA absence, for example, can lead to short-notice cancellation of this type of work. All of these aspects can lead to logistical challenges in scheduling and conducting this kind of research. This has two key implications: first, it highlights the importance of ensuring that activities are as accessible as possible for disabled people, who are often already often marginalised by the inaccessibility of existing ways of making their voices heard in civic conversations. Secondly, it suggests that it may be difficult to organise such a rich, experiential approach of conveying disabled people's situated knowledge to decision makers who are likely to have other professional demands on their time. Adapting this method to such contexts and engaging these people directly will therefore require considerable care.

A second aspect was the difficulties of visualising the sensor data and making it meaningful to participants. Unlike the maps, there was limited engagement with accelerometer sensor data which was perceived as hard to interpret. This was partly an issue of scale: this data was at the same scale as the entire GPS route of the journey which could be several hours long. Although broader patterns were visible, such as the relative smoothness of a bus or tube journey, the bumpiness associated with specific video clips such ones captured while going over as a kerb were simply too small to be seen in such a visualisation. This suggests the need for more intuitive methods of visualising accelerometer data, which enables users to make sense of data at different temporal and geographic scales. For example, the ability to move from data visualisations at the scale of the journey as a whole (GPS trace and macro patterns in accelerometer data) to those at the scale of and tied to individual clips would help users see how these data relate to each other.

One interesting aspect of this research was that many participants adopted an 'evidential' framing: they conceptualised the data itself as demonstrating issues to others, focusing in particular on how the visual nature of the videos was felt to show issues in ways that a textual explanation simply could not. This perhaps speaks to the primacy of the visual and in particular video as a form of proof that someone was present in a particular context, the 'been there' phenomenon (Puikkonen et al., 2009). As already discussed, the discussion around the data was an important aspect of the success of JourneyCam in providing insights into disabled people's situated knowledge. One could therefore consider how JourneyCam data might be more clearly foregrounded as a resource for discussion around experiences

rather than (on its own) evidence of specific barriers. Another aspect of the JourneyCam data, the qualities and perspectives produced by the footage, could help in this process: rather than criticise the shakiness of the footage, participants talked about how it accurately reflected their and their chair's experiences of how these experiences felt.

7.5.3 Project limitations

During this project I worked with fifteen participants in total and went on go-along journeys with thirteen of them, while nine took part in at least one workshop. Despite advertising recruitment nationally, all participants were located in England and most lived in larger conurbations or suburbs. They were people who were already engaged with and interested in the topic of accessibility, and in many cases had either work experience or had been involved in campaigning around this issue or others that affect disabled people. A majority of participants in this study were relatively affluent and had experience of tertiary education and/or a professional career. As such, their experiences are not necessarily representative of those of powered wheelchair users from other social backgrounds or geographies.

I do not consider this to be a weakness, as this research was intended to generate an in-depth understanding of powered wheelchair users' experiences of mobility and access rather than to be a representative and generalisable sample of all powered wheelchair users. Engaging with situated knowledge is, by definition, to refuse totalising narratives that would seek to speak about 'all' powered wheelchair users' experiences. Nonetheless, it is notable that the findings of this research suggest that, despite some significant differences in participants' geographies and social backgrounds, many of their experiences overlapped significantly. In particular, the barriers and enablers of mobility and access they identified, and the situated knowledge that they developed around these, showed striking similarities. This suggests that these aspects of experience are common amongst wheelchair users, lending support to the social model's identification of disabling barriers as a form of societal oppression against disabled people.

Finally, given the time and logistical constraints of the PhD, my original aim of working with decision-makers remained unfulfilled. I had hoped to conduct joint workshops that brought powered wheelchair users into dialogue with the decision makers, to explore ways in which disabled people's situated knowledge might be incorporated into service provision. Given the productive nature of the conversations amongst powered wheelchair users during the workshops that did happen, I believe it would have been very valuable to have taken the

next step of facilitating similar conversations between them and decision makers as a way of exploring avenues for mutual understanding and recognition of situated knowledge. Such an engagement would have also provided the opportunity to explore and gain additional perspectives on the suggestions made during the workshops by powered wheelchair users for 'next steps' building on this research, which are briefly discussed below.

7.6 Future Work

This research has identified that disabled people's situated knowledge offers a rich source of insight into processes of societal disablement, and how these might be addressed to create more inclusive and accessible environments. As a critical aspect of this has been to acknowledge the epistemic authority of disabled people's situated accounts (Scully, 2011), it is important to ground considerations for future work in the suggestions for next steps that participants themselves made during this research.

The suggestions that participants made are summarised in Table 7 in Chapter 6. These 12 suggestions were clustered into four broad thematic areas. The first was to take the findings of this research project further, through a report (1), video documentary (2), or meeting with policymakers (3). The second was to conduct additional research and create firm policy proposals, through creating 'ideal' processes (4) and scoping existing rights or charters to see how these might be applicable to improving disabled people's experiences (6). The third was to become involved in training by educating the next generation of professionals (5), creating a 'professional group' of wheelchair users who could be consulted (9), and enabling policymakers to 'ask them anything' (10). Finally, participants made suggestions which could be broadly categorised as empowering disabled people: creating a website for reporting accessibility barriers (7) or sharing knowledge with each other (8), developing JourneyCam further as an easy to use tool for capturing experiences (11), and continuing the discussions from the workshops via other means such as a podcast (12).

Clearly, there are significant degrees of overlap between these themes. Some participants might find educating professionals or being involved in a documentary to be an empowering experience. Similarly, opportunities to continue sharing their expertise with each other could generate knowledge that might help to further engage policymakers. Indeed, many suggestions for 'what next' are built around and rely upon the sharing of participants' situated knowledge and bringing this into conversation with decision-makers. I view this as a

critical aspect of closing the circle on this research, given that it was an area which had to be omitted due to logistical considerations.

For this reason, if further funding and time were available, I would prioritise exploring ways in which disabled people's knowledge might be brought into dialogue with policymakers. One aspect of this would be by considering ways of bringing the existing findings of this research to decision makers: for example, many of their practical suggestions for addressing the disabling barriers discussed in Chapter 4 would make a meaningful difference to powered wheelchair users' experiences. However, I would seek to go further than this, and further explore how digitally supported methods such as JourneyCam might be expanded to engage decision-makers in conversations around disabled people's situated knowledge. This would involve working with both disabled people to further develop digitally-supported methodologies such as JourneyCam to capture aspects of situated knowledge, and to explore workshop methodologies to ensure their voices are brought into conversation with decision-makers.

7.7 Concluding Remarks

This thesis highlights the ongoing importance of the social model of disability in providing both a political and practical focus for the removal of disabling societal barriers. In doing so, it also offers a shared vision of an alternate future. However, the complex embodied and interactional experiences of mobility and access among powered wheelchair users highlighted by this research demonstrates that the social model should be regarded as a pragmatic tool rather than a dogmatic focus. It needs to engage productively with individual disabled experiences, in all their diversity and complexity. One way of approaching this is to combine the social models' insights with those of other theoretical approaches, including how feminist understandings engage with situated knowledges and individual narratives, and critical disability studies and STS which demonstrate how certain bodies 'misfit' in inhospitable environments.

This research also highlights the importance of finding commonalities between these different disabled experiences, and building upon them through collaboration and co-creation. Not only does this allow for the possibility of envisioning pragmatic solutions to address disabling barriers which are rooted in disabled people's situated knowledge, but it also provides a way of building solidarity and shared purpose in line with the social model.

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Appendices

Appendix A: Original project documents

Information Sheet for JourneyCam Users

Newcastle University

Information Sheet for JourneyCam Users

Thank you for your interest in this research, which is being run by Sunil Rodger, a PhD student at Newcastle University.

What is the research about?

The research explores the experiences of people with neuromuscular conditions in the built environment (for example, around cities, towns, and villages) and using public transport. It has four stages:

1) People with neuromuscular conditions will be invited to use mobile-phone based technology to capture their experiences of the built environment and public transport.
2) They will then be asked to discuss their experiences, and the data they have captured, in interviews with the researcher.
3) They will be invited to take part in a small group workshop, to discuss these experiences with others with neuromuscular conditions and people from transport and local government organisations.
4) Anonymised data from the journeys and workshops will be used with partners from transport and local government organisations, to explore ways that peoples' experiences may help to improve accessibility.

We would like to ask for your help by going on journeys to collect data on accessibility, and discussing this with you (Stage 1 and 2). You will also be invited to take part in the workshops in Stage 3.

What will participation involve?

1) Journeys: You will be accompanied by a researcher on journeys around the built environment and using public transportation in the North East. During these journeys, you will be asked to use "JourneyCam", a mobile-phone based app for capturing your experiences. It lets you record video, audio, location, and "bumpiness" information about your journey by pressing a button.

2) Interview: Following these journeys, you will "talk through" them, and the data you have collected, in an interview with the researcher. This is to understand your experiences in more detail, and relate it to the data you have recorded.

JourneyCam activities will take place during autumn 2016, and it is possible that further journeys may take place during 2017. If you decide to do one journey, you do not have to do additional journeys later if you do not want to.

3) Workshops: If you wish, you can also take part in a small group workshop with other people with neuromuscular conditions, and with partners from Muscular Dystrophy UK or other partner organisations (such as Nexus, the transport agency for Tyne and Wear). Any personally identifiable information will be anonymised to protect your privacy during this workshop. The aim of the

workshops is to understand common experiences that are shared by different people, and convey these to partner organisations.

There is no 'right' or 'wrong' way of doing any activity, or 'right' or 'wrong' answers to any questions that you might be asked. We want to understand people's experiences as fully as possible.

Who can take part?

You are being invited to take part in a journey and interview because you are living with a neuromuscular condition and have expressed an interest in accessibility (for example, through involvement in MDUK/Trailblazers events or campaigns).

How will the data be used?

Different types of research data will be created at different stages of the project.

JourneyCam data includes video, location, and movement data you collect with JourneyCam, and visualisations of these data such as maps of journeys.

Interview data includes audio recordings and transcripts from interviews.

If you decide to take part in a workshop, the data from that will include audio recordings and transcripts of workshops, and things that are created during the workshop, such as maps or timelines of journeys.

All information you provide will be treated confidentially. Audio will be transcribed (typed up) and anonymised, so anything that might identify you – such as your name or other personal details – is removed from the transcript **before** it is analysed and shared with others in the research team.

Extracts from the transcripts, or data from the workshops/journeys, may be written up in publications about the research. If this is done, additional care will be taken to ensure your privacy is protected. For example, someone might be described as "a man in his twenties living in the North East of England" rather than specifying their precise age or where they are from.

What are the benefits of taking part?

You have the opportunity to take part in research on the accessibility of the built environment and public transport. The information you provide will be used to understand the experiences of people with neuromuscular conditions.

You will also be able to influence the design of technologies that will be used to document people's experiences. JourneyCam is an ongoing research project, and your feedback will help us to create both the tool itself, and visualisations of data that represent people's experiences.

Finally, your experiences will feed into an ongoing process of working with partners (such as Muscular Dystrophy UK and Nexus) who are working to improve the accessibility of the built environment and public transport.

What are the risks of taking part?

We believe there is a low risk to taking part in data gathering with JourneyCam. You will be accompanied on journeys around the built environment and public transport by a researcher, so you will not be alone while doing research. This is to help with safety (for example, to watch for traffic). If others around you are uncomfortable with your collection of video and other data, the researcher will explain the research to them and if necessary halt the activity. We will fully discuss how to carry out the journeys, and plan the activity, before we begin.

Taking part in the interviews and workshops is expected to be very low risk. However, it may be possible that you become upset by a topic that is discussed, for example, if you are reminded of a previous distressing experience you have had on public transport.

It is possible that you may wish to publicly talk about your experiences in this research, or use the data you have gathered. If you do, the researcher will explain how data you share like this might identify you. However, the research itself is designed to respect your privacy and not identify you.

How can I withdraw from the research?

Participation is completely voluntary, and you can withdraw at any time. At the beginning of each activity, the researcher will provide an overview of the research and an outline of what will happen in that activity, as well as giving the opportunity for questions and checking you are happy to continue.

You can stop participating (either temporarily, or entirely) at any stage without explanation. If you wish to take part in some stages of the research but not others, that may also be possible. However, we will be unable to withdraw your data from the research more than 30 days after your participation, as it will already be included in ongoing analysis.

Questions or comments?

This research project has been approved by the Faculty of Humanities, Arts and Social Sciences Ethics Committee, Newcastle University. It is supervised by Professor Janice McLaughlin and Dr John Vines.

If you have any questions or comments about the research, please contact us:

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Dr John Vines
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Information Sheet for JourneyCam Workshop Participants

Thank you for your interest in this research, which is being run by Sunil Rodger, a PhD student at Newcastle University.

What is the research about?

The research explores the experiences of people with neuromuscular conditions in the built environment (for example, around cities, towns, and villages) and using public transport. It has four stages:

1) People with neuromuscular conditions will be invited to use mobile-phone based technology to capture their experiences of the built environment and public transport.
2) They will then be asked to discuss their experiences, and the data they have captured, in interviews with the researcher.
3) They will be invited to take part in a small group workshop, to discuss these experiences with others with neuromuscular conditions and people from transport and local government organisations.
4) Anonymised data from the journeys and workshops will be used with partners from transport and local government organisations, to explore ways that people's experiences may help improve to accessibility.

We would like to ask for your help by taking part in a workshop to discuss data about accessibility (Stage 3).

What will participation involve?

You are invited to take part in a small group workshop with people with neuromuscular conditions, and with partners from Muscular Dystrophy UK or other partner organisations (such as Nexus, the regional transport agency in the North East).

Workshops will take place during summer and autumn 2016, and it is possible that further workshops may take place during 2017. If you live with a neuromuscular condition, we will only ask you to take part in one workshop. If you are a staff member or volunteer at a partner organisation, we may ask you to take part in more than one workshop.

Data used for discussion during these workshops will be anonymised. The aim of the workshops is to understand common experiences that are shared by different people, and convey these to partner organisations.

There is no 'right' or 'wrong' way of doing any activity, or 'right' or 'wrong' answers to any questions that you might be asked. We want to understand people's experiences as fully as possible.

Who can take part?

You are being invited to take part in a workshop because you have expressed an interest in accessibility (for example, through involvement in MDUK/Trailblazers events or campaigns); or because you are a member of staff or volunteer at a partner organisation.

How will the data be used?

Different types of research data will be created at different stages of the project.

Workshop data will include audio recordings and transcripts of workshops, and things that are created during the workshop, such as maps or timelines of journeys.

All information you provide will be treated confidentially. Audio will be transcribed (typed up) and anonymised, so anything that might identify you – such as your name or other personal details – is removed from the transcript **before** it is analysed and shared with others in the research team.

Extracts from the transcripts, or data from the workshops/journeys, may be written up in publications about the research. If this is done, additional care will be taken to ensure your privacy is protected. For example, someone might be described as "a man in his twenties living in the North East of England" rather than specifying their precise age or where they are from.

What are the benefits of taking part?

You have the opportunity to take part in research on the accessibility of the built environment and public transport. The information you provide will be used to understand the experiences of people with neuromuscular conditions.

You will also be able to influence the design of technologies that will be used to document people's experiences. JourneyCam is an ongoing research project, and your feedback will help us to create both the tool itself, and visualisations of data that represent people's experiences.

Finally, your experiences will feed into an ongoing process of working with partners (such as Muscular Dystrophy UK and Nexus) who are working to improve the accessibility of the built environment and public transport.

What are the risks of taking part?

Taking part in workshops is expected to be very low risk. However, it may be possible that you become upset by a topic that is discussed, for example, if you are reminded of a previous distressing experience you have had on public transport.

If you are involved in campaigning, we understand that you may wish to discuss the experiences you have while taking part in this research with other people, or use the data you have gathered for campaigning. If you choose to do this, the researcher will explain how any data you share might make you individually

identifiable. However, the research itself is designed to respect your privacy and not identify you.

How can I withdraw from the research?

Participation is completely voluntary, and you can withdraw at any time. At the beginning of each activity, the researcher will provide an overview of the research and an outline of what will happen in that activity, as well as giving the opportunity for questions and checking you are happy to continue.

You can stop participating (either temporarily, or entirely) at any stage without explanation. However, we will be unable to withdraw your data from the research more than 30 days after your participation, as it will already be included in ongoing analysis.

Questions or comments?

This research project has been approved by the Faculty of Humanities, Arts and Social Sciences Ethics Committee, Newcastle University. It is supervised by Professor Janice McLaughlin and Dr John Vines.

If you have any questions or comments about the research, please contact us:

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Information Sheet for Policy Workshop Participants

Thank you for your interest in this research, which is being run by Sunil Rodger, a PhD student at Newcastle University.

What is the research about?

The research explores the experiences of people with neuromuscular conditions in the built environment (for example, around cities, towns, and villages) and using public transport. It has four stages:

1) People with neuromuscular conditions will be invited to use mobile-phone based technology to capture their experiences of the built environment and public transport.
2) They will then be asked to discuss their experiences, and the data they have captured, in interviews with the researcher.
3) They will be invited to take part in a small group workshop, to discuss these experiences with others with neuromuscular conditions and people from transport and local government organisations.
4) Anonymised data from the journeys and workshops will be used with partners from transport and local government organisations, to explore ways that people's experiences may help improve to accessibility.

We would like to ask for your help by taking part in a workshop to discuss how data about accessibility might be used in policy making and service provision (Stage 4).

What will participation involve?

You are invited to take part in a small group workshop with people from some of our partners from organisations with an interest in accessibility in the built environment and transport.

Workshops will take place during summer and autumn 2016, and it is possible that further workshops may take place during 2017. We may ask you to take part in more than one workshop if you would like to.

Data used for discussion during these workshops will be anonymised. The aim of the workshops is to understand how the experiences of different people may be used by different organisations to improve accessibility.

There is no 'right' or 'wrong' way of doing any activity, or 'right' or 'wrong' answers to any questions that you might be asked. We want to understand people's experiences as fully as possible.

Who can take part?

You are being invited to take part in a workshop because you are a member of staff or volunteer at a partner organisation.

How will the data be used?

Different types of research data will be created at different stages of the project.

Workshop data will include audio recordings and transcripts of workshops, and things that are created during the workshop, such as maps or timelines of journeys.

All information you provide will be treated confidentially. Audio will be transcribed (typed up) and anonymised, so anything that might identify you – such as your name or other personal details – is removed from the transcript **before** it is analysed and shared with others in the research team.

Extracts from the transcripts, or data from the workshops/journeys, may be written up in publications about the research. If this is done, additional care will be taken to ensure your privacy is protected. For example, someone might be described as "a member of staff at a charity" rather than specifying their job title or other details.

What are the benefits of taking part?

You have the opportunity to take part in research on the accessibility of the built environment and public transport. The information you provide will be used to understand the experiences of people with neuromuscular conditions.

You will also be able to influence the design of technologies that will be used to document people's experiences. JourneyCam is an ongoing research project, and your feedback will help us to improve the utility of the tool itself, and the visualisations of data that represent people's experiences, so it is as useful as possible for policymakers and others who seek to improve accessibility.

What are the risks of taking part?

Taking part in workshops is expected to be very low risk. However, it may be possible that you become upset by a topic that is discussed, for example, if you are reminded of a previous distressing experience you or someone you know has had on public transport.

If you are involved in campaigning, we understand that you may wish to discuss the experiences you have while taking part in this research with other people, or use the data you have gathered for campaigning. If you choose to do this, the researcher will explain how any data you share might make you individually identifiable. However, the research itself is designed to respect your privacy and not identify you.

How can I withdraw from the research?

Participation is completely voluntary, and you can withdraw at any time. At the beginning of each activity, the researcher will provide an overview of the research and an outline of what will happen in that activity, as well as giving the opportunity for questions and checking you are happy to continue.

You can stop participating (either temporarily, or entirely) at any stage without explanation. However, we will be unable to withdraw your data from the research more than 30 days after your participation, as it will already be included in ongoing analysis.

Questions or comments?

This research project has been approved by the Faculty of Humanities, Arts and Social Sciences Ethics Committee, Newcastle University. It is supervised by Professor Janice McLaughlin and Dr John Vines.

If you have any questions or comments about the research, please contact us:

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Newcastle University

Consent Form: Experiences of people with neuromuscular conditions in the built environment and on public transport

I agree to take part in this research with Newcastle University, and confirm:

Please tick each box

1. I have read and understood the information sheet about taking part. ☐
2. I understand that I can ask questions at any point during any of the activities about any aspect of the research. ☐
3. If I undertake journeys with JourneyCam, I understand that I may collect location, movement and video data, and that researchers will anonymise this to protect my privacy. ☐
4. If I take part in an interview or workshop, I understand that this will be digitally recorded and transcribed (typed up) with any identifying information removed to protect my privacy. ☐
5. I understand that electronic and paper research data will be stored securely (password protected for electronic data; in locked storage in a secure room for paper data) at Newcastle University. ☐
6. I agree that the anonymised data that I contribute (e.g. JourneyCam data, interview/workshop transcripts and outputs) will be archived at Newcastle University and may be reused by other researchers in the future. ☐
7. I understand that the information collected for this study will only be used for research purposes. ☐
8. I understand that my name, or personally identifiable information, will not be used on any documents about the research. ☐
9. I understand that I can leave the study at any time without explanation. ☐

Signature ……

Name (in capitals) ……

Date……..

If you have any questions, please contact the researchers:

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S. Rodger (2016) Consent Form

Debrief Sheet: JourneyCam and Interviews

Thank you for taking part in this research, which is being run by Sunil Rodger, a PhD student at Newcastle University.

Research overview

The research explores the experiences of people with neuromuscular conditions in the built environment (for example, around cities, towns, and villages) and using public transport. It has four stages:

1) People with neuromuscular conditions will be invited to use mobile phone based technology to capture their experiences of the built environment and public transport.
2) They will then be asked to discuss their experiences, and the data they have captured, in interviews with the researcher.
3) They will be invited to take part in a small group workshop, to discuss these experiences with others with neuromuscular conditions and people from transport and local government organisations.
4) Anonymised data from the journeys and workshops will be used with partners from transport and local government organisations, to explore ways that peoples' experiences may help to improve accessibility.

What happens now?

- The data you gathered (Stage 1) and the recording of the interview in which you discussed it (Stage 2) will first be anonymised to protect your privacy.
- After this, and informed by what we discussed in the interview, the data will then be used:
    - In Stage 3, as part of workshops with other people with neuromuscular conditions.
    - In Stage 4, with partners from transport and local government organisations to try and improve accessibility.
- You are invited (but do not have to) take part in a workshop as part of Stage 3 – we will provide more information about this. Other people at that workshop will not know that the data they are discussing was captured by you, unless you choose to identify yourself.
- The research findings will be written up as part of Sunil Rodger's PhD thesis, which will be assessed by Newcastle University.
- In a modified form, the research findings may be submitted for publication at an academic conference or journal, and written up for reports.
- **No personally identifiable information will be included in any of the above documents.**

Questions or comments?

If you have any questions or comments about the research, please contact me using the details below. Thank you for taking part.

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Open Lab, Newcastle University

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Debrief Sheet: Workshops

Thank you for taking part in this research, which is being run by Sunil Rodger, a PhD student at Newcastle University.

Research overview

The research explores the experiences of people with neuromuscular conditions in the built environment (for example, around cities, towns, and villages) and using public transport. It has four stages:

1) People with neuromuscular conditions will be invited to use mobile-phone based technology to capture their experiences of the built environment and public transport.
2) They will then be asked to discuss their experiences, and the data they have captured, in interviews with the researcher.
3) They will be invited to take part in a small group workshop, to discuss these experiences with others with neuromuscular conditions and people from transport and local government organisations.
4) Anonymised data from the journeys and workshops will be used with partners from transport and local government organisations, to explore ways that peoples' experiences may help to improve accessibility.

What happens now?

- The workshop you have taken part in will be transcribed (written up) and anonymised before analysis.
- The research findings will be written up as part of Sunil Rodger's PhD thesis, which will be assessed by Newcastle University.
- In a modified form, the research findings may be submitted for publication at an academic conference or journal, and written up for reports.
- **No personally identifiable information will be included in any of the above documents.**

Questions or comments?

If you have any questions or comments about the research, please contact me using the details below. Thank you for taking part.

Sunil Rodger
Open Lab, Newcastle University

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Appendix B: Revised documents (Journeying)

Journeying Information Sheet

Information Sheet – JOURNEYING: experiences of power wheelchair users in the built environment and public transport

What is the research about?

Thank you for your interest in this research. We are exploring the experiences of people who use powered wheelchairs in the built environment (for example, around cities, towns, and villages) and on public transport.

We hope these experiences will help to improve accessibility in these spaces, by working with charities, local government, and transport providers.

Our research involves a range of activities, and we will discuss with you which you would like to do. You have a choice of ways of being involved, and can take part in as many or as few as you wish.

The research is run by Sunil Rodger, a PhD student at Newcastle University.

What will taking part involve?

Journeys:

- You will accompany the researcher on a journey around their local built environment and using public transportation.
- You will be asked to capture your experience using mobile phone technology, which can record things like video, audio, location, and the bumpiness of the surfaces you are traveling on. The technology is designed to be easy to use.
- The activity will last between 45 minutes and 1.5 hours.

Interviews:

- You will be interviewed by the researcher, about your experiences of the built environment and using public transport
- If you have used technology as part of a **Journey** (above), this will also let you "talk through" that specific journey and the different forms of data you have gathered, so that we can understand your experience in more detail.
- The interview should last no longer than 1 hour.

Workshops:

- You will take part in a small group workshop with other people who use powered wheelchairs, to discuss your experiences of the built environment and public transport.
- Workshops may also involve participants from charities, local government, and transport providers. This is to explore ways that peoples' experiences might help these organisations to improve their services.
- If any data from **Journeys** (above) is used to help facilitate discussions during these workshops, it will be anonymised beforehand.
- Workshops should last between 2 and 3 hours.

You will be given a gift token to thank you for your help with our research.

Although there may be the chance to take part in each activity more than once, you will not be asked to do this unless you want to. There is no 'right' or 'wrong'

way of doing any activity, or 'right' or 'wrong' answers to any questions that you might be asked. We want to understand people's experiences as fully as possible.

Who can take part?

Anyone who uses a power wheelchair due to a significant physical impairment is invited to take part. We are also working with people from charities, local government, and transport providers.

How will the data be used?

Different types of research data will be created at different stages of the project.

Journey data includes video, location, and movement data you collect with the mobile phone technology, and visualisations such as maps of journeys.

Interview data includes audio recordings and transcripts of interviews.

Workshop data includes audio recordings and transcripts of workshops, and things that may be created during the workshop, such as timelines of journeys.

All information you provide will be treated confidentially. Audio will be transcribed (typed up) and anonymised, so anything that might identify you (like your name or other personal details) is removed **before** the transcript is analysed and shared with others in the research team.

Extracts from the transcripts, or data from the workshops/journeys, may be written up in publications about the research. If this is done, additional care will be taken to ensure your privacy is protected. For example, someone might be described as "a man in his twenties living in Northern England" rather than using their precise age or location.

What are the benefits of taking part?

You have the opportunity to help research the accessibility of the built environment and public transport. The information you provide will be used to understand the experiences of people who use powered wheelchairs, and how experiences can be used to improve accessibility.

You can also influence the design of the technologies used to document your experiences. Your feedback will help us to create both the mobile phone technology, and the visualisations of data that represent people's experiences.

What are the risks of taking part?

Overall, we believe the project is low risk to anyone taking part.

During **Journeys**, you will be accompanied at all times by a researcher. This is to help with safety (for example, to watch for traffic). If others around you are uncomfortable with your use of the mobile phone technology, the researcher will explain the project to them and if necessary halt the activity. We will fully discuss how to carry out the journeys, and plan the activity, before we begin.

Taking part in **interviews** and **workshops** is expected to be very low risk. However, it may be possible that you become upset by a topic that is discussed, for example, if you are reminded of a previous distressing experience you have had on public transport. If this occurs, we will give you the option of moving on

in the interview to talk about something else, or leaving the workshop for a while, or in either case ending the activity at that point.

We understand you may wish to talk about your experiences of taking part in this research publicly. The researcher will explain how any information you share like this might identify you. However, we have designed the research itself to respect your privacy and not identify you.

How can I withdraw from the research?

Participation is completely voluntary, and you can withdraw at any time. At the beginning of each activity, the researcher will provide an overview of the research and explain the activity, as well as allowing you to ask questions and checking you are happy to continue.

You can stop participating (either temporarily, or completely) at any point without explanation. However, we will be unable to withdraw your data more than 30 days after your participation, as it will already be being analysed.

Questions or comments?

This research project has been approved by the Faculty of Humanities, Arts and Social Sciences Ethics Committee, Newcastle University. It is supervised by Professor Janice McLaughlin and Dr John Vines.

If you have any questions or comments about the research, please contact us:

Sunil Rodger	**Professor Janice McLaughlin**	**Dr John Vines**
Open Lab	Geography, Politics and Sociology	Open Lab
Newcastle University	Newcastle University	Newcastle University
s.d.rodger@newcastle.ac.uk	janice.mclaughlin@newcastle.ac.uk	john.vines@newcastle.ac.uk

Journeying Consent Form

Consent Form

Newcastle University

Consent Form – JOURNEYING: experiences of power wheelchair users in the built environment and public transport

I agree to take part in this research with Newcastle University, and confirm:

Please tick each box

1. I have read and understood the information sheet about taking part. ☐
2. I understand that I can ask questions at any point during any of the activities about any aspect of the research. ☐
3. If I go on **journeys**, I understand that I may collect location, movement and video data, and that researchers will anonymise this to protect my privacy. ☐
4. If I take part in an **interview** or **workshop**, I understand that this will be digitally recorded and transcribed (typed up) with any identifying information removed to protect my privacy. ☐
5. I understand that electronic and paper research data will be stored securely (password protected for electronic data; in locked storage in a secure room for paper data) at Newcastle University. ☐
6. I agree that the anonymised data that I contribute (e.g. Journey data, interview/workshop transcripts and outputs) will be archived at Newcastle University and may be reused by other researchers in the future. ☐
7. I understand that information collected in this study will only be used for research purposes, and research findings will be shared with policymakers. ☐
8. I understand that my name, or personally identifiable information, will not be used on any documents about the research. ☐
9. I understand that I can leave the study at any time without explanation. ☐

Signature : ……

Name (in capitals): ……

Date: ……

If you have any questions or comments about the research, please contact us:

Sunil Rodger	**Professor Janice McLaughlin**	**Dr John Vines**
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Debrief Sheet

Newcastle University

Debrief Sheet – JOURNEYING: experiences of power wheelchair users in the built environment and public transport

Thank you for taking part in this research project.

Activities

You have just taken part in one or more of the following activities:

Journeys: Accompanying the researcher on a journey around the built environment and using public transportation, and capturing your experience using mobile phone technology

Interviews: Being interviewed by the researcher about your experiences of the built environment and using public transport

Workshops: Taking part in a small group workshop with other people who use powered wheelchairs, to discuss your experiences.

What happens now?

If you have taken part in a **Journey**, you are also invited to take part in an Interview and a Workshop. Anonymised data from your Journey will be used as part of your Interview, and may be used in Workshops with others. Others taking part will not know who created the data unless you chose to identify yourself.

If you have taken part in an **Interview**, you are also invited to take part in a Workshop, as above.

In all cases, personally identifiable information will be anonymised to protect your privacy. Where audio recordings have been made these will be transcribed (typed up) and any personally identifiable information removed.

The research findings will be written up as part of Sunil Rodger's PhD thesis, which will be assessed by Newcastle University.

In a modified form, the research findings may be submitted for publication at an academic conference or journal, and written up for reports.

No personally identifiable information will be included in any of the above documents.

You will be given a gift token to thank you for your help with our research.

Questions or comments?

This research project has been approved by the Faculty of Humanities, Arts and Social Sciences Ethics Committee, Newcastle University. It is supervised by Professor Janice McLaughlin and Dr John Vines.

If you have any questions or comments about the research, please contact us:

Sunil Rodger	**Professor Janice McLaughlin**	**Dr John Vines**
Open Lab	Geography, Politics and Sociology	Open Lab
Newcastle University	Newcastle University	Newcastle University
s.d.rodger@newcastle.ac.uk	janice.mclaughlin@newcastle.ac.uk	john.vines@newcastle.ac.uk

Appendix C: Example letters to charities and neuromuscular registries

From: **Sunil Rodger (PGR)** s.d.rodger@newcastle.ac.uk
Subject: Re: Research into experiences of powered wheelchair users
Date: 10 November 2016 at 14:56
To: [redacted]
Cc:

SR

[redacted]

I formerly worked at the John Walton centre in the TREAT-NMD team, so was keen that my PhD would be of benefit to the neuromuscular community – hence my focus on mobility and accessibility.

The project is called **Journeying** and has 3 aims:

* To better understand the experiences of powered wheelchair users
* To explore how technologies like mobile phones can be used to understand these experiences
* To work with organisations like transport providers, councils, and charities to look at ways that people's experiences might improve accessibility.

Although the project is broader than neuromuscular conditions, I am hopeful that these communities will be well represented, and am working with TREAT-NMD and MDUK/Trailblazers as well as reaching out to other disability charities and organisations.

I have Newcastle University ethics approval to recruit interested participants via the website, FB page, Twitter, and in person, and to distribute information broadly. This means people will have to contact me in order to participate, and the need to publicise the project as widely as possible. I am happy to work with people nationwide and will arrange events/fieldwork to have as broad a reach as is logistically possible.

I would be very grateful to work with you via newsletters, social media, or any other means you suggest – please don't hesitate to get in touch if you have any questions.

Thanks for the introduction [redacted]

Best wishes,

Sunil Rodger

On 10 Nov 2016, at 14:27, [redacted]

[redacted]

A researcher, Sunil Rodger, here in Newcastle is doing some work looking at the experiences of powered wheelchair users in the built environment and public transport. It is not a NMD specific piece of work but he wants to include these groups too. We hope to send out information through the registry but thought it could be something for your Facebook page or other channels as well.

I've attached a flyer and Sunil is in copy so he can provide more information,

Best Wishes

[redacted]

From: **Sunil Rodger (PGR)** s.d.rodger@newcastle.ac.uk
Subject: Journeying - research project
Date: 23 November 2016 at 11:20
To: [redacted]

SR

Dear [redacted]

Thanks for your time just now on the phone, I really appreciate your help! As I mentioned I'm a PhD student at Newcastle University, having previously worked in the neuromuscular team around care for people living with Duchenne muscular dystrophy.

My PhD project, Journeying, aims to understand the experiences of power wheelchair users in the built environment and public transport. Within this broad theme, I am exploring the use of mobile phone based technologies as a means of capturing experiences, and to see the ways in which people's experiences can be used to bring about policy change.

I am trying to get the word out as widely as possible so that interested participants can get in touch directly (via the project email account, journeying@newcastle.ac.uk). There are a variety of ways people can take part: going on a journey, with me accompanying them; being interviewed about their experiences; and taking part in small group workshops.

What people choose to do is up to them, and I am flexible about both their choice of activities and the geographic locations – I will try to get to as many people as I can, and arrange any group activities to convenient for as many people as possible.

As I mentioned I'm really keen to get the word out about the research to as many people as possible. I'm working with Muscular Dystrophy UK, and some people may find out about it through their events, as well as publicising the project through SMA Support UK and other neuromuscular charities and patient registries.

However, I know there is an active community of power wheelchair users beyond the neuromuscular community, and I would very much appreciate any help you might be able to give in reaching out to them via social media, existing mailings, etc.

Aside from the website I have also set up a Twitter account and Facebook page, and I am very happy to supply press releases/information about the project to fit in with your requirements. I attach PDF copies of A4 and A5 flyers (and can supply hard copies if that would be helpful) – please feel free to distribute these if you would like. I also attach the project information sheet, which provides more details about the project, for your reference – this is what I would send once someone contacts me as being interested in taking part.

Once again, thanks for your time and any help you can provide.

Best wishes,

Sunil Rodger
[redacted]

A4Flyer.pdf A5Flyer.pdf Journeying_Information..eet.pdf

From: **Sunil Rodger (PGR)** s.d.rodger@newcastle.ac.uk
Subject: UK registry – research request
Date: 8 November 2016 at 10:42
To: [redacted]

SR

Dear [redacted]

I hope you are keeping well. I wanted to briefly update you on my PhD, and enquire about the procedure for using the registry to distribute information about the project.

The project is called **Journeying** and I am looking at the experiences of powered wheelchair users in the built environment and public transport. It has 3 aims:

* To better understand the experiences of powered wheelchair users
* To explore how technologies like mobile phones can be used to understand these experiences
* To work with organisations like transport providers, councils, and charities to look at ways that people's experiences might improve accessibility.

Obviously this has a wider reach than simply [redacted] opeful that these communities will be well represented, so I am approaching the UK TREAT-NMD registries in addition [redacted] as well as working with MDUK/Trailblazers directly.

I have Newcastle University ethics approval to recruit interested participants (via the website, FB page, Twitter, and in person) and to distribute information broadly in order to recruit directly. In other words, people have to contact me in order to participate - which is one of the reasons I'd like to distribute information via the registries.

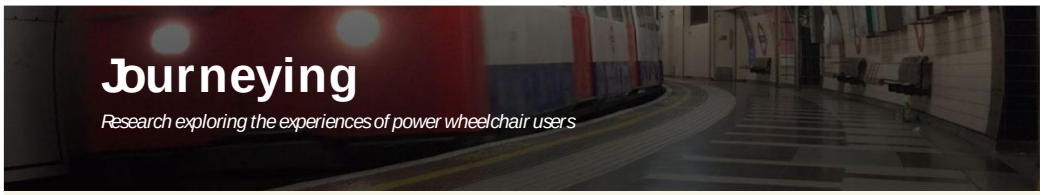
Could you let me know a) what the procedure is for this to happen (I expect it needs approval from the Steering Committee), and b) approximately how long this would take?

I attach an A4 and A5 flyer about the project which summarises the information and am more than happy to sort out a 'press release' and/or news story etc. for [redacted] newsletter/website too.

With best wishes,

Sunil

Appendix D: Project website



About Journeying Take Part Contact About Us

About Journeying

Journeying is a research project exploring the experiences of power wheelchair users in the built environment and on public transport. **If you use a power wheelchair, we need your help: please take part!**

The accessibility of the built environment and public transport can sometimes be challenging for people who use power wheelchairs.

At other times, journeys can be pleasant and hassle-free. But everyone's experience is different, and it is important to understand both shared and dif erent experiences.

I am Sunil Rodger, a PhD student at Newcastle University. I am researching the experiences of power wheelchair users in these spaces.

My research aims:

- To better understand the experiences of people who use power wheelchairs
- To explore how technologies like mobile phones can be used to understand people's experiences
- To work with organisations such as transport providers and local government to explore ways that people's experiences might help bring about accessibility improvements

Find out more and take part.

Acknowledgements

Newcastle University

Open Lab at Newcastle University

EPSRC Engineering and Physical Sciences Research Council

Take Part

Do you use a power wheelchair? We need your help!

Picture by Stephen B Calvert, CC BY-SA 3.0

You are invited to take part in a research project about your experiences of the built environment and public transport, and will receive a gif voucher to thank you for your time. For more information on the research, see About Journeying.

You can take part in the research in dif erent ways, and we will discuss with you which you would like to do. You can do as many or as few as you wish, and taking part might involve a combination of the following:

- Going on a journey with a researcher, and using piece of technology we supply to capture your experience
- Being interviewed by a researcher about your experiences
- Taking part in a small group workshop to discuss any issues you face in the built environment and public transport

What you will do will be something we can work out together and does not need to be fully decided when you begin. These activities will take place between autumn 2016 and summer 2017, in locations convenient for as many people as possible to take part.

It is very important that a **wide range of people's experiences**, both good and bad, are included. If you are interested in taking part, please contact me.

Acknowledgements

Newcastle University
Open Lab at Newcastle University
EPSRC Engineering and Physical Sciences Research Council

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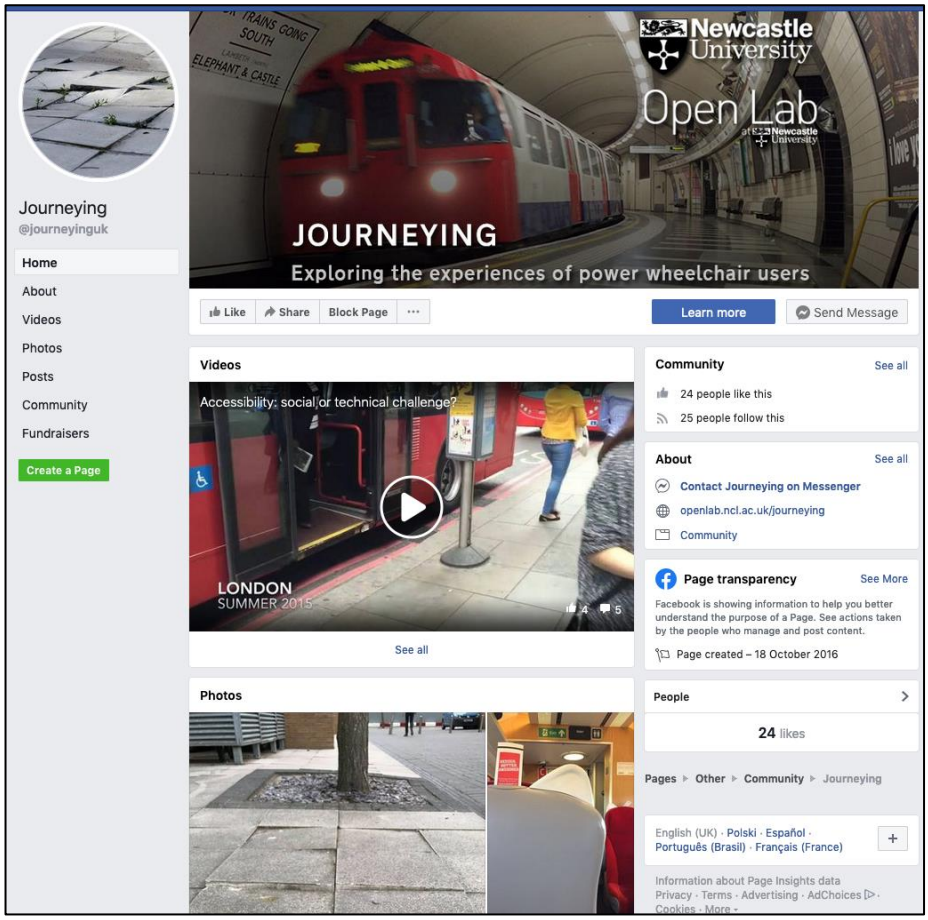
Appendix E: Project Twitter and Facebook profiles



Appendix F: Project flyers

A4 Flyer

Power Wheelchair User? We Need Your Help!

The accessibility of our towns, cities and public transport can sometimes be challenging for power wheelchair users.

Image: Stephen B Calvert, Wikimedia Commons CC-BY-SA-3.0

Journeying is research project to understand the experiences of power wheelchair users in these places. I am Sunil Rodger, a PhD student at Newcastle University.

My research aims:

- To understand the experiences of power wheelchair users
- To explore how new technologies can be used to communicate people's experiences
- To work with organisations like transport providers and local councils to explore ways that these experiences might be used to improve accessibility

How To Take Part

Taking part can involve as many or as few of the following as you wish:

- Going on a **journey** with a researcher, and using technology we supply to capture your experience
- Being **interviewed** by a researcher about your experiences
- Taking part in a small group **workshop** to discuss your experiences

Activities will take place in 2016-2017, in places convenient for you.

Interested? Please email Sunil on journeying@newcastle.ac.uk.

JourneyingUK http://openlab.ncl.ac.uk/journeying

Power Wheelchair User? We Need Your Help!

Sometimes the accessibility of our towns, cities and public transport is challenging for power wheelchair users. At other times, journeys can be pleasant and hassle-free.

Stephen B Calvert, Wikimedia Commons CC-BY-SA-3.0

I am Sunil Rodger, a PhD student at Newcastle University. **Journeying** is my research project. I am interested in understanding the range of experiences of power wheelchair users in cities, towns and on public transport.

My research aims:

- To understand the experiences of power wheelchair users
- To explore how new technologies can be used to communicate people's experiences
- To work with organisations like transport providers and local councils to explore ways that these experiences might be used to improve accessibility

Want to take part?Turn over to find out more…

How To Take Part

You can take part in different ways, which we will discuss with you.

Taking part might involve any of the following activities, and you can do as many or as few as you wish:

- Going on a **journey** with a researcher, and using technology we supply to capture your experience
- Being **interviewed** by a researcher about your experiences
- Taking part in a small group **workshop** to discuss your experiences

What you choose to do is something we can work out together. It does not need to be fully decided when you begin.

These activities will take place between autumn 2016 and summer 2017. They will take place in as many places as possible, to make it convenient to take part.

If you are interested in taking part, please contact me on journeying@newcastle.ac.uk. I will reply as soon as I can.

Thank you!

JourneyingUK **JourneyingUK**

http://openlab.ncl.ac.uk/journeying

Appendix G: Example publicity

Journeying UK Retweeted

Limitless Travel
@LimitlessTr4vel

Are you a power #wheelchair user? @JourneyingUK needs your help!! Take a read to find out more.. ow.ly/Qptz307G65Q #disability

5:00 PM · Jan 4, 2017 · Hootsuite

5 Retweets **1** Quote Tweet **3** Likes

Tweet your reply

Reply

/dev/null @sunildvr · Jan 6, 2017
Replying to @LimitlessTr4vel
Massive thank you to @LimitlessTr4vel for blogging about my PhD research with power #wheelchair users! Please get in touch if you can help

Limitless Travel @LimitlessTr4vel · Jan 4, 2017
Are you a power #wheelchair user? @JourneyingUK needs your help!! Take a read to find out more.. ow.ly/Qptz307G65Q #disability

1 1

Journeying UK Retweeted

Spinal Muscular Atrophy UK
@SMA_UK_

The @JourneyingUK project seeks power wheelchair users to share experiences of accessibility in public spaces: bit.ly/2fYI2fA

11:26 AM · Nov 23, 2016 · Twitter Web Client

2 Retweets **1** Quote Tweet **1** Like

Latest Updates

RESEARCH ABOUT EXPERIENCES OF ACCESSIBILITY IN PUBLIC SPACE AND TRANSPORT

22 November 2016

Sunil Rodger, a postgraduate at Newcastle University, is seeking power wheelchair users to take part in research about their experiences of accessibility in public space and transport.

The Journeying project is exploring how mobile technologies allow people to capture experiences, express experiences to others, and help bring about policy changes. Power wheelchair users aged 16+ can take part by:

- Going on journeys with the researcher and using new technologies
- Being interviewed about their experiences
- Taking part in a small group workshop

The choice of activities is flexible, and participants will receive shopping vouchers as a token of appreciation.

Contact Sunil on journeying@newcastle.ac.uk for more information.

FIND OUT MORE

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Appendix H: Interview guide

Journeying: Interview Guide

Individual

- Background – family, occupation etc.
- Motivation

Reflecting back: how did you find the experience of Journeying?

- **{ Talk through data }**
    - Why capture that specific issue? Thoughts at time?
    - Typical (or atypical) of experiences? Things **not** captured?
- Did you behave differently, because you were taking part in research?
- Specific routes/modes of transport you took or avoided?

Using the technology

- How did it feel using technology? Un/comfortable?
- Perceptions on reactions of others to you. Considerations e.g. privacy, safety.
- Data captured – helpful or not? Why/how?
- Perspective of footage? Height, 1st person?
- Future: could you see yourself using this and under what circumstances?
- Opinion on using this tech as way of conveying your experiences to others

Broader past experiences

- Specific good/bad experiences of built environment/transport.
    - What kinds of thing makes a good or a bad journey/experience?
- How have things changed over time? Easier/harder?
    - Are some issues now 'bigger' or more important to you? How/why?
- Do other people understand the issues you face?
- Do you feed back about your experiences to operators/service providers? Why? What are their responses?
-

Broader issue – accessibility of built environment/transport

- What is accessibility to you?
- Can you describe the importance of accessible transport/places to you? Why?
- What is the most important thing?

Appendix I: Initial coding framework

Initial themes and codes

1. Understandings of Accessibility

Conceptualising accessibility

- Accessibility as a legal issue
- Accessibility as freedom or barrier-free existence
- Accessibility as rights and equality

Progress or lack thereof

- Lack of progress
- Progress and improvement

Impact on people's lives

2 Environmental Factors

Human Environment

- Crowds or busy places
- Smoking

Natural Environment

- Dirt and Muck
- Light level
- Temperature
- Weather

3 Specific Places, Spaces & Issues

Accessibility Services, Assistance and Features

- Absence of accessibility feature
- Accessibility as built in
- Announcements
- Accessible counter
- Disabled toilets
- Lift
- Maintenance
- Ramp assistance
- Signage and information provision
- Turn up and go service

Surfaces, Bumps and Clutter

- Blocked Pavement
- Clutter
- Dropped kerbs
- Roads vs paths
- Rough surface
- Steepness

Transport Mode Specificities

- Buses
- Plane
- Taxis

Trains
Tube

4 People and Interactions

Significance of Interactions
- People can make a difference (or not)
- Conflict

Staff & Service Providers
- Staff attitude
- Lack of staff training
- Absence of staff
- Personal connection with staff

Everyday Indignities
- Back door treatment
- Being Invisible (or forgotten about)
- Being stared at (or in the way)
- Being disbelieved or blamed
- Miraculous recoveries

Doing the wrong thing
- Intrusive helpfulness
- Lack of awareness & making assumptions
- Patronising & Negative Attitudes
- People's reactions to wheelchair

Positive attitudes
- People want to help
- Others being aware of accessibility

5 Feelings & Emotions

Confidence
Emotions
Feeling uncomfortable
Frustrations
Acceptance or dealing with it
Safety
Surprise at good accessibility
Surprise at inaccessibility

6 Many Disabled Experiences

Attitude toward disability
Impairment
Constraints on Freedom
- Enforced Detours
- Anticipatory tension
- Lack of choice
- Physical imprisonment

Disabled Agency

Actively choosing accessible places
Not letting things get to me
Taking risks
Overcoming barriers or challenges
Standing up for oneself
Subversion
Enjoy just getting out
Just being myself

Desire respect like anyone else

Being part of society
Not standing out as different
Respect

Wheelchair Dichotomies

Constant vigilance & assessing situation
Independence vs reliance on others
Planning ahead vs Spontaneity

Embodied Chair-Knowledge

Costs associated with being wheelchair user
Damage to chair or environment
Understanding chair attributes or capabilities
Innate Expertise
Disabled person's point of view
Everyday things & small improvements

7 Bringing About Change

Campaigning and Activism

Complaints and Responses

Accessibility not taken seriously
Complaints that are public
Given up complaining
Onus on passenger
Repeated complaints
Response from decision makers
Social media

Strategic Engagement

Being consulted as a disabled person
Cost of making things accessible
Political activism
Suggestion solutions

8 Technology and Research Participation

Feelings & Behaviour Participating

Behaviour using the technology
Data gathering as tedious
Enjoyed participating in research
Enjoyment of using technology

	Other people's reactions to tech
	Perception of interesting vs ordinary experiences
	Self-consciousness of using technology
	Tech and data as impressive
	Wanting practice with technology
	Would use the tech
Motivations	
	Affects others
	Affects them
	Bring about dialogue
Role of data collected	
	Degrees of evidence
	Different forms of data together
	Video as evidence
	Video as prompt
Tech attributes	
	(In)visibility of technology
	Changing the technology
	Other people's privacy
	Own privacy
	Perspective of tech
	Tech as a theft risk
	Tech as convincing
	Tech as easy to use
	Tech as difficult to use
	Tech for evidence gathering
	Tech to promote understanding

Appendix J: Final coding framework

Revised Themes and codes

Ch4: JourneyCam

- 4.1 Evidential framing
  - Anticipating use as 'evidential'
  - Different forms of data / different degrees of evidence
  - Data as evidential
- 4.2 Using JourneyCam and creating data
  - Invisibility of the technology
    - Privacy (own/others)
    - Others' reaction
  - Choice of interesting vs ordinary experiences
  - Person vs chair perspective
  - Shakiness of footage / qualities of the data
- 4.3 JourneyCam insights and in use
  - Hidden knowledge removed from the visual/data (e.g. cost, discrimination)
  - Explanatory narrative critical

Ch5: Enablers and Disablers (was Barriers and Interactions)

- 5.1 Materialities
  - Surfaces (qualities of): steepness, bumps, smoothness
  - Blockages or obstructions
  - Specificities of transport modes: trains, tubes, buses, etc
  - 'Natural' environmental factors: light, season, weather, temperature, dirt and muck
- 5.2 Interactions
  - Interactions with other people
  - Behaviours of others: crowds, smoking
  - Positive and negative attitudes of others
  - Role of staff in experiences
- 5.3 Features or services meant to assist disabled people
  - 'Accessibility' features
  - Non-existent accessibility feature
  - Maintenance (of environment or facilities)
  - 'Built in' accessibility
    - Everyday things and small improvements

Ch6: Effects and Impacts

- 6.1 Constrained choices
  - Lack of choice
  - Choice (of route or other aspects)
  - Enforced detours
  - Independence vs reliance on others
  - Planning ahead vs spontaneity

Imprisonment

Freedom

6.2 Emotional/physical labour

"Everyday Indignities"

Discomfort, frustration and anger

Feeling (un)safe

Confidence (or lack of)

Constant vigilance and assessing the situation

Anticipatory tension

Surprise (by good/bad access)

{concern for} Damage to chair or other people/things

6.3 Disabled knowledge and expertise

Know chair attributes/capabilities

'Innate' knowledge [or is this embodied experiential knowledge?]

Costs of making things accessible

Disabled person's POV

Costs of being disabled/being a wheelchair user

Progress and lack of progress

Being consulted as a disabled person

Ch7: Responses

7.1 Spectrum of individual agency: from acceptance to contestation

Acceptance or 'dealing with it'

Not letting things get to me

Enjoying getting out

Just being myself

Overcoming barriers/challenges

Being prepared to take risks

Choosing accessible places

Standing up for oneself

Subversion

7.2 Campaigning and activism for change

Complaints and public nature of complaining

Onus on the passenger

Activism

Being a campaigner

Suggesting solutions

Responses from decision makers

Not being taken seriously

Appendix K: Worksheets A and B

Worksheet A

Journeying: Workshop 1 Preparation Sheet

Introduction

Thank you for agreeing to take part in 'online workshops' as part of the Journeying project, which have three aims:

1. To make sure the analysis and findings of the project accurately represent your experiences, views, and opinions.
2. To work with you to develop practical ideas which we might share with policymakers or organisations to improve the experiences of powered wheelchair users.
3. To seek your input into the next steps for the Journeying project.

Because of the number of topics to discuss, we have planned for two workshops, each up to 1.5 hours long. These will take place roughly one week apart, with the discussion we have in the first workshop feeding into the second.

If there is a lot to discuss, and we look like we are running out of time, we could also have a third workshop with those who would like this.

Workshops will be conducted in groups of 3-5 people, and will either take place 'live', via Skype or similar, or as a series of emails. Each workshop has two activities, which are described below (1 page per activity).

Please read through the following material carefully, as there are some small tasks I would like you to do as preparation for each workshop. These should take no more than 30 minutes for each workshop:

Tasks for Workshop A

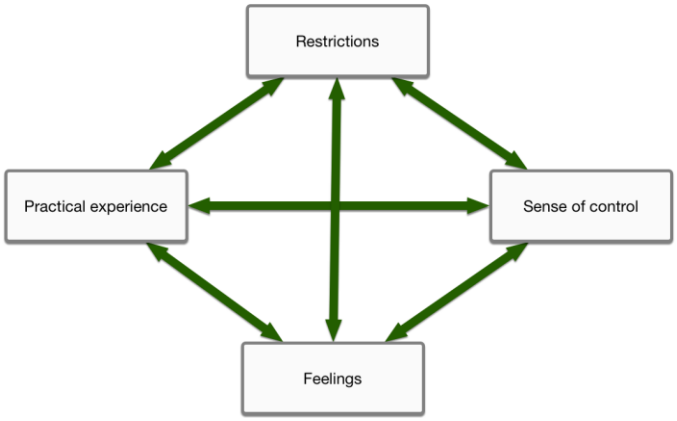
- **Activity 1: Thinking about experiences** – think about the 'framework' of four factors which is described below.
- **Activity 2: Video discussion** – watch four short video clips and read the associated comments made by the people who captured the clips. Write down your thoughts about how the experiences might be improved.

Workshop A

Activity 1: Thinking about experiences

From the video clips you captured, and our conversations, I have created this diagram, which is **just one way** of looking at people's complex experiences.

Four factors seem very important to people's experiences: I have labelled these **Restrictions**, **Sense of control**, **Practical experience** and **Feelings**.



Restrictions: things that constrain powered wheelchair users from going where they want, when they want to, and how they want to.

E.g. physical barriers; interactions with people; issues to do with impairment.

Sense of control: ways that powered wheelchair users respond to the problems they face in their day to day lives, that make a difference to their experiences.

E.g. overcoming obstacles; subverting difficult/awkward procedures; getting out and about.

Practical experience: the knowledge and expertise that each individual has built up over time about being a powered wheelchair user, which other people simply do not have.

E.g. knowing the best way to get from A to B; knowing the capabilities of their power chair.

Feelings: how people feel about the particular experiences of mobility and accessibility they encounter.

E.g. how a good/bad experience affects emotions; how feelings influence people's actions.

These four factors interact with each *other* in complex ways: for example, a **restriction** may lead to particular **feelings**, which spur someone to **act and exert control** in a specific way.

Questions to think about:

- Does this 'model' or 'framework' make sense to you? Why, or why not?
- How might it be improved? Is there anything missing?
- Are the four labels appropriate and useful? If not, what would be better?

Activity 2: Video discussion

People often mentioned particular **themes**, and some frequent ones are listed below. For example, many people talked about having to take what I have called "**enforced detours**".

I have chosen a video clip to try to illustrate each theme (except 5 and 10), which you can view by clicking on the blue links in the table below. I have also included what the person who captured the clip had to say about what happened.

Take 4 themes of your choice, one from each coloured section (A, B, C, & D). Watch the video clip, where it exists, and read what the person said. Have a think about:

- Are there things that organisations/policy makers could do differently to help here?
- **Why** would those things help?

Jot down any thoughts you have in the "Notes" column for each video you decide to watch.

	Theme	Notes: what could be done? How would it help?
A: Restrictions	**1. Enforced Detours** *"A-boards are a great nuisance, especially on smaller streets… I'm very happy to fold them up and lay them flat against the building, and leave them like that, if I'm not happy with them… We had a little chat. I can see his point of view, he doesn't want to be liable if someone did drop the scaffolding pole onto us… he wouldn't want to be the one that let me through… They should have put out one of those plastic ramps… that come off the kerb temporarily"*	
	2. Lack of choice or spontaneity *"You see there's just no pavements here at all… crossing here is a bit scary. You just make sure it's clear. I could go up the kerb there, but there's no way to get down the other side. Plus it's overgrown anyway. [I was] a little bit nervous! It's just really want to just get off it as quickly as I can. But then again not going too fast, to cause an issue with the other cars. You can see there's a nice paved bit there, that I can't get onto. If they just made a drop kerb there, it'd make it a lot safer. [My PA] mentioned there was a car behind, so I thought it was best to let them past on this bit. Rather than carrying on. Give them time to get round, and a few other cars to stop. Like this one here stopped to let everybody past me."*	
B: Sense of control	**3. Actively choosing accessible places** *"**Interviewer:** How do you feel about the fact that the wheelchair space on that one, you actually have to get people to move?* ***Participant:** Oh, um. Fine. I've, I feel a strong sense of entitlement, and I feel … very confident in those situations, and it's bolstered by everyone I've ever encountered being very helpful and moving. I've never had a bad experience with people. [Some] people are a bit slow sometimes, or a bit reluctant, but they're never unpleasant"*	

	Theme	Notes: what could be done? How would it help?
	4. Subversion: 'just turning up and going' *"**Participant:** This is really just to see how. Well, the wonderful video of the greeting of 'have you pre booked?'. Which is a constant irritation and really upsets a couple of my able-bodied friends, who think it's monstrous to think you can't just roll up at a station and expect help… So that's me challenging her. In a polite way* ***Interviewer:** 'It'll be a bit tight'… when she said that I was looking at the time and thinking we've got four minutes. Which is plenty of time-* ***Participant:** -plenty of time exactly, it meant she didn't want to do it, and she was hoping the guy that was coming on would do it. But he was happy, 'cause he's the main guy that works there and he's very happy guy to do that"*	
	5. Challenging negative situations [No video clip] Several people talked about challenging negative situations, either in person at the time, or later through formal complaints, e.g.: *"I got up briefly out of my wheelchair, [and she] said to her friend and to everyone around 'look, there's nothing wrong with his legs!'. So… I gave her a tongue lashing!"* *"There are some things that could have been thought out better. Some of the signage isn't ideal. The supposedly accessible [toilet] is completely diabolical. I really must write them a complaint letter about it. I am most certain it's not Part M compliant"*	
C: Feelings	**6. Comfort and discomfort** *"It's very busy there. And as you can see the pavement's not good… it's very uneven, and… the cambers go all ways. I mean sometimes, it might help if the camber went one way at least it'd give you a fighting chance! … As you can see, I fought very hard not to run into the substation thing. But there's only so much that you can do. And in the end, I think I put my foot out. Which can be dangerous, and I have hurt myself in the past doing that. But sometimes you've no options. Um, I do get quite angry. Because… they put an awful lot into roads, it's about time they put something into footpaths"*	
	7. Confidence or lack of confidence *"this is getting off the other side of the train… Again, I asked him if he'd hold the back of my chair, he said yes that was fine which is fantastic. Now that was a little diddy ramp, wasn't it? … I think that was a smaller ramp"*	

	Theme	Notes: what could be done? How would it help?
	8. Vigilance and tiredness *"This is one of my favourite shops that I love going in but there is a problem as you will see with stuff being put in aisles and trying to get around is impossible… It's a skill I've gained… because of doing it and… I've had a few accidents where I've run into things or knocked things off a shelf.* *So, it's taken me ten years now and I can just about manage to get around a shop like that. It is quite hard, as well, because you've got to concentrate but I've got [my dog] with me so I've got to keep an eye on her on one side and control her on the other side. So, yes, mentally, it's difficult, you can't just see something you want to see and just go straight to it, you've got to think of what's the best way to get there in a shop. Which, you shouldn't have to really, you should be able to just be able to do something like anybody else would but that's obviously something that you can't do in a shop like that"*	
D: Practical experience	**9. Unique Perspective** *"You were assisting me, but normally I would get a customer who was walking past, or sometimes you get a member of staff, not often in that store, and that was the point I was going to make, that manager didn't offer me assistance. I think they should, as you go in as a wheelchair user, I think it would be only polite… [some items are] always on the top shelf!"*	
	10. Unexpected costs [No video clip] Several people mentioned hidden costs associated being disabled, e.g.: *"There's quite a lot of shops in [town] that I just can't get in… Some people might go to both shops, say, and see what the prices are and sometimes you've got to pay more because it's the only one you can get into. I mean, it's probably just pennies sometimes but it's another one of those issues that people don't understand that being disabled sometimes costs you money"*	
	11. Knowing chair capabilities and limits *"What we got this day was one of the easiest ways it ever goes because [the bus driver] didn't ask any questions or pull any faces, or … make me feel uncomfortable. He just got out and did it. That's actually quite rare. Usually you get, you know, attitude is the best way to describe it…* *Then there was no one sat in the seats where I have to pull round. The lady I asked to move just moved without any you know, 'uhh' … As you can see, it requires a bit of manoeuvring… because of the way the space is designed."*	

Worksheet B

Journeying: Workshop 2 Preparation Sheet

Introduction

Thank you for agreeing to take part in 'online workshops' as part of the Journeying project, which have three aims:

1. To make sure the analysis and findings of the project accurately represent your experiences, views, and opinions.
2. To work with you to develop practical ideas which we might share with policymakers or organisations to improve the experiences of powered wheelchair users.
3. To seek your input into the next steps for the Journeying project.

This is the second of two workshops, which builds on the work we did last week. If there is a lot to discuss, and we look like we are running out of time, we could also have a third workshop to finish off our discussion (or you can share additional thoughts with me by email).

Please read through the following material carefully, as there are some small tasks I would like you to do as preparation for each workshop. These should take no more than 30 minutes:

Tasks for Workshop B

- **Activity 3: Ideas for improvements** – think about how you might answer three questions to do with ideas for improving experiences
- **Activity 4: Sharing experiences and next steps** – think about three questions to do with sharing data, and next steps

Workshop B

Activity 3: Ideas for improvements

In workshop A, we discussed some **ideas for improvements**. These are summarised below:

Idea	What could be different	How it would it help

As a group, we will choose the most important or interesting 3 to 5 ideas to brainstorm.

Have a think about which ones you will choose, and think about the following questions:

1. What is the actual, 'actionable' change or improvement?
   - Is it a change to the physical environment, a process, or people's attitudes? Or both?
   - Is it a "best practice" that would help powered wheelchair users?
2. How could we make this change happen?
   - Does it need to be highlighted to a specific organisation or person, and who?
   - Is it about campaigning, lobbying, or raising public awareness?
   - Is it about sharing knowledge with other powered wheelchair users?
3. How would your experiences of going on journeys be different if this change happened?
   - Imagine what this experience would be like for you, if it was just how you wanted

You might want to use the table below to make a note of your ideas.

Idea	1. What is the change?	2. How do we make it happen?	3. What would this be like, if the change happened?

Activity 4: Sharing experiences and next steps

Have a think about the following three questions

1. **How could the project data and findings be explained or narrated to other people?**
   - How can 'hidden' issues, or ones which aren't easy to explain, be conveyed?

2. **What are the next steps for Journeying Project?**
   - Should we make some of the data you have captured public? To whom?

Some examples of things we might consider doing, perhaps in conjunction with other organisations. Some of these are ambitious or could become large projects, so also think about what might be practical, and whether you would like to be involved.

- A report, like the *MDUK Trailblazer report*.
- A short documentary film or a website using the video clips you have captured, photos we took, and written or spoken narration/explanations of the issues.
- An "Ask Me Anything" session with policymakers so they can ask you questions (or you can ask them)! Example: *Chris Hadfield, astronaut*.
- Think about how we could develop JourneyCam, such as making it available publicly or adapting it into a tool for campaigning.

3. **To make some of the data you have collected public, what issues should we consider?**
   - Under what circumstances should things be made public, and to whom?
   - What forms of data could this involve?
   - How do we balance making a difference in this way, and ensuring your privacy?

Thank you again for taking part in the workshops and the research!