University of Southampton

Faculty of Environmental and Life Sciences

School of Geography and Environmental Science

My Existence is Resistance: Exploring spaces and forms of disability activism in the United Kingdom during a time of austerity

by

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Thesis for the degree of Doctor of Philosophy

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Abstract

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With the onset of austerity, disabled people in the United Kingdom have faced a sustained period of financial cuts, including cuts to personal income, social care and advocacy organisations. Many individuals have found themselves in increasingly precarious situations, having to rely increasingly on non-statutory, more informal structures of care. Disabled people, however, have not accepted these changes in silence but have often been vocal in their opposition to these cuts. Opposition and resistance can be seen through increased lobbying, the establishing of disability anti-austerity protest groups and the emergence of numerous online campaigns. Austerity has been accompanied by a recent growth in disability activism, as individuals find ways of resisting and coping under increasingly difficult conditions. To date, there has been very limited documentation or analysis of the political struggles of disability activists during a time of austerity. Through adopting a qualitative approach, this study examines the lives of those involved in disability activism, and the places in which their activism is enacted. The findings are drawn from 27 biographical interviews and participant observation at 13 disability activist events. Rather than being a representative study, this research seeks to provide a deep and nuanced insight into the lives of a small number of disabled people who are engaging in activism in response to austerity. It is hoped that this thesis will serve as a form of activism in itself, as a space in which stories can be both shared and heard and used as a possible resource for future generations.

Table of Contents

Table of Figures

Table of Figures

Research Thesis: Declaration of Authorship

Print name: **Angharad Butler-Rees**

Title of thesis: **My Existence is Resistance: Exploring spaces and forms of disability activism in the United Kingdom during a time of austerity**

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission

Signature: .... Date: ....

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I would like to also thank all the volunteers and clients at Swaythling Foodbank who have taught me so much about the impacts of austerity on the everyday lives of people across the UK. It has been a great privilege to work alongside such committed volunteers. I also very much enjoyed and valued the opportunity of a weekly reprieve from the PhD.

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Chapter 1 Introduction

1.1 Autobiography of the study

At the outset, it is important to recognise my motivations behind conducting this study and how I came to focus on this particular research topic. My history is that I have a visual impairment and thus have identified and been identified as disabled since a young child. My visual impairment, however, is not that noticeable to the outside world so I can 'pass' readily (Goffman, 1963). These personal circumstances have driven my desire to explore and unpack the 'black box' of the personal world of disability, researching how disabled people have been and continue to be excluded and marginalised from wider society. I was drawn to this topic, both to its timeliness and to demonstrate that disabled people have an active, political voice worthy of being listened to. I was further saddened and disheartened by the lack of recognition of the Disabled People's Movement and I felt it was important that the political struggles of disability activists during a time of austerity be documented and examined, so they may be used as a possible resource for future generations. The research, therefore, aims to give voice to the various experiences of disability activists and serves as a space in which stories can be shared, recognising how personal experiences are often deeply political, being framed by various structures of inequality (see Hanisch, 1970). Amid busy everyday lives, it can often be difficult for activists to find the time to reflect upon or document their activism. The research, therefore, provides a reflective space in which this can partly be achieved.

Further, I decided to undertake a PhD on this particular topic because I was troubled by how disabled people were becoming increasingly segregated and isolated due to austerity cuts. I was eager in my small way, to contribute to the opposition of austerity. I wanted to explore the life stories of disability activists, documenting and sharing their individual narratives and experiences. I felt that by undertaking a PhD. I could share stories that needed to be told and to give recognition to the determination and tenacity of disability activists.

When originally embarking on this Ph.D., I perceived my personal engagement in disability activism to be somewhat limited, perhaps consisting of the odd message on social media and my efforts to speak out about ableism and equality within my family, school, and workplace. However, the more I grappled with the notion of 'activism', the more I realised that it underpinned much of my everyday activity, for example, in identifying openly as disabled, researching and writing on issues of disability inclusion and accessibility, participating in online disability support groups and so forth. Such forms of activism are far from spectacular, grandiose, or iconic, but I would argue have the potential to bring about slow and gradual change. This journey has therefore at times presented me with numerous personal and intellectual opportunities and challenges.

1.2 Background to the research. Why does it matter?

> Disabled people were the victims of the financial crash, not the cause of it. But they were treated as if they'd caused all the problems for our country (Richard).
>
> They didn't expect us to fight back. They thought we'd roll over and play dead. Disabled people have a long and proud history of fighting for our rights (Rebecca).
>
> I think the distinguishing mark of disabled people's special position is that they tend to 'challenge' in their relations with ordinary society (Hunt, 1966: 146).

Austerity is a large political-ideological project operating across many Western high-income countries, promulgated as a means of addressing the problem of public debt (Clarke and Newman, 2012). While having a long and complicated history, it became of particular significance as a response to the global financial crisis of 2007-8 (ibid, 2012). Austerity is based upon the principle that economic difficulties have been caused by the state's overspending in the public sector. A programme of fiscal retrenchment and 'structural reform' is therefore introduced in an attempt to reduce the debt (Allen, 2017), being framed as if they were the only option (Clarke and Newman, 2012). Austerity is not necessarily a radical change but instead builds upon a pre-existing neoliberal model that sought to shrink the state by reducing public spending, while at the same time, abolishing regulations on the freedom of capital (Harvey, 2010). While austerity and cuts to public spending have had manifold impacts across Europe and the United States (Arampatzi, 2017; Davies and Blanco, 2017; Leon and Pavolini, 2014; Peck, 2012), the United Kingdom serves as an acute example, whereby reforms have led to growing inequality, increased destitution, dependency on food banks and a national mental health 'crisis' (Bambra and Garthwaite, 2015; Bambra et al., 2015; Connolly, 2017; Ginn, 2013; Hall, 2019; O'Hara, 2014). The impact of austerity has not however been felt equally across all facets of society, with, for example, women, lone parents, the disabled, Black and minority ethnic communities, and individuals of low socio-economic status experiencing the ramifications more profoundly (Emejulu and Bassel, 2015; Greer Murphy, 2017; Moffatt et al., 2015). Many individuals may also have intersections across these identities, creating multiple disadvantage (Crenshaw, 1989). Disabled people appear to have been particularly affected as some of the main users of social welfare and public services within our society. Austerity cuts are having a very direct attack on individuals' lives, with the re-assessment and retrenchment of key disability welfare benefits, the withdrawal of the Independent Living Fund (ILF)[1] and reductions in social care provision, as a result of reducing social care budgets.

To garner public support for cuts to social welfare spending, the Conservative government drew on the narrative of 'scrounger versus striver' (Briant et al., 2013) and public sector overspend. Misleading comparisons were made, depicting the national budget as being equivalent to that of a household budget (Clarke and Newman, 2010; Hamnett, 2014; Painter, 2017; UNCRPD, 2016). Social welfare has long served as a vital safety net in British society. Consequently, those impacted greatest by austerity cuts and the gradual curtailment of social welfare have been the most marginalised in our society. Disabled people were chosen as the focus of this study, due to the disproportionate impact austerity has had on their lives as the main users of social care and welfare (Riley-Smith, 2012; UNCRPD, 2016). Austerity has brought about significant social and economic impacts for disabled people and has led to a regression of disabled people's rights (UNCRPD, 2016). Cuts to public expenditure have, for example, impacted upon disabled people's right to live independently, to work, and achieve an adequate standard of living.

Disabled people have not faced such changes in silence. Individuals have sought ways of resisting and coping under increasingly difficult conditions. While a number of disabled people have become involved in visible and high-profile direct action protest such as 'Disabled People Against Cuts', 'ATOS Kills'[2] and 'Save the ILF', less is known about the more mundane and private forms of resistance that are taking place, such as the development of online networking, blogging, advocacy networks, awareness-raising, and mutual aid. Such acts have often been overlooked as forms of resilience, as opposed to those of resistance. While a small yet growing body of research has sought to explore and conceptualise disabled people's resistance (Berghs et al., 2019; Soldatic and Johnson, 2019), little has been written explicitly on disabled people's activism in response to austerity. The context of austerity has brought about an urgent need to examine the spaces and types of activism emerging. This research is therefore original in seeking to draw attention to lives that have been silenced by

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[1] The Independent Living Fund was a reserve provided by the UK government to enable disabled people with high care and support needs to live independently in the community rather than in residential care. The fund was closed by the UK government on July 1st, 2015.

[2] 'ATOS Kills' was a campaign which took place during the summer of 2012, in opposition to the contractor ATOS who were at the time responsible for carrying out the Government's Work Capability Assessments. The campaign was largely driven by the UK disability campaign group Disabled People Against Cuts (DPAC).

austerity and in examining the variety of forms and spaces in which disability activism is currently taking place.

During the final stages of writing up the thesis, the coronavirus (COVID-19) pandemic hit the globe in an unprecedented way, bringing the UK to a near halt in the spring of 2020, causing businesses to close and bringing about mass unemployment (Inman, 2020). As a response, the government claimed that ‘austerity is over’ with a massive expansion of government investment on infrastructure and the Coronavirus Furlough and Job Retention Scheme[3] (Inman, 2020). Notably, however, disabled people have largely been the casualty of COVID-19, forgotten yet again by central government, with no further investment into adult social care or disabled people's services to support them during the pandemic (Haynes, 2020; Ryan, 2020). Cuts to social care spending as a result of austerity measures, further made managing during the pandemic increasingly difficult for those who relied on already curtailed services and support. In the summer of 2020, we consequently, find ourselves in a time of flux, apprehensive of what lies ahead, a return to austerity, or an ideology markedly different. This study is therefore situated in a particular period in time. However, the stories shared by activists will inevitably endure time and potentially serve as a useful resource for future generations of activists. I have no doubt that disabled people’s activism will adapt in the face of new challenges.

1.3 Overview of the research

Back (2007:7) compellingly argues that ‘our culture is one that speaks rather than listens’. In doing this, he draws upon the example of political rallies, reality television, and social media as some of the platforms through which individuals in our society compete to tell their stories, be heard and recognised. However, inevitably it is often those with the greatest social and economic capital, whose voices, opinions, and experiences dominate. Conversely, there are certain marginalised groups, whose voices and experiences remain relatively hidden. This thesis seeks to highlight the lived experience of disabled people as a marginalised group who are actively seeking to be heard in the context of punitive and targeted austerity measures. Regardless of their conviction and persistence, many disabled people find themselves continually silenced, ignored, and pushed aside by a government that appears to be unable to accept the link between austerity and

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[3] The Coronavirus Furlough and Job Retention Scheme, was established by the UK government to enable employers to designate those employees who were unable to work due to the pandemic as ‘furloughed workers’. Through this scheme, the government pays part of furloughed employees’ salaries, potentially protecting them from redundancy.

hardship (see UNCRPD, 2016). Sections of the British media have also been complicit in promoting the authoritative narrative underpinning austerity, along with promulgating discourses around welfare fraud and dependency and in concealing the lived realities of those living at the sharp end of austerity.

Disabled people have been conceptualised as service users or welfare recipients long before the onset of austerity, rather than as competent social and political actors (Imrie and Edwards, 2007; Slater, 2012). The government's ability to make cuts to disability welfare and support is therefore based on longstanding views that disabled people are disempowered and without agency. Further, their political actions have often been disregarded or belittled by wider society as trivial and insignificant. To date there has been relatively little recognition or documentation of the plight of disabled people for civil rights (in comparison to other minority groups i.e. LGBT, women, and Black rights), this has led to a significant part of history being obscured, concealed, and forgotten (Rose, 2015). Similarly, today at a time of austerity, the political actions and resistant practices of many disabled people appear to have become sidelined (perhaps inadvertently or purposefully) from public consciousness. This research, therefore, aims to document and bring some of these struggles to light.

Through adopting a qualitative approach (consisting of biographical interviews and participant observation), this research explores the life experiences of disability activists. While disability activism has been around for some time, I am particularly interested in how it has evolved and what forms it has taken in response to austerity. Through exploring the life stories of disability activists, this study examines the roots of individuals' advocacy and the role activism has come to play within their daily lives. This is of particular importance as there has been little qualitative research that has sought to bring together the voices and experiences of disability activists engaged in activism in response to austerity, with existing research in this area largely based upon self-reflective accounts or media analysis of protest events. Furthermore, this research is original in exploring how different spaces may inadvertently shape forms of disability activism. By drawing upon participants' individual accounts, this research will give voice to the diverse experiences of disability activists and highlight the various ways in which they are responding to and resisting austerity. Further, it will challenge conventional conceptual binaries between acts of resilience and resistance, seeing both concepts as inherently intertwined.

1.4 Research aims and objectives

This thesis draws upon critical work from the fields of social and political geography, geographies of disability, disability studies, and social movement studies. In these fields, little scholarship until recently has conceptualised disabled people as political actors, focusing instead largely on the barriers disabled people face to inclusion (Gaete-Reyes, 2015; Imrie, 1996; Kitchin and Law, 2001). While there is evidence of a small yet growing body of research into disabled people's activism (see Berghs et al., 2019; Kim 2014; Soldatic and Johnson, 2019, Trevisan 2017a, b), there remains to be a shortage of qualitative studies bringing together disabled people's variant experiences of engaging within activist practices and spaces. Existing literature is seen to be heavily reliant on autobiography and self-reflective accounts of engaging in activism, along with that of media analyses of disability protest events. This research thus seeks to add to the existing literature by bringing together the experiences of multiple participants engaged in disability activism across a range of different spaces. Furthermore, it explores the nature of disability activism in the unique context of austerity and provides an explicitly geographical focus, looking at the spaces in which these acts of resistance are taking place.

Disabled people have largely been omitted from literature in the field of social movement studies which has been predominantly orientated around the male, white, young, and able-bodied activist (Coleman and Bassi, 2011). While there has been growing research exploring the activism of women (Bobel, 2007; Craddock, 2017, 2019; Culley and Angelique, 2003) and BME communities (Beriss, 2018; Emejulu and Bassel, 2015; Gill, 2016), the role of disabled people remains relatively overlooked. This research, therefore, seeks to speak to social movement studies and to consider what broader messages might be learnt from analyses of disability activism and protest, particularly concerning the use of the individual body in activism and the importance of creating inclusive spaces for different embodiments.

This thesis thus seeks to:

(i) advance existing scholarship on political space and the geographies of resistance by drawing upon the narratives of disability activists engaged in a variety of different forms of activism from the ostensibly public to the private and small-scale.

(ii) contribute to an emerging body of work on ‘everyday activism’, highlighting the significance of private acts of resistance such as caregiving and mutual aid.

(iii) advance geographic scholarship on the impacts of austerity by providing further first-hand accounts of how disabled people have been impacted and are supporting one another under austerity.

The key research questions are as follows:

1. What forms and spaces of disability activism are emerging and adapting in the context of austerity?

2. What does activism mean to disabled people who seek to create spaces that challenge and transform the status quo?

3. What motivating factors and experiences have encouraged individuals to become involved in disability activism?

4. How might more personal or private forms and spaces of activism begin to challenge what critical human geographers traditionally perceive as ‘activism’?

1.5 Structure of the thesis

In addition to this introductory chapter, the thesis comprises of eight further chapters.

Chapter two provides a critical appraisal of the relevant literature, exploring disabled people’s role as political actors along with the emergence and evolving shape of the Disabled People’s Movement in the United Kingdom. The chapter takes a chronological approach, exploring how disabled people have historically been excluded from society and notions of citizenship, along with how they have sought to challenge this. Thus, serving to provide background context to help understand how disability activism has evolved over time and adapted under austerity. The chapter ends with the current day, exploring the impact austerity has had on the lives and rights of disabled people in the United Kingdom and outlining how disabled people have increasingly mobilised against barriers to their rights.

Chapter three continues with the literature review by providing an appraisal of the existing literature on activism and political space, highlighting the ways in which disabled people have been largely overlooked (particularly from the field of social movement studies), with political actors conventionally understood as male and able-bodied, and activism often associated with masculine, public and militaristic acts such as protest and direct action. The chapter, therefore, turns its attention towards alternative forms of activism, those which reach beyond the militant and the public, drawing upon the burgeoning scholarship on everyday, online, and quiet activism. In doing this, the chapter also draws upon literature that critiques the conceptual binary between resilience and resistance, recognising how forms of resilience (e.g. the creation of solidarity networks) may also serve as forms of resistance.

Chapter four provides a discussion of the methodological groundings for the study, its research design, and how it was implemented. It also addresses issues concerning research ethics and positionality.

Chapter five is the first of four interlinked chapters, which form the core of the discussion. The chapter provides an overview of participants’ various understandings of the term ‘activism’ i.e. what is activism and how does one engage in it? The chapter also further explores participants’ differing experiences of becoming involved in disability activism in response to austerity.

Chapter six moves on to consider the nature of the spaces in which disability activism is currently taking place. This particular chapter examines the experiences of participants engaged in public forms and spaces of activism, including that of protest and direct action.

Chapter seven then turns its attention to examine alternative forms of activism, those which are taking place in liminal space i.e. between the public and the private. Boundaries between the two are often fluid and ambiguous, with several forms of activism traversing both the public and the private and/or sitting somewhere in-between.

Chapter eight as the final chapter of analysis, looks at the more 'private' and everyday forms of disability activism, those which might often be overlooked as trivial, insignificant, or banal.

The analysis chapters have been structured in this way, to foreground disabled people's experiences of becoming involved in disability activism in response to austerity, and to explore how different spaces of activism may call upon particular tactics. This structure was chosen to try and make sense of the multiple spatialities in which disability activism takes place, and seeks to draw out some of the commonalities identified between the various forms and speeds of activism operating within these spaces. Inevitably the decision to categorise the data in line with the above structure (i.e. dividing the findings chapters into public, liminal, and private spaces of activism) could be critiqued, as clearly many forms of activism operate across multiple, fluid spaces, which are not demarked by clear boundaries. Further, it was difficult to place people's lives and stories into boxes, when people's lives are fluid, messy and their activism exceeds neat spatial boundaries. Some activists, for example, had been involved in multiple forms of activism that traversed the space of the public, private, and liminal. This thesis, therefore, does not seek to fix or impose boundaries between public, private, and liminal space but instead recognises their fluidity. I have taken great care in writing up to recognise and draw attention to this fluidity in terms of spaces, lives, and forms of activism. Writing up qualitative research is inevitably a messy, complex, and intricate process, which produces and 're-crafts realities and creates new versions of the world' (Law, 2007: 143). Teasing out connections between the data can often feel superficial, biased, or partial. As Law (2007: 143) notes, the writing up of qualitative research is a creative process that creates 'truths and non-truths, realities and non-realities, presences and absences, but also arrangements with political implications…'. The research therefore inevitably presents data in such a way that a clear and coherent narrative can be built, in the process, removing some of the messiness of everyday lives and lived realities. Further, in order to construct a coherent account and to add clarity, a partial picture is presented, with some narratives inevitably falling outside the scope of the analysis.

The thesis concludes with Chapter 9, which revisits the research questions and provides a summary of the main findings. The chapter ends by outlining areas for future research.

Following the main body of the thesis, various appendices are included that provide data collection documentation. These include a participant profile table to help contextualise participants' accounts, consent forms, a participant information sheet, and photographs of various disability activist events in which participant observation was conducted.

Chapter 2 Literature Review: Disabled people as political actors

2.1 Introduction

> The great majority of human beings who have been at history's margins will come into their own and create a new history, which while still imperfect will contain more positive elements and exhibit fewer errors (Gramsci quoted in Campbell and Oliver, 1996: 167).

Relatively little academic research has explored disabled people's role as political actors (see Campbell and Oliver, 1996; Hande and Kelly, 2015; Kim, 2014 for some exceptions). Disabled people have a long history of engaging in political action around discrimination and social inclusion, however much of their struggles and achievements remain largely hidden and undocumented in wider social movement literature (e.g. Della Porta and Diani, 2014; van der Heijden, 2014). Research around disability in the discipline of geography has until recently largely focused upon disabled people as service users and welfare recipients rather than as competent social and political actors (Imrie and Edwards, 2007). This conceptualisation of disabled people appears to be underpinned by notions of passivity and vulnerability (Goffman, 1963; Keith, 1996).

This review engages with scholarship around disabled people's citizenship, noting how concepts of inclusion for disabled people have changed over time. The review provides a chronological account of changes to disabled people's rights, which have occurred largely in response to the development of the Disabled People's Movement in the UK and internationally (Campbell and Oliver, 1996). Despite the prevailing discourses of vulnerability and passivity commonly being associated with disabled people (Slater, 2012), individuals have long been involved in various forms of political action. The analysis begins by looking at how disabled people have historically been excluded from wider society, through, for example, institutionalisation, economic exclusion, and inaccessibility. The synthesis also explores notions of citizenship and how these have changed in the wake of the industrial revolution and the monetarisation of labour. Disability has been argued by activists to be a capitalist creation brought about through industrialisation and the inability of disabled people to engage in new forms of work systems (Clifford, 2020). Following this, the review moves on to outline the various ways in which disabled people have actively sought to challenge their exclusion, tracing the emergence of the Disabled People's Movement and its conceptual frameworks. Disabled people have long been prominent in securing their rights, as seen through, for example, their role in bringing about the closure of institutions and the establishment of the 1995 Disability Discrimination Act. Austerity has however brought about a change in the climate in which disabled people are political actors. The final substantive section of this chapter explores the impact austerity has had on the lives and rights of disabled people, along with the overall strides and gains of the Disabled People's Movement. The synthesis concludes by highlighting some of the challenges which lie ahead for the movement.

The aim of this critical evaluation of the literature is threefold: first, to outline how disabled people have historically been (and continue to be) excluded from society; second, to summarise both the development of the Disabled People's Movement and its advances to disabled people's rights; and third, to lay out how austerity has increasingly hindered the advancement of the Disabled People's Movement. While this synthesis is predominantly a historical account of changes to disabled people's rights, it will trace the conceptual evolution of ideas that have evolved through the movement. It therefore will provide an important background and basis for the research study.

As stated, disabled people have long been involved in various forms of political action. This has been demonstrated through the emergence of the Disabled People's Movement (Campbell and Oliver, 1996) and the development of disability studies as an academic discipline – as examined later in the chapter. While recent years have seen a surge in interest in disability studies and a growth in scholarship exploring the theories underpinning the Disabled People's Movement, there remains a need for greater research into the activist practices and political actions of disabled people. Both Berghs et al. (2019) and Soldatic and Johnson (2019) have published edited books exploring the changing nature of the global Disabled People's Movement today, providing a useful insight into both how and why disabled people are engaging in activism and advocacy. However, neither of these books are situated within the field of geography nor do they engage with the life courses of activists and the importance of space in altering their forms of resistance.

To date, geographers have touched upon social justice issues (Dear and Wolch, 1987), notions of citizenship (Gaete-Reyes, 2015), and civil rights relating to accessibility (Hall, 1994), but have scarcely engaged with the disability rights movement or the political actions of disabled people. Without a broader acknowledgement of the radical critiques and insights offered by the Disabled People's Movement, geographers risk obscuring disabled people's engagement and success as political actors. An extensive search of the literature only revealed two studies, Chouinard (1999) and Kitchin and Wilton (2003), which engage explicitly with the Disabled People's Movement. Kitchin and Wilton (2003) examine how successful the Disabled People's

Movement and in particular disability organisations, have been in Ireland and Canada at 'jumping scale' and in bringing about change. Chouinard (1999) in contrast, explores disabled women's experiences of activism in Canada, revealing how they may feel marginalised from both within the disabled people's movement and the women's movement. While the above two studies may be seen as starting points in the analysis of the disability movement from within the field of geography, there is evidently a need for further research. Disabled people have not traditionally been portrayed as political actors, but rather as passive recipients of charity and care (making it difficult for them to lay claim to a political voice), or as agents able to reciprocate care through peer-support (Power et al., 2016). As such very little geographical research has focused on their activism or political engagement. This is a major omission in geographical research. However, before considering some of the various political practices of disabled people in striving for rights, it is important that we first look at the factors which have brought about disabled people's marginalisation and social exclusion, which they have sought to challenge.

2.2 Disabled people's history of social exclusion and partial citizenship

The Disabled People's Movement has been motivated by a wide range of different, but overlapping oppressive forces and barriers. One key overarching motivation has been the partial citizenship status that has been afforded to disabled people throughout history. Marshall (1950) through his publication of *Citizenship and Social Class* was credited with establishing citizenship as a subject of sociological inquiry. Citizenship as Marshall (1950: 28) describes, is 'a status bestowed on those who are full members of a community. All who possess the status are equal with respect to the rights and duties with which the status is endowed'. Citizenship is understood as both a legal status and a 'social contract' (Waldschmidt and Sépulchre, 2019) between a nation-state and its citizens. Citizens are provided with access to rights along with obligations and duties which they much exercise (Johansson and Hvinden, 2007; Lister, 2003). As Blair (1996: 218) notes, 'A modern notion of citizenship gives rights but demands obligations, shows respect but wants it back, grants opportunity but insists on responsibility'. There is an expectation of reciprocity, with obligations being recognised as a return for rights. According to Marshall (1950), there are three types of rights bestowed on citizens – civil, political, and social, asserted at the scale of the nation-state (Bauböck, 1994; Joppke, 1999).

- Civil rights - the freedom to own property, exchange goods, services, and labour.
- Political rights – the freedom to vote and exercise political power.
- Social rights – assurance of an appropriate standard of living including, for example, social welfare, cultural heritage, and the ability to live a civilised life.

The extent to which these rights have been acquired by all people is however debatable, with many having had them denied. Citizenship thus becomes inevitably exclusionary as a way of defining personhood (Lister, 1997). Citizenship has a long history of inciting tremendous suffering from the denial of rights, respect, freedoms, and dignity by one group over another (Epp et al., 2014; Kabeer, 2005; Richardson, 1998; Sharkey and Shields, 2008). Armstrong (2006) however notes that it may not only be those who lie outside geographical borders (whom he described as ‘genuine outsiders’) who are excluded from citizenship but also some who live within a nation’s borders.

The distinction between citizens and non-citizens should not be seen as a binary (Tambakaki, 2015; Tonkiss and Bloom, 2015). Instead, citizenship should be conceptualised as a gradient category with different degrees of citizenship bestowed on individuals (Cohen, 2009). People may experience a whole scale of rights from full, semi to no rights. Disabled people have, for example, often been said to only have partial access to citizenship rights, depicted as 'shadow citizens' (Chouinard, 2001: 188), an ‘underclass’ of failed citizens (Murray and Field, 1990) or as ‘absent citizens’ (Prince, 2009). I seek to highlight disabled people’s partial citizenship throughout this analysis, by illustrating the various ways they have been denied their rights (Morris, 1998).

The image of the 'ideal citizen' while depicted as universal, tends to reflect the personal characteristics of the most powerful group in society, which in this case are non-disabled, middle-class, well-educated, employed, white men. Achieving a good degree of education along with paid employment, and living independently has been central to the notion of the 'good citizen'. Disabled people however do not always have equal opportunities to live up to this ideal due to social and structural inequalities (see Snyder and Mitchell, 2010 on 'ablenationalism'). Models of citizenship such as Marshall’s (1950) have been critiqued for their failure to acknowledge how social differences can affect people’s experiences of citizenship (Kymlicka, 1991; Young, 1990). As Waldschmidt and Sépulchre (2019: 439) note:

> [Citizenship] implies an ideology of ableism, namely the assumption that citizens ought to be healthy and exercise productive social roles. Receiving social assistance has therefore often gone along with the loss or the reduction of civil and political rights. This applies in particular to persons with disabilities who are a main target group of the welfare state.

Notions of citizenship as a consequence, serve to legitimise rather than reduce social inequality with many people unable to live up to this image. Altermark (2017) for example, has argued that notions of citizenship exclude people with learning disabilities, generally being based on ableist notions of a rational and independent agency (Dowse, 2009). Notions of active citizenship have also been used to justify policies that seek to get disabled and unemployed people into work and away from benefits (Carmel et al., 2007), thus helping people to become what is deemed ‘productive citizens’ (Grover and Soldatic, 2013; Morris, 2005).

My analysis of disabled people’s partial citizenship is informed by my overarching theoretical framework - critical disability studies. Critical disability studies may be seen as:

> a lifted-out space: a platform or plateau through which to think through, act, resist, relate, communicate, engage with one another against the hybridised forms of oppression and discrimination that so often do not speak singularly of disability (Goodley, 2017: 641).

Through disabled people and their allies highlighting the complexity of disability, critical disability studies has come to regard disability as a social construct, brought about by environmental and social or attitudinal barriers. It has also built upon this by considering how the body and impairment can be critically included in discussions of disability and disablement. Critical disability studies, therefore, seeks to challenge the ableist assumptions which underpin our society and bring to the forefront disabled people's voices, to counter those which undermine the value of disabled people's lives. Critical disability studies serves as an important basis for political action to advance the rights of disabled people and has become very much involved in debates around citizenship (Lister, 2007). Disability has largely been overlooked within political and sociological theorisations of citizenship (see Beckett, 2006 for an exception). Some disability studies’ scholars see disability as a denial of citizenship (Oliver, 1992b), the direct opposite of citizenship (Linton, 1998), or as an identity that is largely devalued due to its difference and 'otherness' (Barton, 1993).

According to Kitchin (2003), in order to dispute and challenge the social injustices faced by disabled people and ensure the creation of more inclusive landscapes, attention must be directed primarily towards redefining notions of citizenship along with challenging public attitudes and mindsets. Critical disability scholars have been proactive in seeking to develop new inclusive models of citizenship (Lister, 2007), which include notions of reciprocity and interdependency (Mladenov, 2012; Oliver, 1993), with value being attributed to contributions made to society beyond solely monetary. Working outside of critical disability studies, Hamja Ahsan (2019) as a writer, artist, and disability activist, has written '*Shy Radicals, The Antisystematic Politics of the Militant Introvert’*, which blends first-person accounts with a political manifesto and satire. The book presents an alternative view of citizenship, which presents the political demands of 'shy people' and makes the case for a world that is more inclusive of neurodiversity. Ahsan (2019) highlights how spaces of political representation, such as the House of Commons, are tailored towards neurotypical, assertive, and extroverted people, and therefore questions the notion of representative democracy and equal opportunities for political participation. Here he draws upon the term 'extrovert supremacy' to describe dominant culture and presents an alternative image of civic participation, which is more inclusive, for example, of shy and autistic people.

Morris (2005) a disabled feminist, in a discussion paper prepared for the Disability Rights Commission, discusses what a more inclusive view of citizenship might mean for disabled people. She highlights three integral principles, which would enable disabled people to claim full citizenship: self-determination, participation, and contribution, along with what legislative action might be required. I draw upon these three key principles in the following section to examine the central strands of social exclusion that the Disabled People's Movement has sought to challenge.

Arguing for disabled people’s full citizenship has always been a central focus of the Disabled People’s Movement (Barton, 1993; Beckett, 2006; Halvorsen et al., 2017, 2018; Oliver, 1993). Throughout history, disabled people have been segregated and excluded in various forms from wider society. The following section highlights three of the key ways in which disabled people have historically been excluded from full citizenship, a) institutionalisation, b) inaccessibility and c) exclusion from participation, which prompted the initial strands of the Disabled People’s Movement.

2.2.1 Institutionalisation

Disabled people's oldest form of social exclusion has arguably been their enforced segregation through institutionalisation. Disabled people have a long history of being segregated against their will and made to lead lives outside of society or on its margins i.e. in prisons, reformatories, 'lunatic asylums', or special schools. While segregation and exclusionary practices existed for a long time prior to the 19th century, it is in this period that ‘asylums’ and hospitals for the long-term sick and disabled proliferated, serving as key sites of exclusion and confinement. Initially, it was widely thought that disabled people were best served in these settings, driven largely by the growing influence of the psychiatry profession (Walmsley, 2005). However, campaigns for the legalisation of institutions were largely built on fear, and the predominant arguments were based around the need to protect society from the menace and criminality of those characterised at the time as 'feeble minded'[4] (Jackson, 1996). In Foucault's (2001: 40, translation of the 1961 original) *Madness and civilisation* he describes early mental institutions as 'houses of confinement', serving as 'establishments of religion and public order, of assistance and punishment, of governmental charity and welfare measures'. Institutions were not only for people with learning disabilities and mental health but also for people with physical and sensory disabilities (see for instance Leonard Cheshire Homes formally founded in the UK in 1948) (Clark, 2003). Institutionalisation was an outcome of the lack of self-determination and autonomy disabled people had at the time.

The number of British institutions continued to rise during the early twentieth century (Trent and James, 1994), serving as a means of containing, controlling, and managing disabled people. Before the industrial revolution, families were the main providers of care for disabled people. However, with the industrial revolution bringing about great economic and societal change, disabled people became increasingly marginalised, unable to participate, and subsequently became the responsibility of the community. The way in which the community often approached this responsibility, was to send disabled people away to 'asylums' and poor houses.

The Ely Inquiry into a psychiatric hospital in Cardiff, showed how impoverished life was within these hospitals for the long-term sick and disabled (HMSO, 1969). The inquiry in 1969 exposed instances of severe neglect along with physical and psychological abuse of patients. This prompted inspections of similar services and led to the 1971 white paper *Better Services for the Mentally Handicapped*. These inquiries sparked the first main period in disability activism, which will be explored later in this chapter. While the focus of this thesis precludes me from going into too much detail here, a more complete history of this time can be found by Johnson and Traustadóttir (2005), Walmsley (2005), and Wright and Digby (1996). My focus is instead on understanding the original kernels of where disability activism emerged.

Institutions, 'asylums', and residential special schools were widely prevalent across the UK up until the 1980s, underpinned by exclusionary government policies. It is generally assumed that citizenship entails free choice and the exercise of autonomy. With disabled people often being considered as in need of 'care', this has at times served to undermine their autonomy, with wider society often assuming that it is right to make decisions on their behalf. As will be discussed later in this review, self-determination has been at the core of both the independent living and self-advocacy movements to date.

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[4] 'Feeblemindedness' was a term that emerged in the US during the mid-nineteenth century to describe individuals exhibiting what was then termed 'mental deficiency' or 'idiocy'. Towards the end of the century, 'feeblemindedness' came to be understood by medics as a biological and hereditary defect (Katz and Abel, 1984; Rafter, 1992).

2.2.2 Inaccessibility

Gaete-Reyes's (2015) study of female wheelchair users living in Greater London and Leicestershire reveals yet another way in which disabled people's citizenship status has been curtailed, that is through their lack of access to public space and consequential inability to participate in society. Her choice of research participants is particularly interesting as disability, patriarchy, and citizenship are inherently connected; both women and disabled people have conventionally been perceived as being limited by their bodies and as such have been recognised as lesser citizens (Bacchi and Beasley, 2002).

Gaete-Reyes (2015) in her research draws attention to how the impaired body has for a long time been overlooked in transport planning with the requirements of disabled people often being misunderstood or plainly ignored. This is thought to have been influenced by how policymakers often construct disabled people as lesser citizens (Bacchi and Beasley, 2002). Citizenship, as a social construct, has long been associated with those who are deemed (economically) contributing members of society (Painter and Philo, 1995). Citizenship is therefore linked with the everyday practices of moving in 'able-bodied' ways, accessing public space, and being economically productive through participating in paid work (Valentine and Skelton, 2007).

Imrie (1996) famously drew attention to how the Western-built environment is designed and inscribed with the values of non-disabled people, presenting an ableist view of society. Imrie (1996) refers to this as 'design apartheid' whereby building forms and designs exclude, alienate, and constrain the movement of disabled people. Kitchin (1998: 343) expands upon this by explaining how spaces are configured to keep disabled people ‘in their place’, and to express when they are ‘out of place’. This practice serves to maintain a clear boundary between self and ‘other’ (Imrie, 1996), which impacts how disabled people feel about themselves and their self-identities in particular spaces (Valentine, 2007). Disability, as a result, is understood as being spatially, as well as socially constructed (Kitchin, 2003).

Research by Kitchin and Law (2001: 287) on the socio-spatial construction of (in)accessible public toilets, similarly argues that the ‘lack of provision is expressive of a wider set of ableist power geometries and signifies that disabled people do not, as yet, have the same civil rights as non-disabled people’. Kitchin and Law (2001) argue that despite the rhetoric of civil rights for everyone (as is apparent in much government legislation), disabled people are still being treated as 'second-class citizens', prevented from accessing, participating, and contributing to wider society.

Disabled people experience numerous access barriers to community participation, with meetings (as the most common method of participation) relying heavily on the spoken word and on printed material. Similarly, electoral voting as the primary means through which citizens exercise their political rights, remain inaccessible to some disabled people (Moore, 2017; Ryan, 2015). Disabled people are also often excluded by default (due to ableist assumptions) or through inaccessibility from participating in jury service. With both freedom and citizenship having long been associated with the ability to participate in shaping the political decisions that affect one's life, for a number of disabled people this remains largely prohibitive. Ultimately, the inaccessibility faced by disabled people is informed by societal attitudes and behaviours (Fine and Asch, 1988; Hawkesworth, 2001). Within this thesis, I will, however, explore how disabled people have sought to challenge this, to ensure that their voices are heard and that they are included in political decisions about their lives – something which disabled people have long been denied.

2.2.3 Exclusion from participation

> In a society where life chances are entirely dependent on individual wealth and ability, inequality and intolerance will be played out in the disadvantages experienced by disabled people (Morris, 2005: 36).

Disabled people (and historically women's) citizenship has continuously been challenged, due to their presumed inability to contribute economically to society. Disabled people have a long history of being excluded from the workforce and economic activity, due to inaccessibility and negative or hostile societal attitudes, leading to a lack of opportunities for disabled people's participation. This can have manifold impacts on disabled people's lives with both participation and contribution serving as key pillars of citizenship. The economic exclusion of disabled people is said to have intensified since the industrial revolution and even more so under neoliberalism. Capitalist society is dependent on the fast, efficient, 'able' body for capital accumulation. Those who are unable to live up to this 'perfect' corporeality of the capitalist worker (such as the sick, elderly, disabled) are consequently often marginalised, excluded, and/or oppressed (Mould, 2018b).

Gaete-Reyes' (2015) research echoes previous studies that highlight the association between citizenship and work (Brown and Patrick, 2012; Centeno and Cohen, 2012; Desforges et al., 2005). Work has been considered as a key determinate of citizenship (Brown and Patrick, 2012), excluding those who may not be able to partake in paid work, such as the elderly and disabled (Griffiths, 2016; Parker and Cass, 2005), who are often regarded as recipients of social welfare as opposed to being citizens with full rights (Gleeson, 1999; Young, 1990).

With social and economic status being largely dependent on accessing the labour market, disabled people are put at a great disadvantage (Barnes and Mercer, 2005; Kitchin et al., 1998). Exclusion from the labour market through a lack of opportunities for participation, or marginalisation within it (Hall, 2004) bring about substantial social and economic consequences. Baldwin and Johnson (1994) have stated that disabled employees are more likely to be paid less than their non-disabled colleagues who are working in the same roles. Kitchin et al. (1998) and Wilton and Schuer (2006) note that disabled people often experience exclusion from the workplace through open discrimination including abuse (verbal, psychological, and physical), wage discrimination, and less direct forms of discrimination (limited job security and inaccessible building design).

Disabled people have rarely been portrayed as active citizens but more often as passive recipients of care (Morris, 2005; Slater, 2012). It is not uncommon for disabled people to be seen by the government and wider society, as individuals who neither contribute nor give back to society. This has long been the case with charities in Britain (and other Western democracies) being underpinned by values and ideologies that perceive impairment as a personal tragedy. Disabled people are consequently portrayed as dependent and requiring care. Charity, as a Christian concept is understood as a one-way relationship, whereby disabled people and those who are deemed 'in need' become recipients of good deeds. Within this relationship, disabled people are seen as having no contribution to make themselves. This is further echoed in a range of social policies. Receiving welfare or charitable support takes place within relationships which often do not allow space for reciprocity. Underpinning this is an implicit assumption that if someone requires support, they are not anticipated to undertake their duties as citizens. This point is articulated by Blunkett (2003: 16) who notes that ‘a citizen cannot truly be an equal member of the community if he or she is reduced to a state of permanent dependency on the support of others. If a person is simply reliant on income transfers, he is not genuinely free and enabled to participate’. Concepts of equality and reciprocity, which are deemed essential to notions of citizenship are rarely discussed in relation to disabled people. The only contribution disabled people are often assumed to make is monetary, through paying for care services.

The belief that disabled people cannot contribute to society, has often led to individuals being denied the support and assistance necessary, for them to contribute and fulfil their responsibilities as citizens. Recent citizenship debates have focused on individuals’ responsibility to contribute as opposed to their right to do so. By focussing on individuals’ responsibility to contribute as opposed to society’s role in enabling this, the social barriers to disabled people’s (and other marginalised groups) participation are overlooked (Morris, 2005). Disability scholars and activists are of the opinion, that if recognition was given to disabled people’s right to contribute (as a key pillar of citizenship), disabled people’s social exclusion and partial citizenship could begin to be addressed (Barton, 1993; Morris, 2005; Waldschmidt and Sépulchre, 2019).

It is important to note that the political and social contributions of disabled people have rarely been acknowledged. This is something that I therefore strongly want to highlight and acknowledge throughout this evaluation of the literature and resulting thesis. While recent decades have seen an emphasis on 'user involvement', there is still relatively little acknowledgement of the decades of commitment by disabled people to establish Disabled People's Organisations (DPOs), providing advocacy, information, and peer to peer support (Finkelstein, 1991). Additionally, as this chapter outlines, disabled people and their organisations have had a great influence on bringing about numerous successful campaigns which have led to the establishing of the Disability Discrimination Act, Direct Payment Act, and the Independent Living Fund, along with many other substantial changes impacting upon the lives of disabled people within our society.

As this review has illustrated thus far, self-determination, participation, and contribution are all required for disabled people to be full citizens. This analysis will now turn its focus to look at how individuals have sought to mobilise against their marginalisation and exclusion.

2.3 The emergence and evolving shape of the Disabled People’s Movement

In response to the three key forms of social exclusion and partial citizenship status that disabled people have faced, a disabled people’s social movement emerged to challenge what has become the status quo. While barely documented or conceptualised within geographical literature, there has been a longstanding history of disability activism in the UK, going as far back to disabled people’s trade unions in the 19th century (see Barnes, 2007 on the National League of the Blind and Disabled) and efforts by the Disablement Income Group during the 1960s to ensure equal access to social security benefits. It was however in the 1970s and 80s, where the Disabled People's Movement and its subsect - the Independent Living Movement really took hold, as spaces for mutual support, the sharing of skills, advice, and for the recognition of shared injustice (Campbell and Oliver, 1996). The history of the disability movement in Britain and its various strands has been documented and critiqued by disability studies scholars (Campbell and Oliver, 1996; Griffiths, 2016; Hosking, 2008; Oliver and Barnes, 2006; Shildrick, 2013). The following sections examine these different strands. Before this, I outline the overarching conceptual underpinnings that emerged – the social model and its various critical incarnations – which helped galvanise a movement.

Inspired by the civil rights movement in America during the 1960s, disabled people in the UK began to become visible in the public sphere, taking direct action against poor access, discrimination, and inequality (Campbell and Oliver, 1996). Further, disabled people were adamant that they should be included in policy decisions about their lives, as the slogan of the movement states ‘Nothing about us without us’. This assertion of the need for disabled people’s inclusion and self-determination became a key focus of the movement. The emergent movement expressed its demands through the language of equality and rights, engaging in various forms of direct action in order to increase visibility and achieve its overall aims (Bickenbach, 1993). A key UK disability rights organisation of the period was UPIAS (the Union of the Physically Impaired Against Segregation). UPIAS was founded in 1972 by Paul Hunt, whose ideas stemmed from his experience of living in an institution (Le Court, the first Leonard Cheshire home for disabled people) where he and others had struggled with the authorities over the right of disabled people to control their own lives. Paul Hunt was a notable disability activist, who had previously published an important edited collection of essays by disabled people entitled *Stigma, The Experience of Disability* (1966); challenging widely held public perceptions of disability as a form of personal tragedy and suffering. UPIAS transpired to be a hugely influential organisation, igniting the Disabled People’s Movement in the UK and was responsible for the conceptualisation of the ‘social model of disability’ in 1978. UPIAS insisted that it was society, built and governed by non-disabled people, that was preventing disabled people from participating in a full working and social life, as opposed to an individual’s impairment. The social model of disability served as a means through which to explain the exclusion and marginalisation of disabled people. The model was predicated on the idea that:

> … it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society (UPIAS Founding Statement 1974b).

A clear differentiation is made here between ‘impairment’ as a functional limitation and ‘disability’ as being the consequence of society’s exclusionary practices. The social model marked a radical shift away from the medical and pathological model of disability, which had previously dictated attitudes and behaviours towards disabled people in society. The medical model presented disabled people as 'victims of misfortune', who needed a cure. Seen as being unable to participate in society, disabled people were frequently ‘depersonalised, institutionalised and hidden away from a society which saw no real imperative for change’ (Richards, 2010:1101).

The social model of disability has undoubtedly been pivotal to the success of the Disabled People's Movement, having a widespread influence on multiple spheres, such as national legislation (including a drive towards inclusive education), international declarations, and the growing prominence and popularity of disability studies degrees (Gabel and Peters, 2004). Studies focused on social and environmental barriers along with the geographies of exclusion, also influence many research spheres, including that of architecture and design, with its explicit role in the creation and maintenance of disabling built environments (Butler and Bowlby, 1997; Imrie, 1996; Kitchin, 2003; Kitchin and Law, 2001). Rather than seeing physical barriers as fixed and absolute, research in this area has sought to shed light on the political, institutional, and social processes which create disabling spaces (Gleeson, 1998; Imrie and Hall, 2001; Kitchin, 2003).

The social model of disability has not however gone without critique. A broadly feminist critique of the social model of disability, first emerged in the 1980s. Many scholars critiqued the model for its failure to consider the embodied and corporeal experience of impairment (Crow, 1996; French, 1993; Meekosha and Shakespeare, 1998; Morris, 1991; Shakespeare, 2006; Thomas, 2004). Attention had been directed towards the social experience of disability as opposed to that of the emotional and corporeal (Hughes and Paterson, 1997). Hall (2000) suggests that by arguing that disability only comes into existence in the social realm, the lived embodied experiences of many disabled people are denied. This was particularly deemed to be the case for people with chronic illnesses and learning disabilities, who found their experiences did not fit easily within this narrow framework (Campbell and Oliver, 1996; Meekosha and Shuttleworth, 2009; Sheppard, 2018). As a consequence, several feminist theorists working within the field of disability studies (Hall, 2000; Hughes and Paterson, 1997; Parr and Butler, 1999), later sought to advocate for a relational bio-social theorisation of impairment that ‘allows us to think through, rather than around, the intersections and interaction of disability (social oppression) and impairment (bio-social functions of our bodies)’ (Thomas, 2001: 57). A number of geographers have similarly recognised the need to acknowledge the varied corporeal and embodied experiences of disability, alongside that of the social model. There has, for example, been a substantial increase in research around pain and the personal (Dyck, 1995; Moss and Dyck, 1996; Park et al., 1994; Sheppard, 2018). However, historically there has been much fear and apprehension regarding this change in approach, for ‘to mention biology, to admit pain, to confront our impairments, has been to risk the oppressors seizing on evidence that disability is ‘really’ about physical limitations after all’ (Shakespeare, 1992: 40).

With its roots in the social model, a new framework named the ‘cultural model’ of disability emerged in the 1990s. The cultural model draws upon the feminist concept of intersectionality to acknowledge that a number of different factors including e.g. race, culture, gender, sexuality, age, and religion could affect an individual’s lived experience of disability along with their self-identification. As Devlieger et al. (2003: 9) note, disabled people 'are same and different'. Further, the cultural model recognises the role of both the media and wider societal and cultural attitudes (e.g. in the construction of stereotypes and popular media representations of disability) in shaping how individuals self-identify as disabled (Devlieger et al., 2016; Goodley, 2017; Waldschmidt, 2018).

Building on the cultural model, a new strand of disability studies has emerged since the early 2000s under the title ‘crip theory’ (Peers et al., 2012). Crip is a provocative term both adopted and reclaimed by the disabled community (deriving from the word ‘cripple’) to signify disability culture. ‘Crip’ culture is about openly showing and embracing one’s stigma instead of hiding it or feeling shame (Löfgren-Mårtenson, 2013; McRuer, 2006). Crip theory bridges the divide between disability studies and queer studies, exploring intersectional experiences and how ‘compulsory heterosexuality and compulsory able-bodiedness generate sites of containment, where disability and queerness are managed, contained, kept quiet, kept silent’ (Peers et al., 2012: 148-9). Crip theory is therefore about generating new visions of the body, desire, and community, which challenge and move beyond attempts to curb, contain, and manage it. Furthermore, it is about a conscious critical questioning of the norm: 'Why is a ‘perfect’ and functioning body better and more desirable than another? What exactly is a normal body?’ (Löfgren-Mårtenson, 2013: 414).

2.3.1 Disabled people’s role in the closure of institutions and in establishing Independent Living

Emerging from the roots of disability activism outlined above, disabled people have long been proactive in campaigning for self-determination and against segregation and institutionalisation. The origins of the Independent Living Movement in Britain, emerged from the actions of a few residents at the Le Court residential home in Hampshire (the same home as was occupied by Paul Hunt who established UPIAS), inspired by the success of the Independent Living Movement in America. John Evans, one of the founders of the Independent Living Movement in the UK, spent several months in the US where he came into contact with the Independent Living Movement there and the world's first centre for Independent Living in Berkeley, California (Brindle, 2008). Disabled people living at Le Court at the time, had limited autonomy, with no say around how their days or lives were structured (Miller and Gwynne, 1972). However, from this powerlessness and lack of autonomy came an assertion of self-determination. During the late 1950s and 60s, residents at Le Court Home campaigned for greater autonomy and sought a position for themselves on the Management Committee to ensure that their voices were being represented (Mason, 1990). They came together to discuss and confront their experiences of discrimination, segregation, and exclusion (Acheson and Williamson, 2001). The challenges they faced became the basis for redefining ‘independence’ and ‘independent living’, as Ratzka (2005: n.p) an independent living advocate explains:

> Independent Living does not mean that we want to do everything by ourselves and do not need anybody or that we want to live in isolation. Independent Living means that we demand the same choices and control in our every-day lives that our non-disabled brothers and sisters, neighbours, and friends take for granted.

Their actions generated the subsequent campaign ‘Project 81’ in 1979 by some residents to leave the home and live independently in the community by 1981 (International Year of Disabled People). Drawing upon the principles of independent living, they successfully negotiated a financial package to enable them to live in the community. The local authority provided them with money, which could be used to pay for necessary support such as employing personal assistants.

John Evans was the first person to achieve this ambition in December 1983 and all the other remaining Project 81-ers (or as they were later called by the disabled singer Ian Dury – ‘escape committee’) by the end of 1984 (Brindle, 2008). Whilst financial support was required from local authorities to enable this transition, the campaign originated from the efforts of disabled people. Whilst being motivated by residents’ self-determination it was also the product of their endeavour.

Both 'Project 81' and the subsequent Independent Living Movement led to the founding of the Hampshire Centre for Independent Living (CIL) in 1983, which claimed to be the first in the UK. Every CIL was run and controlled by disabled people, to ensure that they had the right emphasis and empowered disabled people. Centres such as the Hampshire CIL enabled the sharing of expertise around independent living issues between disabled people through the form of information, peer support, and training. During the 1980s, CILs developed slowly, with local authorities somewhat hesitant to hand over control to disabled people.

Since the late 1980s, there has been a gradual shift in government policy with an increased emphasis on social inclusion and the right to live independently in the community. The Independent Living Fund was introduced in 1986, triggered by the actions of disability activists, providing disabled people with monthly payments to top-up social care and help with the purchase of personal care and domestic help (Elder-Woodward, 2016).

As part of their campaigning for self-determination, disability activists were also proactive in lobbying for direct payments[5]. The Direct Payment campaign was launched in the UK in 1989 by the BCODP (British Council of Disabled People), a national, democratic, representative organisation of disabled people. The legislative campaign was established to aid local authorities in setting-up direct payment schemes and to ensure that disabled people across the UK, had equal access to independent living. The Direct Payment Act 1996 was finally implemented on 1st April 1997, allowing disabled people access to money from their council to pay for their care and support needs (Brindle, 2008). Direct payments gave disabled people more autonomy and greater control over the services they used and where they were obtained. Legislation now requires local authorities to implement direct payments by law. The establishing of direct payment schemes along with the ILF, represent a major shift in power to disabled people, brought about through the continuous efforts and persistence of disability activists to ensure that all disabled people have equal opportunity to live independently in the community.

2.3.2 Disabled people's role in establishing the Disability Arts Movement

Alongside the Independent Living Movement (ILM), another key strand of disability activism that emerged was the Disability Arts Movement, which began in the late 1970s. This emerged out of the more general Disabled People's Movement and provided a new channel to promote a newly discovered identity (Campbell and Oliver, 1996). The movement sought to encourage disabled people's participation in cultural activities and the arts, while also breaking down barriers to accessibility and social inclusion. The arts have traditionally been regarded as elitist (Delhaye, 2008), so the Disability Arts Movement was an attempt to level the playing field and make the arts more inclusive.

Disabled artists became heavily committed to breaking down accessibility barriers (both physical and attitudinal) that were preventing disabled people from fully participating in society. They sought to express their frustrations (i.e. around inaccessible infrastructure, lack of understanding, and discrimination) in the form of pictures, sculptures, or performances (to name only a few mediums). In 1987, the London Disability Arts Forum (LDAF) was launched to encourage disabled people's participation in the arts. From this several disabled artists emerged (including singers, actors, comedians, and poets), often expressing through their work a new-found liberation. Not long after, in 1988, a notable disabled people's cabaret was established by Geoff Armstrong under the symbolic name - 'The Workhouse'. The club provided disabled artists

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[5] Payments given directly to individuals to purchase services that the local authority would otherwise provide.

with an accessible venue to perform and air their views, of which there were very few at the time (Campbell and Oliver, 1996). ‘The Workhouse’ continues to hold a great legacy within the Disability Arts Movement today, as a space through which disabled people were able to come together, share experiences and collectively challenge their oppression through the arts. Disability arts was (and remains to be) political, often expressing disability as a cultural identity, as opposed to ableist ‘overcoming’ narratives, that perceive disability as an adversity over which one must ‘triumph’ (McRuer, 2018).

Recent efforts have been made to preserve such histories with the National Disability Arts Collection and Archive opening in mid-2018. Disability arts remains to be a prominent part of the Disabled People’s Movement today. Disability arts represent a stark move away from previous forms of charitable disability crafts (Hall, 2013), with disability arts often being underpinned by a clear political message or serving as a means of building community and morale amongst disabled people (Minkler, 2005).

Disability arts are seen by some as a clear and direct engagement with oppression and resistance (Cameron, 2009). Meanwhile, for others, it is regarded, as a more subtle expression of the lived experiences of disabled people and a declaration of a distinct disabled or 'crip' cultural identity (Swain and French, 2000). Much of disability arts has been about making disability and the disabled body visible. The disabled body has been seen as a site for self-empowerment and a vehicle through which to challenge common perceptions of disability i.e. notions of passivity, vulnerability, and dichotomies between disabled/non-disabled, self/other (Kuppers, 2003). Since the beginning of the Disabled People’s Movement, the disabled body has been strategically used and drawn upon as part of disability activism, as a means of garnering greater public attention and support, and demonstrating the extent of disabled people’s marginalisation. As part of this thesis, I will consider how the disabled body has been drawn upon as part of recent disability activism in response to austerity, be that through protest, direct action, the arts, or otherwise.

2.3.3 Disabled people’s role in establishing the Disability Discrimination Act

Rejecting charity and pity, disabled people began to demand equal rights to participate in and contribute (economically, socially, and politically) to society. Disabled People's Direct Action Network (DAN) was one of the core groups pushing for such rights, undertaking their first action in 1993 in Christchurch (Campbell and Oliver, 1996). After several decades of campaigning, a major law was passed in 1995, the Disability Discrimination Act (DDA, 1995). The DDA made it unlawful to discriminate against disabled people as customers, employees, and citizens (DDA, 1995; Rose, 2015). Old and ineffective quota systems to ensure disabled people's access to employment were replaced with anti-discrimination legislation (Goss et al., 2000).

For some, however, the Disability Discrimination Act was insufficient, expressing concerns about its 'extensive exclusions, inadequate enforcement mechanisms, tentative draftsmanship and tight government control over its subsequent interpretations through the court' (Gooding, 1996:3). Many also found themselves sceptical of John Major’s Conservative government’s commitment to disability rights, seeing it as an attempt to avert and curtail militant activism and more radical proposals that were acquiring growing popularity and support (Goss et al., 2000). For others, however, the DDA did more to improve the lives of disabled people than anything else had achieved in the last century. As of the 2nd December 1996, it became illegal to discriminate an individual in recruitment, training, promotion, or dismissal based on their disability (Goss et al., 2000). Employers also must enact reasonable adjustments for disabled staff and applicants e.g. providing adaptions to technology or buildings. The DDA was brought about as a consequence of disabled people’s demands for social and economic inclusion, and for opportunities to contribute to society, key pillars of citizenship (Barton, 1993; Morris, 2005).

While the Disabled People’s Movement has driven major improvements to the rights and social inclusion of disabled people in the UK, austerity has brought with it a number of challenges to the strides and gains of the movement, particularly in regards to independent living and self-determination, as will be discussed in the following section.

2.3.4 Barriers to disabled people’s citizenship during a time of austerity

> Austerity is not a medicine. It’s a cancer, a cancer at the heart of society. (Monroe, 2013, quoted in O'Hara, 2014: vi).

The above sections have focused on the long-standing and overarching societal barriers disabled people have faced and the significant progress that they have made in challenging them. The focus here turns to examine how the disability movement has had to respond and adapt under the context of austerity. The following section examines the impact of austerity has had on disabled people's lives, the barriers it has established, and how it has undercut many of the earlier gains of the movement in achieving fuller citizenship status. It establishes the underlying context for the current research study.

As outlined in the introduction, following the 2008 financial crisis, the United Kingdom experienced substantial cuts in public expenditure, as the UK government sought to lower the national deficit (Hamnett, 2014). While responsibility for the crisis lay primarily at the doors of bankers, mortgage companies, and politicians, the years following the crisis saw a growing shift in blame away from the elite and those in power, onto the most vulnerable members of society. For example, a key objective of the UK coalition-government (2010-2015), became the reduction of what had become termed the 'burgeoning welfare burden'. The Department of Work and Pensions (DWP, 2010, 2015) and The Organisation for Economic Co-Operation and Development (OECD, 2009, 2010) working alongside the government, persistently claimed that economic recovery was being hindered primarily by welfare claimants. The OECD strongly advised upon the need to ‘activate existing benefit recipients’ (OECD, 2009: 5) and ‘overcome a disability benefits culture’ (OECD, 2009: 17). In turn, this served as a means of victim blaming; deflecting attention from the careless acts of the elite and those in power. As Owen Jones, a journalist in the Guardian (quoted in O'Hara, 2014: 252) recounts:

> [The government] very clearly redirected people’s anger away from those (actually) responsible to people’s neighbours. To turn people against unemployed people… proved a very clever firewall I think for the elite in this country.

Following the election of the Conservative-Liberal Democrat coalition in 2010, welfare recipients came under increased scrutiny, with parts of the media and government speaking out about the large number of benefit claimants and the potentially high level of benefit fraud (Garthwaite, 2011; O'Hara, 2014). A significant increase was noted in the use of derogatory phrases directed towards welfare claimants; these included terms such as ‘scrounger’, ‘fraudster', and 'parasite', frequently circulated by politicians and the media (Briant et al., 2013; Walker, 2013). Welfare became increasingly portrayed as a 'life-style choice' (BBC, 2010), with welfare claimants depicted as having become reliant, idle and lazy, living ‘lavish lifestyles’ (McDuff, 2016) paid for by the taxpayer (see for example Channel 4’s 2014 documentary ‘Benefits Street’). Suspicion and hostility towards those claiming unemployment benefits has been longstanding. Taylor-Gooby (2013) notes how public support for social welfare and benefits peaked in 1989, mirroring a rise in poverty and unemployment during the 1980s and early 1990s. Since then, support for social welfare and public sympathy towards the unemployed has gradually declined. Despite an increase in unemployment post-2004, public attitudes towards the unemployed have never recovered, with many believing that benefits are far too high. It is unclear whether the recent increase in unemployment in the wake of COVID-19 will change this.

It is only however over recent years that disabled people and those claiming sickness benefits have become under particular attack. The rise in recent hostility and stigma towards disabled people can arguably be seen to mark a return to Victorian times, where a differentiation was made between the ‘deserving’ and ‘undeserving’ poor (Gough, 1979). As opposed to being unquestionably portrayed as the ‘deserving’ poor (Thatcher, 1993: 590), who are deserving of social and financial support from the state (Briant et al., 2013; Dean and Taylor-Gooby, 1992; Wiggan, 2012), disabled welfare recipients have come under increased public scrutiny. Such change is thought to be a direct result of the government’s exaggeration and distortion of the level of benefit fraud amongst disabled welfare claimants (Briant et al., 2013; De Castella, 2012; Scope, 2011), serving as a political strategy to justify and garner public support for cuts directly affecting disabled people (Hamnett, 2014; UNCRPD, 2016). Disabled people have increasingly been portrayed as a burden on society (Slocan, 2010) as opposed to equal citizens, due to their reliance often on public welfare, and their presumed lack of economic contribution (Jensen and Tyler, 2015).

As a result of the negative portrayal of disability welfare claimants by the government and the media, disabled people have been ‘at the front of the queue of those bearing the brunt of recent austerity measures’ (Briant et al., 2013: 885). A report by Duffy in 2013 revealed that cuts, targeting disabled people were nine times greater than those faced by most other citizens. In 2013, disabled people were bearing a quarter (25%) of all cuts (Duffy, 2013). The financial crisis and the deficit reduction policy were therefore utilised as a means of bringing about welfare changes, which had previously been too politically difficult to carry out (Hamnett, 2014).

Cuts affecting disabled people can largely be divided into two separate categories; cuts to personal income (benefits and tax credits) and cuts to social care (Duffy, 2013). Previously, disabled people had been entitled to claim for two social benefits, Disability Living Allowance (DLA) and Incapacity Benefit (IB). Disability Living Allowance (first established in 1992 in response to the Disabled People’s Movement), was a welfare benefit that sought to help with the additional costs of living with a disability (gov.uk, 2017). In contrast, Incapacity Benefit (established in 1971) was a more stringent benefit, distributed to individuals on the basis that they were unable to work (Garthwaite, 2011). Recent years have seen a radical strategy of benefit 'reform' with both of these being replaced by tougher and more rigid benefits. This has been understood as part of a radical move to save billions of pounds a year from the welfare budget, normalised through a discourse of necessity, unavoidability, and being 'all-in-it-together' (Davies and Evans, 2012; Featherstone et al., 2012; Ginn, 2013).

Incapacity Benefit was the first of the two benefits to be phased out. From October 2008, new claimants had to apply for Employment and Support Allowance (ESA). All new and existing claimants were to be reassessed using the work capability assessment (WCA) in an attempt to move IB recipients onto either ESA or Job Seekers Allowance (JSA) and into work (Cross, 2013). Under ESA all recipients (except those most ill or disabled) are expected to undertake rehabilitation or retraining, as preparatory steps for work (Houston and Lindsay, 2010). The coalition-government hoped that this would help to reduce the 'disability employment gap' (the proportion of disabled people in employment compared to the rest of the population) (Mason, 2015). However, there appeared to be little recognition of the structural barriers which might prevent disabled people from gaining employment such as employers' attitudes (Grover, 2016; James, 2013) or the impact of the closure of Remploy factories in 2008 on the proportion of disabled people in employment (Brindle, 2011; Cross, 2013). The reforms thus locate the problem as being with the individual and in their behaviours (e.g. lack of motivation) as opposed to other environmental factors (e.g. exclusionary employment practices or lack of opportunities).

The introduction of ESA has been hugely controversial (Taylor-Gooby and Taylor, 2015), with the very wording of this new benefit (Employment and Support Allowance) implying that all claimants will move into employment at some point, in a way that Incapacity Benefit does not. This change has been seen as part of a wider change to welfare policy that has become known as 'workfare' (Jessop, 1993, 1995). Under these changes, benefits have become increasingly restricted, capped and dependent on individuals looking for work (Wiggan, 2012). This change in welfare policy firstly became apparent in 1997 with the introduction of New Labour's White Paper '*A new contract for welfare: a gateway to work*' (Department for Social Security, 1998). However, this welfare change was further promulgated and intensified upon the arrival of the 2010 UK coalition government (Hamnett, 2014).

Disability Living Allowance (DLA) underwent similar reform in 2013, being replaced by the Personal Independence Payment (PIP) (Cross, 2013). As part of this process, all existing DLA claimants were reassessed through the form of a face-to-face consultation with an independent health professional. The coalition government had estimated that the introduction of PIP and the tightening of its eligibility criteria, would lead to around 500,000-600,000 people losing their entitlement, potentially saving the government around £2.2 billion (Cross, 2013; Harrington, 2012; Young, 2014). Grover and Piggott (2010) conceptualise ESA and PIP as forms of 'social sorting', whereby benefit claimants who are ill or disabled are organised into groups based upon medical perceptions of their illness or disability and its severity. According to Garthwaite (2011), the process of face-to-face consultations has the potential to both reinforce a medical model of disability and to portray some disabilities or illnesses as deserving of welfare, whilst others are not. As disability is always a social construct (Moraes, 2012), by altering benefit criteria, the government can redefine individuals' entitlement to support and ergo citizenship (Briant et al., 2013; Roulstone, 2015). As fraud levels are low amongst those claiming disability benefits, reclassifying some disabled people as non-disabled (or not 'disabled enough') is seen as a necessary measure to ensure required cost reductions (Briant et al., 2013; Goodley et al., 2014).

Undergoing the process of reassessment for disability welfare benefits has been found to be deeply humiliating, undermining, and traumatic for disabled people (UNCRPD, 2016), with many noting how they were made to feel inadequate, less than human, and as a `lesser citizen' (Garthwaite, 2014). The vast majority of applicants report suffering from increased anxiety, panic attacks, and depression while awaiting their medical assessment and subsequent outcome (Wood, 2012). Most applicants sadly do not contest or appeal their welfare benefit decisions. Horton (2016: 349) suggests that 'the anticipation of funding cuts is having manifold everyday, lived consequences that are arguably more wide-ranging, intractable and troubling that the impacts of funding cuts themselves'. With the vast majority of ESA claimants having little or no savings and relying on disability welfare benefits as their sole source of income, the prospect of their removal can leave individuals in highly precarious and often unbearable situations (Malik and Domokos, 2012; McCarthy, 2012).

The loss of disability benefits can have manifold impacts upon individuals' lives; often leading to reduced freedom, increased dependency, debt, and isolation. These impacts have, in turn, challenged disabled people's citizenship in terms of their self-determination and autonomy, along with their ability to be present, contribute, and participate in society. Losing a disability benefit can also affect an individual's entitlement to other benefits, for example, a car on the Motability scheme[6] (Cross, 2013). Current research suggests that this is likely to lead to job loss – preventing disabled people from contributing economically to society, drastically increased isolation, and dependency upon others (Cross, 2013; Power, 2016). Similarly, with substantial cuts being made to the Access to Work scheme and a growing number of employers coming under increased financial difficulty, implementing 'reasonable adjustments', has become increasingly difficult. Austerity, therefore, poses a great challenge to disabled people's citizenship, rights, freedoms, and social inclusion.

In addition to the wide-ranging and ever-changing cuts and reforms affecting disabled people, there have also been specific government actions which have more directly impacted on the gains of the Disabled People's Movement itself, which are outlined below:

2.3.4.1 The impact of austerity on the gains of the Disabled People's Movement

Firstly, significant reductions have been made in recent years to Local Authority social care services, with an increase in charges for such services. As the main users of social care services, this has had manifold impacts on disabled people's lives (Ginn, 2013; Young, 2014). The tightening

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[6] A government scheme which provides disabled people who are eligible for the higher mobility rate of the Personal Independence Payment (PIP) with an accessible car.

of eligibility criteria for the provision of adult social care is preventing many disabled people from accessing it and taking part in community life, leading to increasing isolation and deteriorating mental health (Brawn et al., 2013; Young, 2014). Alongside this, the closure of many community services and day care centres has left individuals often stuck at home, isolated, and unable to participate in wider society (Butler, 2015b; DH, 2010), renouncing disabled people's citizenship.

Secondly, the Department of Work and Pensions (DWP) decided to close the Independent Living Fund (ILF) in 2015. John Evans (2014) raised significant concerns regarding this, arguing that ILF recipients were 'understandably scared by the prospect of having to move back into residential care'. The DWP claimed that the money allocated to the Independent Living Fund would be given to local authorities, but as the money is not ring-fenced, there is some uncertainty as to whether recipients will be able to gain access to an equivalent level of support (Cross, 2013; Young, 2014). As a result of the closure of the Independent Living Fund along with cuts to welfare benefits and adult social care provision, the number of disabled people under residential age living in residential care has steadily increased, with this often being seen as the most cost effective 'solution' (Bulman, 2017). This change to social care provision has greatly impacted on disabled people's ability to live independently and with autonomy in the community, thus challenging the strides and gains of the Independent Living Movement to date.

The combination of reforms potentially work together in a very harmful way for disabled people's citizenship status. Such reforms present a great risk of a reversal to independent living, along with an infringement of the UK's Article 19 obligations (JCHR, 2012: para 161). An investigation of the UK Government launched by the UN Committee on the Rights of Disabled Persons (CRPD) in 2012, brought about by the campaigning of disability activists and Disabled People's Organisations working largely under the umbrella of Reclaiming our Futures Alliance[7], found that several 'pieces of legislation related to recent welfare policies [did] not fully enforce the international human rights framework related to social protection and independent living' (UNCRPD, 2016: 16). The committee visited six major UK cities in 2015 and conducted an assessment of welfare reforms and legislation. They concluded from their visit that the UK welfare reforms had led to the 'grave and systematic violations' of disabled people's rights (BBC, 2016; UNCRPD, 2016), whereby changes to PIP, social care and housing benefit, along with the closure of the ILF, all 'hindered [disabled people's] rights to live independently and be included in the community' (UNCRPD, 2016: 17).

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[7] https://www.rofa.org.uk/

While cumulative national scale research like that undertaken by Duffy (2014) and the UNCRPD (2016) can be helpful in providing an overview of the impacts of austerity on disabled people, they do not clearly show how austerity measures may affect disabled people differently. Research in the field of geography has focused on the personal and intimate geographies of those social groups who have been disproportionately impacted by austerity measures, these include women (Stephenson, 2016), young people (Horton, 2016), and ex-industrial/working-class communities (Thomas, 2016). Austerity undoubtedly is experienced, lived with, and responded to differently across disparate social groups (Beatty and Fothergill, 2015; Hastings et al., 2015). Further research, however, remains to be done on recognising how multiple forms of oppression and privilege may coalesce and interact in disabled peoples' accounts and experiences of austerity. This thesis will seek to add to this literature by highlighting the everyday experiences of disabled people in living, coping, and resisting austerity, noting how this may differ depending on individuals' situations and characteristics. Furthermore, it will explore how activism may take different forms amongst various communities and may be adapted in line with individuals' needs, desires, and bodily capacities.

2.3.5 The challenges that lie ahead for the movement

Austerity poses a great challenge to the future of the Disabled People’s Movement. Disabled People’s Organisations (DPOs) established through the movement, have experienced widespread funding cuts in recent years, forcing many to close. These organisations play a crucial role in providing independent, accessible information, advice, advocacy, and peer support networks for disabled people (Connolly, 2017). The closure of DPOs is likely to leave many disabled people isolated, with nowhere to turn to for independent advice around benefits, services, or social care. There are also concerns that the 'reduction in user engagement, campaigning, advocacy and peer support activity provided by DPOs greatly undermine the Government's aims of greater participation by Deaf and disabled people in the wider community' (Inclusion London 2012: cited in Dodd, 2014). Alongside this, cuts to legal aid have also left many disabled people with few places to turn to and resources to draw upon in contesting changes to welfare and instances of discrimination (Woolf, 2018).

Whilst the majority do not speak out against such change, a small number of disabled people have not borne the brunt of austerity cuts in silence but have instead demonstrated their role as political actors, vocalising their rights and concerns through online activism, lobbying, campaigning, and direct action (Williams-Findlay, 2011). Vocalising their objections can however come with the risk of repercussions such as the withdrawal of personal benefits and services (Williams-Findlay, 2011). Nevertheless, numerous anti-austerity organisations have been established by disabled people since the onset of austerity in 2010. The most prominent of these groups have been 'Disabled People Against Cuts' (DPAC - a nationwide organisation), 'The Broken of Britain' (a non-partisan UK disability campaign), and 'Black Triangle' (a Scottish protest group). While all three have sought to bring about change, DPAC has arguably been particularly successful in lobbying the government. DPAC was originally founded by three disability activists who were involved in the 'Disabled People Protest' demonstration which was held outside the Conservative Party annual conference on 3rd October 2010 in Birmingham. The demonstration, organised by disabled people, was the first mass protest, lobbying against the impact of austerity on disabled people's individual and collective lives. Since 2010, DPAC has expanded considerably (largely through the use of online activism) with a formal membership of around 1,500 as of 2017 (DPAC, 2017) and 26 local groups located across the UK. The campaign group today operates as an organisation grounded in the social model of disability with an onus on promoting full human rights for all disabled people. Since 2010, the organisation has been responsible for a huge number of local protests, street demonstrations, art exhibitions, and nationwide events (DPAC, 2017). Demonstrations have been focussed upon a variety of issues including the introduction of Personal Independence Payment (PIP), Employment and Support Allowance (ESA), the Bedroom Tax, the closure of the Independent Living Fund, and the conduct of Work Capability Assessments. With the ongoing implementation of adverse cuts and policies targeting disabled people, the number of people engaging in activism appears to be continuing to rise (Pearson and Trevisan, 2015). Individuals are not only operating within campaign groups but also individually and autonomously, using online platforms, journalism, the arts, academia, and literature as avenues to voice their opinions (Pearson and Trevisan, 2015; Pring, 2017).

The Disabled People’s Movement has therefore had to evolve and adapt in line with the experiences and challenges of disabled people today. While many rights have been acquired for and by disabled people over the past forty years, austerity poses a great challenge to a number of these. Oliver and Barnes (2006) argue that the attaining of rights should not be regarded as the end of the battle, as there is no certainty that they will be enacted or achieve their intended aims, neither does it guarantee their longevity or preservation. The climate of austerity has consequently brought about a renewed urgency to disability activism, with disabled people’s rights increasingly coming under threat (UNCRPD, 2016).

2.4 Conclusion

This chapter has sought to outline how disabled people have historically been excluded from wider society and denied full citizenship status, along with the ways in which individuals have actively sought to challenge such forms of injustice. Disabled people's engagement in political action around disability-related issues is not a recent phenomenon but is instead part of a longstanding battle for access and rights. This chapter has emphasised disabled people's roles and achievements as political actors. To date, research in the field of geography has largely focused on disabled people as service users and welfare recipients, rather than as active citizens and political actors. It is this gap in the literature, where I will predominantly focus my energies and attention. There has also been a relative neglect of the historical resistance and success of the Disabled People’s Movement in advancing disabled people's rights within broader resistance literature. This thesis, therefore, draws upon the history of the Disabled People's Movement in order to frame and contextualise activism and resistance today.

Chapter 3 Literature Review: Geographies of activism and resistance

3.1 Introduction

Within this chapter, I examine some of the key political concepts of *political space, political action, activism, resistance* and *resilience* that underpin the study's focus. I begin by exploring some of the dominant literature on political space from within the field of geography and social movement studies. I examine how this scholarship has largely been focused on activism and political action occurring in public space largely overlooking the role of quieter and more hidden forms of activism. Additionally, this literature has had surprisingly little to say about the role of the body in political action: which bodies can and do take part in political action, and how is the body used in protest? Scholarship has tended to reinforce the notion that people's right to full citizenship hinges on their personal autonomy, capacity to protest and/or claim their rights through political participation, as outlined in the previous chapter. Disabled people have been largely absent within studies of social movements and political action, which have largely been focused upon the mobile, able-bodied and predominantly male political actor (Coleman and Bassi, 2011). Disabled people have, in contrast, often been conceptualised in literature and through public discourses as vulnerable and passive, as opposed to militant and resistant (Slater, 2012).

I then move on to consider literature which has sought to critique this conceptual binary between vulnerability and resistance, recognising that vulnerability can be a fundamental and inherent element of both activism and resistance. Through recognising the shared vulnerability inherent in political action, I seek to reconceptualise activists as not necessarily invincible or 'all powerful', as has been depicted in much of the dominant scholarship on social movements (Bobel, 2007; Oliver and Marwell, 1992; Pile, 1997; Routledge, 2017). The chapter seeks to interrogate what it might mean to be 'an activist' as well as what it means to engage in activism. The chapter therefore also draws upon the growing literature around quiet and slow forms of activism occurring beyond the public sphere, in liminal and private spaces. This may, for example, consist of acts such as the making of political artwork or the sharing of advice, knowledge, skills and resources. I seek to challenge the idea that practices such as sharing knowledges and resources are solely acts of resilience, and instead, I want to think about how they might also be understood as acts of resistance. Here, I build upon key academic debates which have sought to critique the conceptual binary between resilience/resistance, seeing resilience practices as having transformative potential and serving as a means of securing a better future (Arampatzi, 2017; Brown, 2014; DeVerteuil and Golubchikov, 2016; Raco and Street, 2012).

In summary, this chapter will build upon some of the key debates and scholarship including that of feminist studies around 1) the nature of political space, 2) who is understood as constituting an ‘activist' and 3) what actions are deemed as embodying activism. In doing so, the chapter calls for greater recognition of disabled people as competent political actors and an acknowledgement of their unique engagement in a vast array of activist practices, which traverse the public, private and the liminal.

3.2 Conventional spaces of resistance

In Britain, there has been a move by wider society away from the political mainstream which is evident through the decline in electoral voting rates (Allen and Birch, 2015; Clarke et al., 2018). However, this decline has arguably coincided with an increase in alternative forms of political participation and mobilisation through, for example, large-scale environmental and ecological campaigns, collective action around identity politics (i.e. sexuality, ethnicity, disability, gender), consumer-based lobbies and neighbourhood movements (Dalton, 2008; Keith, 1997; Routledge, 2019). Some scholars such as Clarke et al. (2018) remain sceptical of this argument, noting that there is not sufficient evidence to suggest that negativity towards formal politics is being compensated by engagement in informal politics. They argue that we should instead see this as an extension to the ways in which individuals are engaging in political action. Dalton (2008) see this as a move away from liberal democracy to a more participatory and engaged democracy, challenging traditional ideas around what it means to be a politically active citizen (Keith, 1997). Austerity has also not gone unnoticed, with several groups having emerged across the Northern hemisphere to challenge austere cuts to social welfare. These campaigns against austerity have engaged all facets of society including, for example, women (Stephenson, 2016), the disabled (Hande and Kelly, 2015) and the working classes (Hearne, 2015). Anti-austerity activism has become an area of increased interest to geographers, with a particular focus on the various strategies that individuals are employing in order to both resist and challenge austerity politics (Arampatzi, 2017; Hall, 2018; Hearne, 2015). This work on anti-austerity activism forms part of a longer history of geographic scholarship on political activism and social movements, which I will now turn to.

Scholarship on political space from within the field of Marxist geography has predominantly centred upon the writings of David Harvey and Don Mitchell, both of whom conceptualise political space (and accordingly, political action) as something that predominantly takes place within the public realm (i.e. on the street or in the square), with public space being seen as the key site of struggle and resistance (see also Arendt, 1958 on the 'Political'). This emphasis on public space is similarly reflected across social movement studies, where traditional academic understandings of activism largely orientated around 'spectacular'; vocal, antagonistic and demonstrative forms of protest and direct action that are enacted in public to bring about change (Crossley, 2003; Tarrow, 1998; Thoburn, 2008; Wallerstein, 1990).

Harvey (2013) in his writing, frames political space as being solely located in the public realm (i.e. on the street or boulevard), but he notes some of the ongoing challenges to public forms of political expression such as that of consumerism, commodification and privatisation. Both Harvey (2013) and Mitchell (2013) argue that spaces for articulation and expression of political discontent are becoming increasingly restricted and that we are experiencing somewhat of the demise of public space as a vital place for political resistance. Traditional spaces of activism and protest are increasingly being closed down, Mitchell (2013) contends through the spatial regulation of free speech. Rather than regulate what can be said, governments are increasingly regulating *where* it may be said; as Mitchell (2013: 45) explains, 'let geography, more than censorship, do the silencing'. Although protest in public forums can only be regulated if it is shown to threaten an important state interest or to cause clear harm, the gradual decline of public space has made protesting increasingly difficult. Most public activities take place on publicly accessible private property, for example, shopping centres, waterfront developments and (privately owned) parks. Within such spaces, the property rights of landowners override the political rights of citizens, preventing people from engaging in political speech and protest activity on these sites. A protest is therefore easily restrained and silenced when the major meeting and gathering points in a city are on publicly accessible private land (Mitchell, 2013).

Cities across both the United States and the United Kingdom are becoming increasingly segregated into protest and no-protest areas, for example, outside significant international conferences, political conventions or abortion clinics (Mitchell and Staeheli, 2005, 2008). Protestors continually have to make a defensive argument for why their voices should be heard and actions seen (Routledge, 2017). Protesters are forced to alter their tactics to fit with a legal system that regards protest as secondary to 'the established order' (Harvey, 2013; Mitchell, 2013). Both Mitchell (2013) and Harvey (2013) therefore draw attention to the growing regulation of political activity through the governing and partitioning of public space. Others, however, have critiqued Mitchell (2013) and Harvey (2013) along with other Marxist geographers for their narrow reading of political space and political action, with feminist geographers noting how the public sphere has historically been a masculine domain (Deutsche, 1991; Thomas, 2012), that has not been open to some bodies such as those of women (Bondi, 1998; Pain, 1991; Staeheli, 1996;

Valentine, 1992), children (Valentine, 1996), Black people (Lefebvre, 1991; McCann, 1999) or sexual minorities (Hubbard, 2001; Valentine, 1993). Disabled people have similarly often been excluded and prevented from participating in public forms of political action, due to various social, cultural and environmental barriers (Fine and Asch, 1988; Gaete-Reyes, 2015; Imrie, 1996). Within this thesis, I will be considering the various 'crip' critiques of traditional forms of protest, including the ways through which the disabled body has often been excluded from such spaces and sought to open up alternative spaces for its inclusion.

3.3 The protesting body

Traditionally, only some bodies have had the freedom and capacity to occupy public space. The public and political space of a protest, in this respect, has traditionally been one occupied by men, in which they may use their bodies to demonstrate power, strength and defiance (Coleman and Bassi, 2011; Craddock, 2019; Langa and Kiguwa, 2013; Sullivan, 2005). Even today when we look at recent protests and uprisings including the Arab Spring (Al-Ali, 2012; Fedele, 2016; Johansson-Nogués, 2013) and the 'Umbrella movement' for democracy in Hong Kong (Ho, Jackson & Lam 2018), they are portrayed largely as spaces occupied by men and as choreographed performances of masculinity (Athanasiou, 2014).

Gender has long been recognised as a key barrier to participation in protest. According to Dodson (2015: 379), 'aggregate gender ideology (widely shared attitudes about gender roles) discourages women from participating in confrontational activism' (see also Hoschild and Machung, 2003). Dodson (2015), Craddock (2017), Thorne (1975) and McAdam (1992) highlight how labour is often divided in social movements with women frequently allotted the more mundane and behind the scenes organisational tasks. Men, as a result, are frequently more visible in protest movements – engaged in the more confrontational and public activities, while women's contributions are largely less visible and more hidden (Craddock, 2017; Dodson, 2015). Even when women do take to the streets, they are often met with a different response – their actions are frequently overlooked or belittled and their demands ignored (Craddock, 2017; Thorne, 1975). Take, for instance, the Arab Spring, despite conceptualisations of the protests as militaristic and as performances of militarised masculinity, many women were involved in the uprisings in Tunisia, Egypt and Libya through engagement in protest rallies and other forms of public action (Morgan, 2011). Such imagery lies in stark contradiction to enduring Western perceptions of Arab and Muslim women as 'victims, oppressed, [and] having little agency' (Joseph, 2012: 10). However, despite their courage, the demands of these women for dignity, opportunity to voice their opinions and be involved in decision-making remain largely overlooked (Johansson-Nogués, 2013).

Within Marxist geography, there has been a tendency to focus on the collective body and the commons rather than that of the individual bodies which make up this mass (Hohle, 2009, 2010). There has as such been a failure to recognise the different ways in which individual bodies may occupy and engage in sites of protest (Wilkinson, 2017). For some bodies (e.g. the sick, elderly and disabled), engaging in protest, which typically consists of energy-intensive activities such as shouting, chanting, engaging in speeches, marching/walking, holding banners and standing ground, can be a difficult if not near-impossible endeavour. The following section will outline the various ways in which bodies are used in protest.

The body serves as a central part of protest and direct action, traditional conceptions of activism conjure up images of people taking their bodies ‘to the street’ in protest. However, the body has largely been neglected within analyses of protest and collective action in geography and social movement studies. As a result, scholarship in these fields has largely focussed on the political actions of those who are able-bodied and mobile, and often male (Harvey, 2012). Such individuals are often conceptualised as ‘all-powerful’ and as devoting themselves and their lives to direct action. In my research, I, therefore, want to think about how individual bodies matter in activist movements (DeLuca, 1999; Sasson-Levy and Rapoport, 2003).

There has been little consideration as to how the very act of ‘taking to the streets’ may already be an act of privilege, with public spaces of activism not always being accessible or open to all. The general tendency in this literature has been to overlook the material and the corporeal. There is however a growing call to recognise the protesting body as agential, as a vehicle through which to convey a message or as a message in itself (Sasson-Levy and Rapoport, 2003; Tyler, 2013).

There has been a recent growing interest (particularly in the fields of gender studies and sociology) into the role of the body in protest (particularly from scholars interested in activism undertaken by marginalised groups, such as women, LGBT people, and ethnic minorities) (DeLuca, 1999; Tyler, 2013). The body has increasingly become recognised as both a means and site for self-expression and empowerment (Davis, 1997). Scholarship has analysed the potential of the body as a site of resistance and self-expression through hairstyle, piercings, cosmetic surgery and body shape (Carroll and Anderson, 2002; Featherstone, 1982; Gimlin, 2006; Twigg, 2007). The body can thus be utilised as a space to protest against normative codes and hegemonic identities. Sasson-Levy and Rapoport (2003) for example, draw upon the Women in Black protests in Israel, which were orchestrated against war and conflict. These protests were undertaken by women and in the process, challenged the patriarchal order and masculine political sphere, establishing women as capable political actors. A political moment occurs when those who are meant to remain hidden enter the public sphere. In the Women in Black protests, the women asserted public identities that had been denied to them, and in doing so, redefined who is a legitimate political participant in the public sphere (Sasson-Levy and Rapoport, 2003). The visibility of certain bodies can therefore be seen as an act of defiance, a refusal to be quarantined, isolated, marginalised or silenced (DeLuca, 1999).

Tyler (2013) has also reflected upon how women in Yarl’s Wood immigration and detention centre (in Bedford, England), sought to use their bodies as the central part of their protest. A group of fifteen women detained in the centre, held a protest outside the staff office, with many of them stripping naked as a direct response to their inhumane treatment. The strategy of using their bodies was not just a way to acquire greater media coverage and visibility, it also served to contest assumptions about the naked and vulnerable female body. The Yarl’s Wood protestors removed their clothes in a deliberate attempt to mark their dehumanisation, and inhumane treatment (see Agamben, 1998: 12 on 'bare life'). Within this protest, the vulnerable body was used as a key site of political resistance.

The vulnerable body has been used in several different forms of political protest and civil disobedience. For example, DeLuca (1999) examines the use of the body within Earth First!, ACT UP (AIDS Coalition to Unleash Power) and Queer Nation actions. He highlights how ACT UP activists chained themselves to the White House gates and conducted public kiss-ins. Employing a similar strategy, Queer Nation invaded straight bars and shopping centres to kiss and make queer identities visible. Such tactics have also been used by environmental movements, including Earth First! activists who put their bodies at risk through sitting in trees or blockading roads and logging equipment. Each of these tactics are about social movements using the body for social change, often attempting to turn corporeal vulnerability into a site of defiant resistance. Such events are orchestrated for mass media dissemination often revolving around pictures of vulnerable, dangerous or ‘taboo’ bodies (DeLuca, 1999). Their bodies however do not solely serve to draw attention but they are also the focal point of the argument. The body is central to their arguments in terms of how it is treated, respected and cared for (DeLuca, 1999). Protests such as those of Queer Nation (DeLuca, 1999) and Yarl’s Wood (Tyler, 2013) have helped to re-conceptualise and expand understandings of what it means to be a political actor and engage in political action (Sasson-Levy and Rapoport, 2003).

3.4 Adapting protest and direct action in line with corporeal and material limits

While the previous section outlined the various ways in which the body is used in protest and how not all bodies are able to participate in conventional forms of protest and direct action, the next section will turn its focus towards how some activists have sought to adapt and shape their actions in line with bodily and material limits.

Genz (2016) researches the activist practices of a group of senior citizens in Berlin, who are engaged in resistance practices against rising rents and gentrification. Genz (2016) notes the unique way in which activists in her case study, sought to occupy political space through adapting their activism. Due to the age and various health conditions of retirees, they often required special equipment when protesting e.g. foldable camping chairs and an accessible bus. They also required supporters for assistance in travelling to and from events, and also while demonstrating, with someone always feeling tired or nauseous. Tasks which might be relatively quick and easy for younger protestors, took considerably longer for these retirees. Through drawing upon retirees' adapted activism, Genz (2016) highlights a slower form of protest, whereby the political actors are not necessarily 'all powerful' but instead work with and around their vulnerability, adapting actions in line with their specific needs, in ways which can be just as effective and powerful.

Notions of vulnerability have, on the whole, been largely obscured in social movement studies with a focus on the 'all-powerful' political actor, largely silencing and obscuring the political actions and experiences of minority groups such as older and disabled people. This thesis will, however, in a similar respect to Genz (2016), seek to highlight the unique ways in which disability activists have sought to adapt their protest in order to accommodate for the varying abilities, working both with and around their various embodiments. For some, this may also involve incorporating their bodily vulnerability as part of their activism, as will be outlined in the following section.

3.5 Resistance and vulnerability

> Assumptions pervasive in several popular and theoretical discourses… hold that vulnerability is the opposite of resistance … vulnerability requires and implies the need for protection and the strengthening of paternalistic forms of power at the expense of collective forms of resistance and social transformation (Butler, 2016: 1).

Resistance has traditionally been associated with masculine concepts of power, strength and defiance while being distanced from notions of vulnerability. Similarities can be seen here with scholarship on urban exploration, whereby discourses ‘emphasize masculinity, fearlessness and physical strength, reinforcing older ideas about what sorts of bodies belong to explorer-subjects [and which do not]’ (Mott and Roberts, 2014: 234-5). Vulnerability has rarely been understood as a feature of resistance. Instead, vulnerability has been conceptualised as a form of passivity, victimisation and the need for protection and support (Butler, 2016; Hedva, 2016; Yeo, 2020). Butler (2016) argues that these commonplace understandings have led to the theoretical positioning of resistance as a site of activity and agency while vulnerability is placed as that of inaction (Butler-Rees, 2017). Through drawing upon these wider debates around the politics of vulnerability, this thesis hopes to dismantle the vulnerability/resistance dichotomy, through emphasising the numerous ways in which vulnerability might be mobilised, re-appropriated and utilised in disability activism.

Particular bodies are often presumed to be ‘vulnerable’ such as those of women (Ahiska, 2016), children (Brown, 2015) and disabled people (Slater, 2012). Titchkosky (2003) has cautioned that use of the phrase ‘the vulnerable’ can serve to overlook structural inequalities and social relations, presenting it instead as the outcome of individual fates. The labelling of certain social groups as ‘vulnerable’ can also serve to undermine their collective resistance and individual autonomy (Brown et al., 2017; Butler, 2016). Scholarship by Roma Hammani (2016) challenges the assumed association between vulnerability and passivity, through drawing attention to how groups of Palestinian women on the West Bank often utilised and reclaimed their bodily vulnerability as a means through which to protect local men and resist military violence. Recognising that Israeli soldiers were less likely to inflict harm on their bodies, women were often found at the forefront of collective action. Vulnerability can therefore be either underplayed or exaggerated and used as a political tool (Butler, 2016).

The scholarship of Butler (2016) and Hammani (2016) help highlight the need for new forms of collective agency, which do not deny vulnerability as a resource. This holds particular relevance to my research, whereby disability activists have historically used their vulnerability as a political tool to help engender social change. Examples of this include disability activists during the 1990s, chaining themselves to public transport and blockading streets in their wheelchairs, aware that police offers would be reluctant to impinge or exert force upon their bodies (Rose, 2015). Similarly, Kim (2014) in observing a crawling protest conducted by activists with physical disabilities in Seoul, notes how vulnerability can be utilised as a political tool to accompany a claim for social justice and human rights. The protest which occurred in 2006, was held to demand that the government provide in-home support. As part of their action, activists deliberately made themselves vulnerable through removing their prostheses, consequently making their impairments visible and in doing so, de-emphasising capacity and independence (Kim, 2004). The act was seen as a means of demonstrating the extent of state abandonment and reminding the government of its responsibility to provide the means for basic survival.

Butler (2016) however argues that vulnerability should not be used as a term only to describe some bodies engaged in protest but rather as denoting a shared experience for *all* activists. Butler (2016) highlights the need to recognise vulnerability as a universal condition (not solely the attribute of a few individuals/groups), and as something inherent within all acts of resistance. Resistance makes us vulnerable. For example, through engaging in protest, an individual may open oneself up to violence, hostility and abuse. Resistance can therefore never be fully removed or distanced from notions of vulnerability. The above scholarship helps us to reimagine all activists as vulnerable, not solely marginalised groups such as the disabled, elderly or women (Kim, 2014). It should however be recognised that some groups are likely to be more vulnerable in their acts of resistance than others as a result of various societal structures and their bodily capacities. Vulnerability is not, therefore, to be understood as a condition inherent within certain individuals but rather as something which is brought about as a result of various structures (Butler, 2016). Furthermore, it should be acknowledged how certain marginalised groups may play with and re-appropriate notions of vulnerability as part of their activism.

The above section has sought to highlight that there is not one universal activist subject who is emblematic of the 'all-powerful', masculine subject and devoid from notions of vulnerability. Instead, there are a variety of different bodies that may constitute the subjectivity of an activist, as will be discussed in the next section.

3.6 What does it mean to be an activist?

With the previous section exploring the prevalence of vulnerability in acts of resistance, it is important to recognise that for some individuals, participation in public forms of activism can be too risky or physically demanding. Many disabled people may, for example, fear repercussions such as the loss of access to welfare benefits, care and support. As a result, many individuals have sought to carve out other alternative spaces for activism. This section will therefore outline why it is important that we consider activism as taking place in spaces and forms beyond that of the public, iconic and the spectacular.

This section reflects upon Martin *et al.*'s (2007) question of 'what counts as activism?'. Feminist scholars have argued that conventional understandings of activism as 'spectacular', vocal and antagonistic forms of protest and direct action (see for example Anderson, 2003; Sparke, 2008; Tarrow, 1998; Thoburn, 2008), renders invisible activism and political action in daily life (Abrahams, 1992; Pain, 2014b; Riemer, 1986), painting a partial and distorted picture. In an attempt to break down such binaries between political action (public life) and everyday life (private life), several scholars have drawn upon earlier feminist scholarship, which has outlined the politics of more 'personal' dimensions of social life, for example, sexuality, family or interpersonal relations (Davis, 1981; Dworkin, 1976; Hall, 2011; Pain, 2014b; Ruddick, 1980). Abrahams (1992) argues that through focusing upon the political activities inherent in everyday life that challenge existing power relations, researchers may not be led to the naïve conclusion that the majority of people are apolitical or disinterested; neither will they presume that the majority of society is completely dominated by institutional power. Such an approach draws attention to the political actions of minority groups, the non-elite and people who are not associated with a particular social movement. This broad conceptualisation of politics highlights how revolutionary political activity may be found in mundane everyday activities, in moments and spaces which we might not instinctively label as 'activist'.

Social movement theorists, in particular, have tended to overlook the political activity inherent in everyday life, by maintaining a clear distinction between everyday life and political action (hooks, 2001). Social movement scholarship has tended to only look at people’s personal everyday lives in order to learn more about the generational dynamics of social movements and how people become mobilised into political action (e.g. as a result of experiences of hardship, relative deprivation or because their livelihoods came under threat) (Brown and Pickerill, 2009; Milligan et al., 2011). Similarly, activism has often been conceptualised as a linear journey, with activists seeming to follow a trajectory and/or activist ‘career pathway’, with individuals seen to be in a state of becoming, rather than recognising how activism may be more nuanced and embedded into everyday life (see for example Maynard, 2018).

My research seeks to complicate some of these dominant conceptualisations of activism, showing how what people understand as 'disability activism' can be highly complex and varied. The thesis seeks to pay attention to how activist practices might not always be spectacular but can be found in quiet moments of care, which are deeply embedded in the everyday. Here, I am building upon the work of several scholars such as McWilliams (1974), Elshtain (1983) and Jones (1985) who have argued that care and community ties are central to political life. This ‘ethic of care’ (Tronto, 1993), and everyday acts of caring are central to sustaining the societies and communities in which we live. This literature has hence outlined how care can be understood as a political act. Abrahams (1992: 329) along with numerous other scholars (see Askins, 2014, 2015; Pain, 2014b; Pottinger, 2017) has argued that ‘we need to consider political action as a type of human behaviour rather than as an *arena*… through which people act or attempt to effect change'. Political action may be understood as a type of behaviour, which involves challenging, changing or re-negotiating social values and resources. It, therefore, takes place across every arena of social life (within both the public and private sphere) and comprises of not only spectacular and staged actions but also everyday acts of solidarity and care. Nonetheless, some geographers remain somewhat sceptical of the transformative potential inherent in private and small-scale acts (i.e. those occurring at the household or neighbourhood scale) (Kitchin and Wilton, 2003; Staeheli and Cope, 1994). Staeheli and Cope (1994) for example, in their analysis of women's citizenship in Pueblo, Colorado, highlight the limitations of small-scale activism and the challenges of scaling-up. They argue that women's activism at smaller scales (i.e. the household, neighbourhood) and their relative absence from larger-scale state and national political parties has led to their activism often being disregarded or belittled. Gibson-Graham (2002) similarly argue that there has been a fixation on politics, mobilisation and resistance at the global scale. They argue that such a vision is masculinist and advocate instead for equal recognition of the local as a space for political transformation, through small, local interventions or new ways of being.

Within the thesis, I will build upon this literature by investigating disabled people's everyday activism, and how this does not always coalesce into discrete forms but is rather more fluid, ambiguous and ever-evolving. In the next section, I will turn to look in more detail at the quieter forms of activism, those which often take place beyond the public domain, in everyday life.

3.7 Quiet activism

Traditional understandings of activism have tended to regard 'being activist' as 'an unconditional state: an identity, mindset, standpoint or self-aware commitment' (Horton and Kraftl, 2009b: 17). An 'activist' is perceived as someone who is out of the ordinary (Baumgardner and Richards, 2000) and who holds values of humility and rigour (Oliver and Marwell, 1992). They must 'live the issue', display a never-ending commitment and devote a great deal of time and effort to warrant the label (Helou, 2005). The rigid nature of this presumed 'activist identity' along with how it is incompatible with daily life, has placed it out of reach for many, including some of those who are most devoted (Bobel, 2007).

In contrast, scholarship on 'quiet activism' has sought to acknowledge and make visible, how many individuals may live out activist identities in their daily lives i.e. through everyday mundane embodied practices of being, making and creating which are often deeply intertwined with one's principles and beliefs. Pink (2012: 4) makes the argument that everyday life and political action are frequently studied in separation from one another. However, as Chatterton and Pickerill's interviews with anti-capitalist activists note, there is 'a strong desire… to reject simple divides between activists and their other – the non-military ordinary citizen' (2010: 478-

480). In a similar sentiment, Bobel's research on 'menstrual activism' revealed that participants often refused to be labelled as activists, contending that 'one can 'do activism' without 'being activist'' (2007: 149). Evidently, there are clear 'attempt[s] to transform activism into a more accessible set of practices and politics that can resonate and influence the political mainstream, rather than existing on the political fringe' (Chatterton and Pickerill, 2010: 480).

Working from within the field of sociology, Fish et al. (2018) highlight how the lesbian, gay, bisexual (LGB) community may engage in forms of quieter, mundane activism on a daily basis. They note how making oneself visible as an LGB parent, through walking down the street together or dancing with one's partner can challenge and extend understandings of family. Through making particular choices about how they live their lives, and not concealing or hiding their relationships, participants in Fish et al's (2018) study were said to be engaging in a form of quiet, quotidian activism that had the potential to steadfastly chip away at some of society's social norms and structures. Everyday activism, therefore, works alongside loud, public and visible political demonstrations, helping to bring about societal change. Fish et al. (2018) in their analysis, outline the transformative potential of everyday actions, through forging social bonds, and the everyday acts that make life liveable. This echos Neal and Murji (2015: 813) weariness about separating the 'ordinary from the extraordinary'. Bobel (2007: 147) argues that this favouring of public and militant acts as the 'perfect standard' of activism, both excludes and makes it unattainable for those who engage in activism in their everyday lives. Studies have also, for example, recognised attending a support group as a form of activism (Allsop et al., 2004) with individuals supporting others and drawing attention to shortcomings in societal structures e.g. healthcare provision. Much of this scholarship on everyday activism takes inspiration from Hanisch's (1970) essay 'The Personal is Political' whereby groups of women who met to discuss their shared experiences of marginalisation and oppression were conceptualised as engaging in a political act. This scholarship conceptualises political actions as not always necessarily loud or disruptive but rather as being present in quiet 'banal, day-to-day practices' (Horton and Kraftl, 2009a: 16). This is of particular resonance to the thesis, where much of disabled people's activism can be said to exist beyond the public, spectacular and the iconic.

Over the past decade, there has been a growing trend amongst geographers to broaden understandings of activism to recognise the often overlooked, small, everyday practices of kindness, kinship and creativity; expanding the political realm beyond the verbalised, into practices of doing and making. These small mundane embodied acts, which are either implicitly or explicitly political have become of increased interest to many geographers including Askins (2014, 2015), Hall (2011), Horton and Kraftl (2009b), Pottinger (2017) and Smith and Jehlicka (2013).

Pottinger (2017) for example, in her ethnography of individuals that are involved in a local seed swap event and a national seed conservation network, observed how gardeners cultivated crops and stored seeds to provide for future generations and to support a broader movement to conserve biodiversity. Pottinger (2017) adopts the term ‘quiet activism’ to refer to these everyday, gently subversive acts of care which can help to bring about a form of slow and gradual, social and environmental change. These small yet valuable acts can be conceptualised as serving as a form of prefigurative politics, whereby individuals ‘express the political “ends” of their actions through their “means”’ (Yates, 2015: 1).

Askins (2014, 2015) draws upon a similar concept of ‘quiet politics’ in her ethnography of a befriending scheme that connects local residents with refugees and asylum seekers in the North East of England. Askins suggests that a ‘quiet politics’ is about small acts of kindness and emotional attachment; politics emerges through the ‘unassuming praxis of engaging with others, in which new social relations are built in/through everyday places’ (2014: 354). The act of initiating interpersonal relationships is therefore inherently activist and political, as these relationships involve reconstructing society at the local level (Askins, 2015). Cloke et al. (2017) in their research into food banks note how they can similarly serve as spaces for liminal encounter in which different social groups are brought together and new social relations can be built from the bottom-up. Similarly, Horton and Kraftl (2009a) during their research at a Sure Start Centre in the East Midlands, identify what they term ‘implicit activism’. They make the compelling argument that political action can be found in small acts and kind words. These practices Horton and Kraftl (2009a: 15) argue, are often overlooked or disregarded as far as conventional conceptualisations of political activism, nevertheless: ‘affective bonds and acts ultimately constituted political activism and commitment, albeit of a kind which seeks to proceed […] with “not too much fuss”’. Similarly, Hall (2018: 247) draws upon how small acts of acknowledgement such as a nod, a smile, short conversation or a few words of encouragement can all be a means of 'building relationality [and] a politics of togetherness' during austerity. Jupp (2017: 353) in a similar sentiment, also highlights acts ‘based on relationships and community building at a macro, everyday level of the home and household, consisting, for example, of sharing childcare arrangements and organising meals together’. Andres and Round (2015) postulate that such acts can be understood as forms of ‘persistent resilience’, whereby individuals and households find new informal ways of coping with diminished incomes, along with the reduction and withdrawal of social welfare and public services. This might be through the formation of support networks, the sharing of caregiving responsibilities or knowledge (e.g. informing others about jobs and discounts at supermarkets) (Andres and Round, 2015). Within this thesis, I will critically interrogate the differentiation between acts of resilience and resistance.

Pain (2014b) perhaps in a somewhat different approach to the above scholars, draws upon the notion of ‘quiet politics’ in her research into activism and acts of resistance amongst victims of domestic violence. Here, Pain (2014b) uses the notion of ‘quiet politics’ to argue that resistance can involve individual acts, moments and interventions, which albeit small and quiet can be hugely instrumental in bringing about wider change. These may include attempts to physically fight back, cope with or minimise the effects of abuse.

Activism need not only be about social change but about momentarily enacting an alternative way of being and ensuring self-preservation during times of hardship. Wilkinson and Ortega-Alcázar (2019) for example, draw upon yet another form of quiet activism in their study of young single people across England and Wales who are in housing need. They note how young people in their study enacted moments of weary withdrawal as a means of coping and self-preservation. Rather than participants’ weariness being seen as a form of apathy, Wilkinson and Ortega-Alcázar (2019) argue that it may be better understood as a form of ‘slow resistance’ against the violence and everyday endurance of welfare reforms, which can lead to a state of fatigue, debilitation and exhaustion (see Goodley et al., 2014; Hitchen, 2016; Moffatt et al., 2015; Shildrick, 2015). They suggest that ‘slow violence is often met with slow resistance: a form of politics that is not spectacular or public, but instead often hidden, gradual and difficult to detect’ (Wilkinson and Ortega-Alcázar, 2019: 157). Weariness served as a means through which individuals could cope and survive. Their research, therefore, highlights a quieter politics and activism, evident in solitary survival. This is seen as being of particular relevance to my study, with many disabled people finding themselves in states of chronic exhaustion, continuously having to justify and fight for access to essential support. At times, the most fulfilling thing to do might be to step back and withdraw, but for some, the risks are for too high.

The aforementioned examples of ‘quiet activism’ (i.e. forming support groups, community solidarity initiatives, engaging in everyday acts of kindness or withdrawal practices), have all at times been overlooked as constituting solely that of resilience practices. Resilience has become ingrained into state policy as a neoliberal discourse which proclaims that despite economic insecurity: households, communities and localities will ‘cope’ because of their presumed resilience (Levitas, 2012; Slater, 2014). Resilience has therefore frequently been critiqued as perpetuating the status quo, as both supporting and strengthening neoliberalism and as lacking transformative potential (MacKinnon and Derickson, 2012; Mould, 2018a). Resilience according to Bracke (2016) impairs the ability to resist, through preventing individuals from imagining an alternative (i.e. beyond that of neoliberalism). Resilience appears to absorb potential transformation in the hope of going back to the same (ibid 2016). Bracke (2016) argues that resilience must therefore be resisted and rejected.

DeVerteuil and Golubchikov (2016) however argue for a move away from this critique of resilience, towards a *critical* resilience, where resilience is envisioned as having the potential to maintain previous and alternative practices, which may counter neoliberalism. DeVerteuil and Golubchikov (2016) note the potential for resilience to be deployed in a more positive way, ‘as an organizing principle… to challenge the status quo and to design and shape alternative futures’ (Brown, 2014: 113). Take also, for instance, Arampatzi's (2017) research into the development of ‘urban solidarity spaces’ in Greece, which comprise of community-cooking collectives, social centres, time banks, work cooperatives and health structures that seek to counter the effects of the economic crisis at the everyday life level. Solidarity initiatives employ survival tactics through addressing the lack of access to basic daily requirements such as food, clothing, electricity and healthcare; while also serving as places where alternatives to austerity may arise, for example through social/solidarity economy and cooperativism (Rakopoulos, 2014a, b). Such initiatives have been thought to be empowering vis-a-vis austerity, as a bottom-up politics which contest top-down charitable practices through providing a space where one can both give and receive support (Featherstone et al., 2012). Arampatzi (2017) therefore in a similar respect to other scholars researching instances of ‘quiet activism’ (Askins, 2014, 2015; Jupp, 2017; Pain, 2014b; Wilkinson and Ortega-Alcázar, 2019), notes how such practices can both support people in ‘getting by’ but also move beyond this by enabling social transformation to emerge from the bottom-up.

Resilience may therefore not simply entail ‘bouncing back’ to a previously stable position but rather provide an opportunity to express an alternative status quo (Raco and Street, 2012). DeVerteuil and Golubchikov (2016) argue that scholars such as Slater (2014) have been too quick in pitching resistance against resilience, as they invariably operate in tandem, chronological sequence or can at times be temporarily co-constitutive. Thus, resilience may be envisioned as ‘less about bouncing back’ and more about attaining a future (Andres and Round, 2015: 678).

The strategies and approaches mentioned above may therefore be seen as co-constituting both those of resilience and resistance. With the focus of my research being on how disabled people have sought to both resist and get by under austerity, many of the above forms of ‘quiet activism’ are likely to highly resonate with the personal accounts of participants. Furthermore, many of the above forms of ‘quiet activism’ open up spaces that are inclusive of disabled people (and the disabled body), which are not reliant upon individuals engaging in energy-intensive, public, vocal and antagonistic forms of action.

I will now turn to look at some different alternative forms and temporalities of activism, firstly online activism, followed by art-activism. Both online and art-activism have served as hugely valuable platforms through which disabled people have sought to speak out about the realities of their lives under austerity.

3.8 Online activism

Over the past few decades, the internet and social media have presented themselves as new arenas for activism and political activity. Social media has been (and continues to be) used to inform, mobilise and cultivate social movements, urban riots and national revolutions (Axford, 2011; Baker, 2012; Zhang and Nyíri, 2014). It has also been used to counter scientific and political doctrine and to set political agendas, as a medium that is hard to censor and control. Not only this but social media has the capacity to respond to global events in real-time and can help to expand their influence and reach (Kitchin et al., 2013). It may therefore be said that this new news outlet which is reliant on an ever increasing network of voices, is fast replacing that of the isolated, hierarchical mainstream media (Berkowitz, 2009), potentially enabling a wider array of voices and opinions to be aired.

Merrin (2009) has perceived social media as offering an opportunity for the 'non-elite' and oppressed social groups to gain visibility in the public realm. In line with this perception, Pearson and Trevisan (2015) have sought to evaluate the potential of social media as a new arena for disability activism (see also Ellis et al., 2015; Trevisan, 2017b, 2018). Austerity appears to have been accompanied by a resurgence in disability activism, enacted through increased social media participation (Pearson and Trevisan, 2015). The disability blogger Sue Marsh (who has written blogs for the online 'Broken of Britain' campaign, 'We are Spartacus' and for her personal blog 'A Diary of a Benefit Scrounger') has termed this engagement with social media as 'from bed activism' (Butler, 2012); providing disabled people with the opportunity to acquire a political voice without having to leave their homes or even their beds. One of the most successful online disability campaigns to date has been the 'We are Spartacus' campaign which gathered a substantial online following (including celebrity endorsements) during 2012. The campaign was also recognised by policy-makers, who invited the founders to a series of meetings in parliament (Pearson and Trevisan, 2015). The 'We are Spartacus' campaign was the first of its kind, actively encouraging disabled people to share their experiences to foster a sense of commonality, mobilise the disability community into action and gain widespread media attention (see Trevisan, 2017a). The Broken of Britain campaign later adopted a similar approach, launching Twitter hashtags such as #TwitterStories, which were intended to build a sense of commonality along with capturing the attention of politicians and the media. While several groups have argued against the use of personal stories as a campaign tool on the basis that their focus on the individual may further disabled people's victimisation (Barnett and Hammond, 1999; Doddington et al., 1994), the practice has become of increasing importance as part of recent anti-austerity activism.

Pearson and Trevisan (2015) make the argument that online disability activism provides individuals with an outlet through which to counter government policy, public opinion and stereotypes of disability (Goggin and Noonan, 2007; Thoreau, 2006). This is deemed particularly important at a time when austerity has been accompanied by an increasingly hostile news media which has largely portrayed disabled people as ‘skivers’, ‘shirkers’ or ‘welfare cheats’ (Briant et al., 2013). Social media may therefore play a critical role in providing disabled people with the opportunity to influence and challenge traditional news media debates and to articulate their own lived experiences.

Discussion forums, blogs and online support communities serve to increase relationships for disabled users, reduce isolation and enable individuals to connect without the need for organisations (Anderberg and Jönsson, 2005; Lewthwaite, 2014; Manzoor and Vimarlund, 2018; Pearson and Trevisan, 2015; Wright and Bell, 2003). Online platforms may facilitate the development of informal support structures, increase independence, emotional wellbeing and quality of life amongst many disabled users (Wright and Bell, 2003). In addition to this and of particular relevance to this research, is the potential online platforms have in politically mobilising people. In a similar respect to Hamisch’s (1970) aforementioned scholarship on feminist consciousness-raising, the sharing of personal stories between disabled people can enable individuals to find others in similar situations. It can also allow individuals to see that the issues they face are a result of wider societal structures of abandonment and violence, and so they no longer need struggle alone.

It is, however, worth noting that alongside some of these more utopian aspects of social media, there has also been growing concern around the surveillance of online platforms, with the boundary between the public and private increasingly becoming blurred. As a result, 'utterances previously expressed offhandedly [are] now released into a public domain where they can have far reaching and lasting effects' (Van Dijck, 2013: 12). Van Dijck (2013: 17) notes how ‘casual speech acts’ online can become transformed into ‘formalised inscriptions’, which can have incredibly damaging consequences to the lives of individuals. With online platforms increasingly being monitored by government departments such as the Department for Work and Pensions (DWP), as a means to call out and identify instances of fraud, the notion of public and private space, as well as public and private selves, appears to have significantly transformed in the context of the ‘roll out’ of neoliberal management schemes, occurring alongside austerity (DeVerteuil and Wilton, 2009; Peck and Tickell, 2002). Burke and Crow (2017) suggest that receiving welfare is dependent on parting with rights to self-determination and privacy. So while social media may be a clear space of political solidarity, it can also have some highly dystopian elements.

Furthermore, research by Goggin and Newall (2003) and Ellis and Kent (2011) has highlighted how people with certain disabilities (e.g. visual impairments and cognitive impairments) may be prohibited from participating in social media (and consequently online activism) due to the often inaccessibility of such platforms, thus re-inscribing disabled people's social marginalisation, with social and digital exclusion coinciding. The 2019 Oxford Internet Survey (an ongoing survey of internet use in Britain) revealed stark inequalities in internet access with 38% of disabled people reporting being non-users, compared with 12% of those who do not report any disability. With advances to technology and the implementation of new EU digital accessibility legislation (see Lewthwaite and James, 2020), it is likely however that this divide will subside. Survey research has also revealed that disabled people's internet usage is heavily weighted towards younger generations, even more so than that of the general population (Williams et al., 2008). While inequalities in internet access remain (Dutton and Blank, 2013), the internet has arguably improved quality of life and helped to promote greater social and political participation among many disabled users (Johnson and Moxon, 1998; Polat, 2005).

Scholars such as Gremigini (2016) have however been critical of the potential of online platforms as an avenue for activism or what Trevisan (2013) refers to as 'armchair army' tactics. While social media is often approached as a free and unrestricted platform, the invisible infrastructures that regulate and govern communication are often overlooked (Gremigini, 2016; Zhang and Nyíri, 2014). This process is commonly referred to as a 'filter bubble' (a term coined by the internet activist Eli Pariser in 2011), with the term being used to highlight the invisible censorships, which are based on algorithms. Gremigini (2016) argues that the internet is fast transforming into a 'filter bubble', whereby free will is a false belief. This process appears to make activism particularly futile as it becomes hard for users to come across people or information that differs from their point of view. Gremigini (2016) also notes the potential for online activism to promote a form of passive political engagement, whereby internet users simply become observers and readers involved in signing petitions. The expression of participation through a 'like' on Facebook, is according to Gremigini (2016) fast becoming a meaningless act, which satisfies politicians by being solely an online platform and appears to prevent or free citizens from the responsibility to engage in 'real life' direct political action. Gremigini (2016) concludes by noting that we must be careful in stating social media's potential as a means for igniting social action. However, I would argue here that for some disabled political actors, social media may be one of the only few platforms accessible to them, and we should not be upholding 'real life' political action as the only valid form of activism. Political change and political activism can take place in myriad forms across multiple spaces.

The above section has sought to consider the potential of online media as an effective campaigning tool for disability activists. It also raises the question of how online activism might disrupt normative understandings of activism and what it means to be an activist. In comparison to other forms of activism, online activism is relatively quick to enact, requires minimal resources and is fairly inclusive due to it not requiring people to engage in bodily action or leave their homes.

The following section will turn its attention to art activism, highlighting how activism can operate at varying speeds and temporalities.

3.9 Art activism

While the previous sections have looked at the different forms and spaces of activism, I am also interested in engaging with literature on the different temporalities of activism, including the varying speeds and tempos through which social change is enacted. While the previous section explored the role of online activism, as a fast-moving platform through which individuals can quickly convey a political message with relative ease to a wide audience, this section will turn to an arena, that has the potential to bring about a much slower form of activism and social change.

There appears to be resistance towards slowness in activism with the ideal activist conventionally being conceived as a mobile person (most likely that of a non-disabled male) who can devote themselves and their lives to direct action (Coleman and Bassi, 2011; Harvey, 2012). Activism is often associated with notions of haste and urgency, leaving little room for the recognition of acts that may bring about slower and more gradual social change (Tostar, 2016).

One of the key ways in which we can think of activism as operating at a different speed is through that of art activism. The visual and performing arts have become increasingly popular mediums for disability activism in recent years (Hadley, 2019). However, the literature on disability art activism remains to be very limited. Hadley (2011, 2017, 2019) has provided an analysis of news coverage and social media commentary on art activism. Meanwhile, other scholars have provided individual reflexivity on their own art activist practice (see Burke and Crow, 2017; Crow, 2014). Notable disability art-activism includes that of disabled artist Liz Crow (2013), who has created several installations and performances in response to austerity and its adverse impacts on disabled people. Crow has been the founder and creative director of Roaring Girl Productions since 1999. Her most well-known work includes that of the 2012-13 touring performance ‘Bedding Out’. Created and performed by Liz, ‘Bedding Out’ was a live durational performance piece that took place across 48 hours. The performance was broadcast live over social media, with Liz laid in her bed in the middle of the performance space, in an attempt to highlight the usually hidden and invisible parts of her life. In doing this, she hoped to highlight the complexity of her lived experience as a disabled woman, along with how her impairment affects her daily life in ways which reach beyond that which is publicly visible. The public were encouraged to engage in ‘Bedside Conversations’ about the artwork, its backdrop and politics. The main aim of the project was to challenge the rationale behind austerity and benefit cuts, along with the ever-apparent rhetoric of benefit scroungers and cheats (Burke and Crow, 2017).

Tostar (2016: n.p) argues that ‘art causes something that no headline can do: it causes participants to spend time slowing down and forming ambivalent, open-ended opinions’. Instead of being presented with a clear message such as through protest and online activism, viewers are often not led to one clear conclusion but perhaps multiple. Yet, Tostar (2016) argues that this does not make it of any less significance; a lot of artwork may leave observers with questions, which might lead to conclusions that are much greater and deeper than that of other forms of activism. Heim (2003) notes how some artworks continue to have an impact far beyond the actual event, passing slowly from person to person through the stories, which are told about them (Brugera, 2011).

Another notable contemporary disability activist whose artwork focusses on the impact of austerity is that of Kaliya Franklin. Kaliya who blogs as both ‘Bendy Girl’ and ‘Benefit-Scrounging Scum’, produced a photo in March 2011 entitled ‘Left Out in the Cold’ which received widespread circulation. The photograph is a nude self-portrait of Kaliya, who is laid alongside her wheelchair on a desolate beach on a cold winter’s day. Her arms are out in front of her, as though she is reaching for the chair and her face is head down in the sand (McRuer, 2018). As quoted in McRuer (2018: 126) Franklin expresses that the image was meant to reflect the way in which ‘sick and disabled people are often left voiceless in society’. The photograph was produced as part of the ‘Broken of Britain’ campaign.

Figure 1: 'Left Out in the Cold' by Kaliya Franklin. Source: http://discodisabilityconversations.blogspot.com/2011/03/left-out-in-cold.html

McRuer (2018) argues that Kalyia's photographic self-portrait could conjure up the figuration of disabled people as akin to waste or drifted accumulation in an age of austerity, as she appeared in the photo to be broken down or crushed (think for example, of the terminology of the 'Broken of Britain' campaign), little more than debris washed up on a cold and desolate beach.

Art activism may not bring about immediate change nor always hold as clear-cut or obvious message as other forms of activism. Nevertheless, its 'slowness' often allows people space and time to ask questions, unpack meaning and decipher their own opinions.

3.10 Conclusion

Until relatively recently, geographical and social movement literature on activism and political action has predominantly been orientated around large, vocal and 'spectacular' acts of resistance undertaken in the public sphere by a collective body of privileged, male, able-bodied and mobile political actors. Activism has conventionally been distanced from notions of vulnerability, with an 'activist' conceptualised as an all-powerful, confident, militaristic, typically male figure. The experiences of disabled people as both activists and political actors have therefore been largely overlooked and obscured from this literature. The thesis will seek to partly fill this gap, by drawing upon the role of disabled people as both activists and political actors, who often draw upon their disabled bodies as a vehicle within their activism and protest. Moreover, my research will also examine how the disabled body inevitably shapes the nature of individual activism along with that of the wider collective body. Further, it reminds those working on the collective body to recognise the importance of the individual body.

This critical appraisal of the literature has also sought to highlight some of the emerging literature around slow, quiet and quotidian forms of activism, which have gradually sought to broaden understandings of what it means to be an activist and engage in activism. While some of these practices such as the establishing of solidarity networks, time banks and cooking/care collectives, could be seen as forms of resilience or ‘survival strategies’, they also have the potential to bring about spaces through which individuals can construct alternative social relations and lifeworlds, beyond that envisioned by neoliberalism and austerity. This synthesis has therefore sought to consider whether resilience in this capacity should be envisioned as an active moderation of social relations that can enable individuals to keep-on-going under austerity, as opposed to being purely a state of passivity.

This thesis seeks to enhance existing research in this area by highlighting disability activists’ engagement in the visual and performance arts, online activism and mutual aid as equally valuable avenues for political action. Such arenas for political action have become of increasing importance at a time when traditional spaces of activism (such as that of the street or square) are becoming increasingly regulated and closed down (Harvey, 2013; Mitchell, 2013). Alongside this, disabled people are increasingly finding themselves unable to participate in vocal, visible and antagonistic forms of direct action due to lack of financial resources brought about as a direct result of austerity, or a fear of repercussion, due to the roll-out of neoliberal management schemes (DeVerteuil and Wilton, 2009).

Equal recognition will be given in this thesis to the wide array of different forms of activism occurring across the public, liminal and private domains. The thesis will explore the potential of each of these platforms and spaces as valuable avenues through which disabled people may seek to voice their opinions and discontent surrounding austerity, along with engendering wider social change.

Chapter 4 Methodology

4.1 Introduction

The following chapter outlines the philosophy that underpins the overall methodological approach of the study, before moving on to discuss the individual data collection methods and their accompanying ethical considerations. In brief, the methodology comprised of 27 biographical interviews with disabled people who to varying extents self-identify as activists or who have been defined as such by others working within their field, along with participant observation at 13 disability activist gatherings and events. The research has largely been motivated and informed by my personal experience as a disabled person living in austerity Britain. Within this research, I position myself as an academic activist (Routledge, 1996), an individual with a longstanding personal engagement and commitment to the issue under study. This commitment is not confined solely to the research but also runs alongside it, underpinning and influencing my everyday activity. Goodley and Moore (2000) note how academic-activist disability researchers have a dual responsibility to produce research, which is both of value to the academy and to disabled people (including their political movements).

4.2 Research questions

The research has sought to critically interrogate four key research questions:

1. What forms and spaces of disability activism are emerging and adapting in the context of austerity?

2. What does activism mean to disabled people who seek to create spaces that challenge and transform the status quo?

3. What motivating factors and experiences have encouraged individuals to become involved in disability activism?

4. How might more personal or private forms and spaces of activism begin to challenge what critical human geographers traditionally perceive as ‘activism’?

4.3 Methodological framework

In order to explore disabled individuals' experiences of activism, a qualitative approach was adopted for this research. The decision was made on the basis that underpinning my research is the ontological perspective that social 'reality' is constructed from people's knowledges, emotions, attitudes and experiences (Gray, 2009). Qualitative research acknowledges that the complexity and messiness of lives cannot be reduced to a simple cause and effect relationship (Patton, 1990).

My epistemological position is based upon interpretivist approaches, which draw on the principles of constructivism, whereby 'access to reality (given or socially constructed) is [thought to be obtainable] only through social constructions such as language, consciousness, shared meanings, and instruments' (Myers, 2008: 38). An interpretivist epistemology supposes that meaningful data about social experiences can only be acquired through people discussing their experiences and sharing their views (Gray, 2009). Interpretivism has been critiqued in terms of its scientific validity and usefulness, being disregarded by some scholars as merely constituting 'storytelling' (Wight-Felske, 1994). Scholars have also critiqued the approach for producing subjective interpretations of the social world (Mack, 2010). However, such critiques overlook the value of individual narratives in establishing 'new knowledge' (Thomas, 1999: 78) and in gaining a more detailed insight into the intricacies and nuances of individuals' experiences.

4.4 Research design

A qualitative, mixed-methods approach was taken towards this research (Bryman, 2012), which consisted of biographical interviews with disabled people (engaged in a diversity of different forms of activism) and participant observation at various public activist gatherings, meetings and events. Together, these methods enabled a greater understanding of the reasons behind why individuals became involved in activism and the various forms of resistance they were engaging in. Biographical interviews provided participants with the opportunity to articulate their experiences in detail and were particularly in-keeping with the research's ontological and epistemological stance, as they place a greater focus upon the participant's individual understandings, interpretations and experiences of engaging in activism (Milligan et al., 2011; Svašek and Domecka, 2012). This viewpoint is also in-keeping with the Mad Movement and some actors in the Disabled People's Movement, who have argued that reality is not tangible but rather made by the individual (Emerick, 1996; Lewis, 2012; Russo and Beresford, 2015). Participant observation was also used to supplement and contextualise data attained from interviews. This method helped gain a greater understanding of what it was like to participate in such activist spaces and practices. While traditional forms of observation mirror a more positivist approach (Baker, 2006) seeing the social world as existing externally to the researcher, participant observation supposes that the researcher can only understand the meanings behind the behaviours they observe, by actively participating in the activities which they are observing (Jorgensen, 2015). The researcher’s own experiences and feelings while engaging in events, therefore becomes a valid form of knowledge production.

4.4.1 Sampling and selection

With regards to the biographical interviews, a type of purposive, non-probability sampling was used, with individuals being chosen to reflect a group within the wider population (Bryman, 2012). For the purposes of this research, this consisted of individuals who self-identified as disabled and had experience of engaging in disability activism, campaigning or resistance activities. While I respect that there are a range of different embodiments of disability, this was not something, which I intentionally brought up when recruiting participants or during the interview process itself, it was instead only reflected upon in so far as participants themselves wanted to discuss them.

The original research proposal consisted of two discrete parts. Interviews were first to be undertaken with 6 'key informants' (e.g. board members or champions of various disability trade unions, organisations and campaign groups well known for their disability activism) and then later with the wider disability activist community. The majority of 'key informants' were selected from the Disability News Service's List of Influence (see https://www.disabilitynewsservice.com/the-list/). These interviews were particularly helpful in providing me with an initial background and insight into the emergence and development of the disability activist community. They also allowed me to revise and reshape my research questions where necessary. However, it later became apparent that the labelling of these individuals as 'key informants' was inappropriate, as every participant could indeed be understood as a key informant in their own right - as experts in their own lives and personal experiences. Differentiating between the two, therefore, became somewhat superficial. These initial interviews with 'key informants' may as a consequence, have been better understood as interviews with 'leading figures within the disability movement'.

Following these initial interviews, a wider call for participants was disseminated online through various social media channels (including Facebook and Twitter), via my own personal networks and Disabled People's Organisations including Disabled People Against Cuts (DPAC), Spectrum (a Hampshire based user-led organisation) and Inclusion London (a pan-London disability equality organisation). Research recruitment posters were also distributed at various disability activist events, and given to participants at the end of each interview to prompt snowball sampling. Equal efforts were however made to recruit individuals not involved in the more public forms of protest, this was achieved through extensive research - locating active disability bloggers, artists, writers and those involved in online advocacy groups and so forth, while also leveraging my own personal networks. When asking participants about how they came to find out about the research, many expressed having heard about it through word of mouth. It is therefore likely that a large number of participants were recruited through a form of snowball sampling (Bryman, 2012) with individuals sharing their knowledge of the project with others in their networks. Despite extensive efforts to recruit participants engaged in a variety of different forms of disability activism, the sample appeared to be somewhat unintentionally skewed towards those engaged in protest/direct forms of action. This was likely a result of two members of the disability protest group (DPAC), accounting for a large number of these referrals. Additionally, despite extensive scoping research and persistent efforts to recruit informants involved in a variety of different forms of resistance, those engaged in the more public forms of protest, were much more likely to respond and put themselves forward. Due to the limited time and resources available to recruit participants, it was necessary to engage with whoever came forward. However, I felt comfortable that the final sample was sufficient enough to demonstrate and unpack the diversity of disability activists’ experiences.

My original intention was to restrict the study to a comparatively narrow range of disabilities and geographic locations, only including those with physical and sensory disabilities in Wales and the South of England. However, through my research, it soon became apparent that individuals often have multiple disabilities, which transect a variety of different disability categories (cognitive, mobility, sensory etc). I also did not want participants to feel as though they had to explain their impairment to me, particularly with the Disabled People's Movement traditionally distancing itself from notions of impairment and instead emphasising a shared experience of disablement. I decided consequently, that any person who self-identified as disabled and who took part in some form of disability activism, would be included within this study sample. Additionally, with individuals finding out about the study and expressing an interest from outside the original geographical parameter, I was reluctant to turn them away - particularly when one's geographical location was found to be a significant factor in dictating an individuals' choice/ability to engage in activism. With additional funding provided by the Royal Geographical Society[8], I was fortunate to be able to travel across England and Wales to conduct these

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[8] In 2017, I received £2,000 through the Albert Reckitt Postgraduate Award from the Royal Geographical Society.

interviews. Despite this additional funding, due to the cost of UK public transport, the decision was made to conduct interviews with participants in Scotland via phone or Skype.

While the research does not claim to be representative, efforts were made to engage participants from a variety of backgrounds, age groups (ranging from 24-72 years old), genders (17 women, 10 men), sexualities, religious beliefs, geographical locations (across England, Scotland and Wales) and disabilities (sensory, physical, psychological and learning disabilities). Efforts were also made to recruit participants with experience in a variety of different forms of activism (e.g. direct action, protest, blogging, research, the arts etc). I also interviewed people who practised their 'resistance' within the 'system' including a House of Lords peer and four individuals working on government advisory committees.

It should however be noted that despite efforts to engage individuals from Black and minority ethnic backgrounds (with individuals being identified and contacted directly), all eventual participants were indeed white British/Irish. Further research would be valuable in exploring the unique experiences of Black and minority ethnic disability activists (of which little has been done to date). Black and minority ethnic communities have traditionally been silenced and side-lined from within the Disabled People's Movement, which has predominantly focussed upon the voices and concerns of white, male, Western, disabled, heterosexual individuals. Even recently, at a national disability activist conference I attended in November 2017, a dispute broke out amongst members of the audience due to the failure of the organising committee to consider or engage with the voices of black and minority ethnic communities. A detailed table of participants' profiles is provided in Appendix A.

4.4.2 Biographical interviews

Twenty-seven biographical interviews were conducted for the purposes of this research with disabled people from across the United Kingdom of varying age groups and backgrounds. Initial interviews took place over 9 months between July 2017 – March 2018, with the occasional follow-up interview for points of clarification taking place between August 2018 – November 2018. Biographical interviews have been recognised as a valuable research tool across many subsections of geography, including but not limited to the geographies of gender, sexuality, family, migration, care, disability, health and activism (Milligan et al., 2011; Svašek and Domecka, 2012). They provide a way of shedding light on hidden or 'silenced' lives (Goodson, 2001) and have the potential to empower and/or give voice to marginalised groups, by placing individuals as experts in their own experiences. A central concern of biographical interviews is the formation and transformation of the life across time and space; exploring how personal and embodied experiences may have been shaped by the places and landscapes in which they are embedded. Biographical interviews as self-narrated and reflective accounts of individuals' lives, enable the analysis of multiple and interwoven life experiences, which cumulatively contribute to who an individual is today (Milligan et al., 2011). Atkinson (1998: 20) postulates that:

> [I]n the telling of a life story, we get a good sense of how and why the various parts of life are connected and what gives the person meaning in life. There may be no better way to answer the question of how people get from where they began to where they are now in life than through their life stories.

Biographical interviews were used for the purposes of this research to uncover the life stories of disability activists, highlighting the roots of individuals' advocacy along with their personal experiences of encountering and resisting austerity (Chamberlayne et al., 2002; Milligan et al., 2011). Biographical interviews enable a space for deep reflection, focussing specifically on the life course as an arena for analysis and highlighting the 'messiness' and contradictions of everyday life.

Feminist researchers have been supportive of biographical methods for their effectiveness in dismantling some of the conventional power relations between the researcher and interviewee (Goodson, 2001), providing the interviewee with the opportunity to both lead and direct the interview (Milligan et al., 2011). Within biographical interviews, the interviewer is cast as a facilitator, a prompter and an empathiser, instead of a questioner (Milligan et al., 2011). Interviewees are encouraged to speak openly and freely about their life histories with little prompting from the interviewer (except occasional words of encouragement and affirmation). Unlike conventional interviews, the biographical interview allows people the time to prepare, with all participants being briefed on the content of the interview beforehand. Biographical interviews, therefore, do not put people as much on the spot (or leave them in the dark) but rather reduce the power dynamics by moving power away from the researcher and placing it with the participant, who may play an active role in influencing the direction of the research (Milligan et al., 2011). It should however be recognised that biographical interviews provide a partial, selective and performative commentary on lived experience (Mazzei and Jackson, 2009; Riessman, 1993; Svašek and Domecka, 2012). However, as this research is interested in how individuals narrate their own life stories (rather than the 'real story') this is not a concern. Factors such as time and place along with the identity or persona of the interviewer, may also greatly influence the nature of stories, with individuals narrating their life stories differently under various circumstances (Milligan et al., 2011).

There are however limitations to biographical interviews, for example, some interviewees may find it easier than others to talk freely about their histories, perhaps due to having previous experience of similar counselling practices or due to other factors such as greater rapport between the interviewer and interviewee due to a shared social characteristic (e.g. gender, nationality, ethnicity) or life experience (Svašek and Domecka, 2012). To circumvent such effects, efforts must be made to put interviewees at ease throughout the research process, through for example asking them to choose the time and location of their interview and adopting a flexible approach, adapting the method where necessary, to ensure participants' full participation.

The majority of interviews were conducted face-to-face and at a variety of locations including participants’ homes, workspaces or coffee shops. The location of each face-to-face interview was decided upon by the participant, to ensure that they felt comfortable and at ease in their surroundings and were able to participate fully (Richards, 2010; Stone and Priestley, 1996). This was particularly demonstrated when I interviewed one participant at a café of his choosing. The smells in the café on this day were said to be triggering his mental health/schizophrenia, it was therefore important that we moved outside in order for him to be able to fully engage and participate in the interview. Ensuring the comfort and full inclusion of participants was deemed to be the highest priority.

When meeting in a coffee shop or café, I would always buy participants a beverage. I saw this as a small gesture, which helped to show participants that I valued their time and had a genuine interest in what they had to say. Similarly, when interviewing participants at other settings (e.g. at their homes, workplaces), I would generally bring along a cake/sweet as a way of thanking individuals for their time, input and hospitality.

Due to the nature of biographical narrative interviews, the length of each interview varied greatly, with the average interview taking approximately 90 minutes. However, due to the open-ended nature of this interview method, many were significantly longer, with some taking up to 2.5 hours. All interviews were recorded through the use of a dictaphone. The dictaphone proved particularly helpful as a prop, helping to indicate to participants when they were in the research context and when they were not.

Where a face-to-face interview was not possible due to ill health or other personal reasons, interviews took place online or over the phone. It should however be recognised that conducting interviews via the telephone or through using online communication software such as Skype does not come without its own difficulties. For example, when using Skype, there were a number of occasions where the internet connection dropped out or voices became muffled and unclear. Additionally, communicating with participants through the telephone or Skype can hinder the process of building rapport and trust. Communicating through these mediums may have prevented me from picking up on any nuanced cues, which might be visible only through facial expressions or body language. Body language and facial expressions have the potential to completely transform the meaning behind what an individual is saying.

The biographical interviews were structured loosely as a biography, beginning with questions about an individual's past, before moving to their current situation and future plans. The interview aimed to illuminate the roots of an individuals' advocacy, their ongoing engagement in disability activism and their future hopes/aspirations. While it is understood that conventional biographical interviews involve the interviewee freely-narrating their story with no interruption from the researcher (as is seen in Schütze (2003) biographical narrative interview method), the decision was made to alter this approach slightly after participants expressed feeling some unease and discomfort at the lack of interview structure. It was also found that interviewees often left various issues unaddressed, which were of particular interest to the research i.e. details about the particular spaces in which their activism took place. An interview schedule was therefore developed and drawn upon when necessary. Rather than referring to each question directly, the 'guide' was used solely as ques and triggers for myself, in order to ensure that the interview flowed naturally and to direct participants (when necessary) in explaining their experiences. The interview guide was revised continuously throughout the research process and altered for every interview, depending on an individual's experiences (i.e. the forms of activism that they had been involved in) and their background.

Biographical interviews were deemed to be a relatively inclusive method due to their open-ended nature (i.e. limited structure), allowing for participants to articulate their histories in whatever way they deemed fit or were able. For some, this meant following a strict chronological order of events, while for others, their narratives were freer, drawing backwards and forwards in time. Some individuals found it helpful to use photographs, newspaper articles or a list of pre-written bullet points as points of reference (such instruments were suggested to participants in advance of their interviews), while others were happy speaking freely without the use of prompts to jog their memories.

Several participants commented upon how much they enjoyed the interview process and how nice it was to have someone genuinely interested in their lives. I was surprised by how many times I heard the phrases, 'I've never been asked before', 'I hope I'm not wasting your time' or 'I'm sure that there are much more interesting people than me'. Many deemed their personal life stories to be mundane, uneventful or insignificant, and so my genuine interest in the intricacies and nuances of their lives was often somewhat of a surprise to them. For some, this was hugely gratifying, giving individuals a sense of both pride and joy that someone was genuinely interested in their lives, regardless of how insignificant or uneventful they deemed their own lives to be. The research process may therefore not necessarily have brought about large-scale transformation, but rather, small everyday acts of recognition, with some participants, leaving the interview feeling valued; the potential of such acts should not be underestimated.

4.4.3 Participant observation

Participant observation was undertaken in order to supplement the biographical interviews and to gain a greater understanding of the different forms of activism participants were engaged in. It felt important to me that I engaged in various forms of disability activism, experiencing what it was like to be engaged in activism through e.g. the arts, writing, committees and protest, before beginning to conceptualise participants' accounts. Participant observation can enable a greater understanding of how these spaces are 'experienced and understood in the everyday lives of people who 'live them out'' (Crang and Cook, 2007: 1). Participant observation was conducted at a total of thirteen activist events between October 2016 – August 2019, including actions, gatherings and meetings where individuals were publicly engaging in forms of disability resistance and activism. This at times involved participating in street protests and demonstrations, leafleting, lobbying parliament, working on a series of art activist installations and attending both local and national disability activist meetings. These events were communicated to me through various organisations, which I had made contact with, along with interviewees and various social media channels.

Participant observation has been recognised as a valuable multi-disciplinary research method, through which to gain a greater understanding of a particular group of people or culture and their practices (DeLyser et al., 2011). Participant observation usually involves spending an extended period, actively involved with a community, engaged in their practices and their cultural environment. Field diaries are kept while in the 'field' with observations made about the experience of participating in the practices of a particular community. Observations may consist of sensory experiences (i.e. what is seen/heard/smelt) as well as the emotional and the embodied (i.e. what emotions are experienced within these spaces). This approach has however been critiqued for being essentialist (forming over-generalisations almost entirely from the researcher's personal interpretations) and non-participatory (not gaining the personal insights of those who are engaged in such communities, spaces or practices). To address some of these critiques, I sought to embed myself within these spaces, engaging with other disability activists and learning from these encounters. The process of reflecting upon some of these discussions and our shared experiences inevitably informed my thinking.

Along with keeping a field note diary, observations were also occasionally recorded verbally (and later transcribed), due to the difficulty in recording written observations when engaging in activity and/or highly energised environments (e.g. protests and direct actions). Photographs were also taken at these events and have served as a valuable resource in helping me to see what I did not see or could not quite make sense of in the moment (Lyon and Back, 2012). As a visually impaired researcher, photographs have been critical in helping me to capture the environments in which I am participating, in greater depth and detail. Some of these images have been used as a resource to supplement and enrich the data (see example photographs in Appendix B).

Both ethnography and observation have been recognised as an inherently ‘messy’ process (Harrowell et al., 2017) which is caught up with our subjectivities as researchers. When undertaking participant observation the researcher's positionality inevitably becomes caught up in/impacts upon our observations and interpretations (Atkinson and Hammersley, 1994). It was therefore important that I recognised my own partial and situated ‘subjectivity’ in regards to the methods and subsequent findings (Crang and Cook, 2007; Malkki and Cerwonka, 2007), making my positionality clear throughout my field note diary and the wider research process.

4.5 Theoretical engagement and influences

The research has been greatly influenced by the earlier work of feminist, emancipatory, participatory and inclusive disability scholars who have called for beneficial research that enables the self-emancipation of disabled people, while remaining vigilant and reflexive to the role of the researcher within the research process. This section examines each of these in turn, while also recognising the influence of activist scholars on the overall research design.

4.5.1 Reflexivity and feminist theory

As a disabled feminist researcher with a visual impairment, I did not approach this research with any degree of 'academic detachment'. Instead, I came to the research as someone who is both passionate and cares deeply about disability issues, not only because they impact upon me and my life but also because they impact on the lives of some of the people closest to me. The topic is as such personal and close to the bone.

Donna Haraway (1991), as a leading scholar in feminist theory, devised the epistemological concept of ‘situated knowledge’, whereby all knowledge is understood as being situated, embodied and partial. The knowledge of a researcher is always partial due to their positionality and perspective on the world (how it is viewed, understood and interpreted) being shaped by their unique combination of gender, sexuality, nationality, race, class and other identifiers, along with their location in both time and space (Haraway, 1991; Kina, 2012; Mullings, 1999: 337). We have a responsibility to reflect upon our positionality in our work and to consider how it may influence the conduct of our research, including the questions we ask and the eventual write-up (England, 1994: 87).

Influenced by feminist theory and Haraway’s (1991) notion of ‘situated knowledge’, this research does not claim to be objective, neutral, universal, exhaustive or the only knowledge possible (Rose, 1993). Instead, this research is seen as representing the voices of a small number of disability activists and is grounded within my own personal interpretations as a white, Welsh, disabled woman. Coffey (1999: 17) notes the importance of 'locating oneself' in regards to recognising the impact the researcher's identity has on the research setting. During interviews, for example, the researcher brings their own identity (Berger, 2015), preconceptions and reveals things about themselves, both verbally and non-verbally (Abell et al., 2006; Jordon, 2006). What is disclosed purposefully or unintentionally can greatly influence the responses elicited at interview. Reich (2013) notes how it is common for researchers to downplay or emphasise certain elements of their identity in order to build rapport and gain access (Mullings, 1999). There may however be certain visible factors and aspects of our identities that we cannot control or hide during interviews and research encounters (Goffman, 1956). Within this doctoral research project, participants expressed being able to share certain things with me as I was disabled but of being unable to share other experiences, due to my positionality as a woman. One male participant, for example, expressed how he had been a victim of sexual abuse while living in an institution but did not deem it appropriate to speak to me as ‘a young woman about it’, despite it having a significant influence on the course of his life (and indeed his activism). Likely, there were also other occasions where my positionality (consciously or unconsciously) influenced the nature of the interview, along with what participants felt able to talk to me about.

Reflexivity involves a process of continuous, critical self-dialogue and self-evaluation of the researcher’s positionality and its effects on the research process and outcomes (Berger, 2015). There are however limits to what is possible to access through reflexivity, as our understandings of what influences the process of meaning-making is only ever partial and may become clearer with the passing of time and distance (both emotional and intellectual) from a research project (Mauthner and Doucet, 2003).

4.5.2 Insider/outsider – critiquing the binary

As a visually impaired researcher interviewing other disabled people, I was granted (to some degree) the position of an ‘insider’ (Browne, 2003), as an individual who shared this mutual experience of ‘disablement’. The concept of the researcher as an ‘insider’ or ‘outsider’ along with its impact on the research process has been widely discussed within scholarship (see Daly, 1992; Mannay, 2010; Morris, 2015). Both supposed positions have their advantages and disadvantages. Outsiders may, for example, miss important factors due to a lack of knowledge or lived experience of the research topic (Berger, 2015). Whereas, insiders’ over-familiarity with the research area, may mean that they disregard mundane yet important features in the life stories and experiences of participants. Researchers may therefore have to find ways of making ‘the familiar strange’ (Mannay, 2010).

The binary categories of 'insider' and 'outsider', disabled and 'able' are however superficial and far too simplistic. People can be insiders in different ways e.g. through being a sibling or working in the field, as such, it cannot be seen as a binary. As Wolf (1996: 16) explains, ‘A number of feminist researchers reject this simplistic dichotomy of insider-outsider. Some feminists say they felt they were neither insider or outsider or both simultaneously’. I personally found myself occupying a space of between-ness or what Mascia-Lees et al. (1989:33) refer to as ‘a position that is neither inside nor outside’. While I may have been perceived as an ‘insider’ due to being registered as disabled and sharing several of the daily realities of being disabled in Western society, I was also simultaneously regarded as an ‘outsider’ due to my position (and privilege) as an academic researcher, who had both accessed and attained a high level of education (although it should be noted that some participants had attained similarly high levels of education). I also became aware during the research process of my tendency to distance myself from participants and the label of ‘disabled’. Despite being registered as visually impaired and consequently being ‘officially’ regarded as disabled, I have always found identifying as ‘disabled’ particularly difficult and uncomfortable (as may be the case for many participants). This might in part, be a result of having a disability which is relatively invisible to the everyday ‘passer-by’. Making my disability known can therefore raise personal concerns around whether people’s perceptions will change of me (i.e. in terms of who I am and my capabilities). Individuals like myself, often engage in the practice of ‘passing’ (Richards, 2010), otherwise known as concealment. This practice is often feasible due to the short nature of encounters and comes from a deep longing to be undifferentiated from non-disabled others.

It is important to recognise that identities are not static and that the 'boundary' between 'insider' and 'outsider' disabled and 'able' is inherently unstable, fluid and superficial (Barad, 2008; Haraway, 1988). Boundaries come into being through the very act of interaction between the researcher and research participants. Through being open about my disability (sharing some of my own experiences as a disabled woman), a greater sense of shared identity and rapport was developed with participants, leading to the development of more open and trusting relationships.

It would however be unrealistic to suggest that commonalities between the identities and/or associations of the researcher and research participants, inevitably lead to the development of research relationships (Mullings, 1999). Instead, it was necessary to spend time building rapport with participants, through being patient, carefully listening, and expressing an interest in them and their lives.

Our shared experience of living with a disability did appear to help create a sense of ease and comfort within interviews, with participants feeling as though they were talking to someone who would likely understand their experiences and not view them as ‘abnormal’ or of insignificance. It is possible that participants may also have greater trust in a disabled researcher to sensitively and accurately portray their lives and lived experiences, as one research participant, Alex recounted: ‘it’s important that *we* [as disabled people] are writing our own history, not anybody else’ (emphasis added).

A sense of shared identity does however have the potential to lead to some difficulties. The researcher might for example, wrongly presume that they know exactly what a respondent means as opposed to delving into further questioning. Similarly, disabled research participants often expect a degree of knowledge about disability-related issues from a disabled researcher. Participants may, therefore, not explain their experiences as fully, because they assume that the researcher understands what they are talking about, due to their knowledge and shared experience (Daly, 1992; Morris, 2015). Participants within this study often said things such as ‘you know what I mean’ or ‘you’ll get this’, assuming that I would undoubtedly understand their experiences and therefore further explanation was not required. It was incredibly important that I questioned and delved deeper into these explanations and asked participants to clarify what they meant, rather than simply assuming that I knew. Through making fewer assumptions, I felt as though I was able to explore the understandings and experiences of participants in much greater depth and detail.

The research also provided a voyage of self-discovery for me as a researcher, causing me to look at various aspect of my life and identity differently. Prior to this research, my disability and impairment had been something, which I had actively sought to overlook/pass over, paying little attention to it or its consequential impact on my life. During the research, however, my disability was often brought to the forefront, particularly when interviewing participants – I would always share my disability (when appropriate) with participants as a way of building rapport and understanding between them and myself. As I was interviewing participants partly about their experiences of disability, I felt that it was important that I be open about my own. The research moreover has prompted me to look differently at my disability, seeing it as an important aspect of my identity and as something, which has greatly influenced the shape of my life (both positively and at times negatively).

Throughout the course of the research, I became more comfortable in identifying as a disabled person and many activists became more comfortable with me and my presence. Those with whom I attended activist events began to see me more as a friend, fellow member and/or activist. I found myself receiving birthday, anniversary and graduation invitations along with numerous friend requests via social media platforms. While I was pleased to have been welcomed (largely) with open hands into these activist communities and the lives of some participants, this at times made it incredibly difficult to maintain a degree of professionalism and a boundary between me, my life as a 'researcher' and also as a 'fellow disabled person'/'disability activist'. This became particularly apparent when one participant said to me following a disability activist event: 'You know what, I don't believe you're doing research. I think you secretly just want to become one of us'. While this statement was meant light heartedly and brought about some amusement to both her and I, it also highlighted the need to continuously remind participants/fellow activists of my intentions behind attending such events.

Situating oneself as an academic activist, with a personal connection to the topic under study can bring about a number of complications. There is a tendency amongst geographers to recognise the 'field' as a temporary space, somewhere the researcher enters to obtain data and then exits at the end of the data collection process. However, what if the researcher can never really leave 'the field' as 'the field' is so deeply intertwined with their daily lives? Alongside this research, I have found myself supporting friends with their loss of disability benefits and services, as well as advising them on appeal procedures. The field' has therefore come to encompass not just a specific, partitioned site but has infiltrated itself into many aspects of my everyday life. Katz (1994: 67) has sought to recognise the artificiality of these distinctions by questioning where the boundaries lie: 'between "the field" and not, between the "scholar" and subject?'. On several occasions during this research journey, I have found myself lying awake late at night thinking and/or worrying about participants, their lives and current situations. When individuals divulge harrowing, unjust or painful experiences of hardship, it is not uncommon for these to linger in the minds of researchers. This is particularly the case when a relationship has been built between the researcher and participants.

As a researcher, with little ability to change the living standards of participants, hearing and consolidating these experiences of suffering and hardship can be incredibly upsetting and challenging - draining one's emotional resources and energies. As Kadambi and Ennis (2004: 2) explain, 'offering support and assistance to those coping with emotional pain, instability, or crisis can significantly tax [one’s] emotional energy and coping resources’. While my role within this research was not that of a therapist, often participants would turn to me for comfort and reassurance when divulging sensitive and painful memories. Pearlman and Saakvitne (1995: 281) note how ‘vicarious traumatisation’ can affect researchers, leading to burnout, emotional exhaustion, feelings of helplessness, isolation and a lack of sense of achievement in one’s work (Kadambi and Ennis, 2004).

There were similarly times during the research process when I was asked to go beyond my remit as a researcher, through helping participants with their daily living needs, for example, cooking, eating or even toileting. While such situations indeed have the potential to raise huge ethical debates, I felt the most just and ethical thing to do in such instances was to help the participant in meeting their basic needs, rather than see them in any pain or suffering. Often, we find ourselves during the research process (particularly when working with individuals deemed as 'vulnerable') occupying numerous subjectivities in relation to our participants such as that of a researcher but also of a carer, counsellor and/or a friend. Developing relationships underpinned by trust are deemed to be an important part of feminist theory, working to build rapport and break down power imbalances. Having developed a bond with participants, switching off and leaving the field can become incredibly difficult (if not impossible). Over a year since completing my fieldwork, I still receive occasional phone calls from participants asking about me, my life and sharing with me their recent joys and woes. It is, of course, feasible that we may never truly leave the field, with the research and its participants having a long-lasting impact on our day-to-day lives.

4.5.3 Doing research inclusively

Alongside feminist theory, the research has also taken inspiration from the work of emancipatory, participatory and inclusive disability scholars. The study seeks to adopt a model of research, which enables the full participation of disabled research participants (Oliver, 1990) and prioritises the voices and experiences of disabled people. Historically, research around disability has been criticised for its oppressive nature. Scholars such as Oliver (1992a) have raised concerns that disability research has often simply extracted knowledge from disabled people and placed it into the hands of researchers, alienating, disempowering and disenfranchising disabled research participants in the process. Consequently, there has been a growing demand to engage in research 'by' and 'with' rather than 'on' disabled people (Chouinard and Grant, 1997). This process requires far more than basic accommodation such as ensuring accessible research practices (e.g. large print/easy read participant information sheets and consent forms) but a more active move towards engaging disabled people in every part of the research process (Kobayashi, 1994).

Stone and Priestley (1996) have advocated that emancipatory disability research should be founded upon the social model of disability, politicise respondents' voices, benefit and empower disabled individuals and be produced under the control of disabled people. There is a danger however that emancipatory disability research with its grounding in the social model of disability may neglect or disregard individuals' experiences that do not adhere to this way of thinking. For research to be fully emancipatory it could be argued that it must recognise the diversity of voices and perspectives amongst disabled people. Corker (1999: 209) has similarly emphasised the need to acknowledge and represent the whole spectrum of different perspectives inherent within the disability movement. Kellett (2010: 31-32) argues that 'we have to guard against creating…. Initiative[s] where a vocal and articulate few monopolise the agenda and hard-to-reach groups languish on the margins'. Inevitably, not all voices will be heard equally and so we must create spaces for oppressed voices and consider whose voices may be missing. Through being respectful and receptive to participants' various experiences, a fuller picture emerges, which potentially enables a greater number of voices to be heard.

Emancipatory research has primarily been focussed upon making a direct impact on the lives of disabled people through the research process. This research, in contrast, does not claim to have made a significant or direct impact on the lives of anyone who participated in the study. It is recognised that an isolated doctoral research project will do little (if anything) to alter the policy agenda of the British welfare state or to advance disability activists' agenda. However, having said this, it is hoped that the research will help equip and support activists in their struggles. This will be achieved through working alongside disability activists, drawing attention to their achievements and supporting them in their work through imparting training and knowledge with them (and vice versa). Research participants and Disabled People's Organisations were provided with a short summary of the research findings, made available in a variety of different mediums e.g. audio and easy-read. The impact may be minimal, indirect and difficult to detect. However, I argue alongside Stone and Priestley (1996: 715) that 'failure to transform individuals lives need not be the sole criterion of 'good research''. This study will serve only as a small building block, within a larger body of research on disability that is striving to benefit disabled people.

Along with emancipatory research, the study also takes inspiration from participatory research. Participatory research and methodologies originally emerged from research with indigenous cultures. Research around indigenous populations, traditionally involved the researcher visiting particular places, extracting indigenous people's knowledges, appropriating it and disempowering participants in the process. As hooks (1990: 151-152) once wrote:

> I want to know your story. And then I will tell it back to you in a new way. Tell it back to you in such a way that it has become mine, my own. Re-writing you, I re-write myself anew. I am still author, authority. I am still the coloniser, the speaking subject, and you are now the centre of my talk.

Growing efforts have been made to decolonise research (Smith, 2012) through building less disempowering frameworks, which respect and value marginalised people's voices and knowledges, seeing individuals as active social agents rather than solely subjects of interest. Participatory research has been defined by Bourke (2009: 458) as 'a research process which involves those being researched in the decision-making and conduct of the research, including project planning, research design, data collection and analysis, and/or the distribution and application of research findings'. This model of research, advocates for the co-creation of knowledge, whereby knowledge is seen as deriving from participants, as much as from the researcher - challenging conventional notions of knowledge transfer, which assume that the researcher has the knowledge and is the expert. Knowledge co-creation becomes 'a much more shared' endeavour (Leibowitz et al., 2014: 1258), whereby knowledges come into dialogue and inform one another.

Taking inspiration from this approach, I understand the participants in this study as 'experts by experience' (Grant and Ramcharan, 2007). While this research does not claim to be fully participatory, the ways in which participatory elements have been embedded into this research include: consultations with disability activists around appropriate methods, interview themes and questions and the later reviewing of transcripts by participants. Participants were also asked directly for any feedback that they may have around the research process, in order to inform and improve future practice. As researchers we can often be reluctant or fearful of asking participants about how they found taking part in the research process, however, this is an important part of participatory research, in order to improve the experiences of future research participants.

Furthermore, this study has sought to do 'research inclusively' (Nind, 2014: 1) through taking inspiration from participatory, emancipatory and inclusive research and scholars. Rather than conceptualising 'inclusive research' (Walmsley and Johnson, 2003) as a list of criterion, I argue alongside Nind (2014: 1) that it is potentially more helpful to move towards 'doing research inclusively', seeing this notion as more fluid and encouraging than a set of clear, rigid criterion. While this research has sought to do 'research inclusively' (Nind, 2014: 1), it is aware of its limitations and failings. The research could have for example (given greater time and resources) engaged a wider variety of voices and involved participants more in the analysis of data. Efforts were however made to display a diversity of views and experiences.

4.6 Ethical considerations

The research project was granted ethical approval by the Faculty of Social, Human and Mathematical Science's ethics committee at the University of Southampton (ERGO reference: 25244). Prior to participating in the research, all participants were asked for their consent (either verbally or in writing). All participants were provided with a participant information sheet (see Appendix C) and a consent form (see Appendix D) in advance. Both documents were available in a range of accessible formats including easy read, large print, electronically and audio, in order to cater for participants' individual needs. Participants were asked to confirm their consent, and that they had read the participant information sheet before they participated in an interview.

In line with the ethics approval, informed consent was not required for participant observation (at various anti-austerity protests and gatherings), as I was not recording any personal information or conversations. Nonetheless, when asked about my participation at various events, I made sure to clearly explain my research and motivations behind attending such events. I also informed the event organisers of my presence when deemed appropriate. Photographs taken at these events have been edited to obscure individuals' faces and personal features. Individuals, therefore, remain anonymous unless consent has been provided through the use of a photo consent form (see Appendix E).

In line with the ethics approval and consent form for participation in interview, all participants were given the opportunity to withdraw from the research at any point up until one month following the interview date (after this date the data was fully anonymised). Only one participant decided to withdraw from the study due to concerns around confidentiality and whether the research could bring about repercussions for his employment. The anonymity of participants has however been preserved with personal details (i.e. names, address, workplaces, affiliations) altered or removed (unless requested otherwise). All participants were given a pseudonym and their transcripts have been stored and coded using a unique ID number. Participants were however given the option of being named and accredited within the research. Some participants did indeed request to be identifiable within the research, seeing this as a means to extend the reach of their activism. Where participants requested that their identity not be anonymised, I have made this clear by indicating that I am using their real name, by inserting an asterisk next to their name in the participant profile table (see Appendix A).

Tilley and Woodthorpe (2011) have written around some of the issues brought about through the normativity of anonymity within ethical codes of practice in social research. They argue that a critique of anonymity has been afforded comparatively little attention, despite the practice not always being required or indeed desirable. Within this study, for example, I felt that giving participants the option of being named, may enable them to feel a greater sense of ownership over the data (Giordano et al., 2007). Data ownership has long been a great concern within biographical research (Atkinson et al., 1997; Mitchell et al., 2006; Traustadottir and Johnson, 2000). Through not anonymising the accounts of those who requested to be identifiable, it was felt that this research could provide a greater sense of empowerment and voice to these individuals.

Biographical interviews due to their very nature seek to create a space in which individuals feel comfortable talking about different parts of their personal histories (be those positive, joyous harrowing or distressing memories). One of the ethical concerns which arises as a result of this research method is that participants may become upset during interviews, when talking about their biographies, potentially not only remembering but re-experiencing past trauma (Svašek, 2008). All participants were asked about their experiences and motivations behind engaging in disability activism, for many this was a direct result of enduring some form of hardship or discrimination. Biographical interviews, therefore, have the potential to raise painful, difficult or confusing past memories and experiences. There was one occasion where a participant became particularly distressed. It was important in this situation, that I helped calm and reassure the participant, giving them the option to withdraw from the interview, move on to talk about something else or to take a break. In this particular instance, the participant decided that she did indeed want to continue the interview but took a few minutes to recompose herself. She also had a friend in the cafe who helped to comfort her. I endeavoured to check-in with the participant, two days later, to ensure that she was ok and that the interview had not brought about any undue harm or distress to her. In order to ameliorate and minimise any potential distress, participants were always informed of their right to stop the interview at any point, or not to speak about a particular issue if they found it too upsetting. Participants were also always given a list of weblinks and contact details for local support groups and advocacy services (in a variety of accessible formats) at the end of their interview.

Recognising the individual circumstances of participants (with the vast majority unemployed, out of work or living in situations of economic precarity) along with the time-consuming nature of biographical interviews, I decided to offer each participant £20 as a form of recognition for the time they had spent participating in the research. Thompson (1996) has noted how paying participants can help to unsettle power relationships between researcher and participant, with respondents acquiring a greater sense of recognition and value for their time. However, as Head (2009) notes, paying participants should not be recognised as unproblematic. There has been growing concern that the offering of financial payment may compromise the ethical principle of free, informed consent. Those in financial hardship may, for example, feel obliged to participate if the financial reward is too high. High payments may also lead to respondents giving false information in order to be eligible to participate, calling the accuracy of the research project into question.

While acknowledging the potential negative implications brought about by offering financial payment to participants, this research like Goodman et al. (2004), Head (2009) and Rowlingson and McKay (1998) sees it as an important expression of gratitude for the time participants spend engaging in the study. The figure of £20 in the form of cash was decided upon, as an amount, which was deemed substantial enough to serve as a form of gratitude for participants' time (recognising that many individuals may be living in situations of economic precarity and that the interviews would take approximately 1-1.5 hours), yet was not too high to be seen as potentially coercive. Participants were provided with cash (acquired through the Royal Geographical Society grant) rather than vouchers as it gave them a greater sense of autonomy and allowed them to use it in a way that would be most beneficial to them. Several participants, however, refused to accept any form of financial payment for their participation, seeing the interview process as a 'privilege' in itself - with someone having a genuine interest in their lives, as one participant explained: 'I feel as though I should be paying you, not you paying me'. For some, the interviews were particularly valuable and enjoyable, helping them to make sense of their experiences. In instances where participants refused payment, the money was given to a charity or organisation of their choosing. Along with providing a payment to participants, it was also agreed that I would always travel to them, to ameliorate any financial strain that this could bring about.

4.7 Data analysis and handling

Qualitative data analysis is often envisaged as a linear and straightforward process, which immediately follows data collection. Scholars such as Flick (2007) and Braun and Clarke (2006) have however been sceptical of such an approach, arguing that there can be no straightforward separation between data collection and analysis. Analysis should be taking place in the field, during the process of data collection, be that through conducting interviews, attaining documents or writing field notes. This study like Flick (2007) and Braun and Clarke (2006) recognised analysis as taking place throughout the research process (helping to continually modify and revise the research questions), rather than solely being reserved for the final stage of the research.

All interviews were recorded and later transcribed fully. Transcription was recognised as an important part of the research process, where meanings were created and a greater understanding was acquired (Bird, 2005). While transcribing, on the whole, proved to be relatively straightforward, there were a few instances where recordings were not as clear due to loud background noises (e.g. music, coffee machines, cars etc) or as was the case in two instances, participants had slurred speech (as a result of cognitive impairments), which made it difficult to identify and disentangle certain words from the audio recordings, without visual cues such as body language and hand signals. In these instances, I decided to revisit the participants and go through the transcript thoroughly with them, clarifying any errors. In addition to this, every participant was emailed a copy of their transcript and given the opportunity to make any amendments, clarify any errors and add any additional information/comments. Participants were given a one-month period to do this within, after this date the transcripts were anonymised and so making any amendments became more difficult. Through providing participants with the opportunity to amend their transcripts, it was felt that a more participatory approach was attainable. Participants were also asked at the end of each interview if they had anything they would like to add, change or clarify, embedding a more participatory approach into the research.

Before beginning coding, I spent a substantial amount of time re-reading transcripts, without seeking to pull out themes but rather familiarising myself with the individual life stories. The principles of both thematic analysis and narrative theory informed my analysis of interviews and fieldnotes. Narrative analysis is understood as being of particular value in analysing life stories - enabling an understanding of how life stories are told and constructed, along with how they may be associated with social structures (McCormack, 2004). Thematic analysis meanwhile allows the researcher to see the prevalence of certain topics and patterns across a dataset. Narrative and thematic analysis were used in combination, constantly informing one another.

Interview transcripts and field note observations were initially uploaded onto a qualitative data analysis programme – NVivo, with overarching themes being identified from the transcripts (Braun and Clarke, 2006; Riessman, 2005). However, I soon found the process to be incredibly dehumanising and preventing a fuller, less fragmented picture of individuals' lives. I therefore, decided to revise my approach to analysis, through moving instead to a combination of narrative analysis and thematic coding by hand, this enabled a more tactile engagement with the data that helped keep the subjective experience at the forefront.

Narrative approaches are interdisciplinary and enable the analysis of the stories we tell, hear and read (Riessman, 1993). Narratives are understood not as being constructed singularly or alone but rather with a specific audience in mind. Stories may therefore deviate depending on the context and to whom they are being told (De Fina, 2009; Wiles et al., 2005). Context becomes crucial when analysing narratives, this may involve considering, for instance, the environment in which the interview took place and the degree of rapport developed between the interviewer and interviewee (Phoenix and Brannen, 2014). Additionally, rather than understanding narratives as completely accurate, narrative approaches consider how individuals may instead seek to present a 'preferred' self (Riessman, 2003: 337). Narrative analysis, therefore, looks at how stories are constructed and told, including, for example, the sequence of events, choice of language and assumed motivation (Frost, 2009). In line with a narrative approach, I made notes and memos after each interview to retain details not captured within the audio recording, enabling a greater understanding of how the story was told and the context in which it was delivered. Following narrative analysis, the transcripts were analysed more thematically.

Thematic analysis as 'a poorly demarcated and rarely acknowledged, yet widely used qualitative analysis method' (Braun and Clarke, 2006: 77) has the potential to produce rich, detailed and complex accounts of data (Ely et al., 1997:205-6). There are several stages involved in thematic analysis (Rapley, 2011). The first stage was to familiarise myself with the data through a close, detailed reading. Initial codes were then created through an inductive approach, drawn from both the data and prior reading. Codes helped to establish connections and commonalities within the data and between the stories told by participants. These codes were inevitably changed and modified several times during the course of the research, as my understandings changed. Following the initial coding, themes were sought through gathering similar codes into potential themes. While partly inductive, some of the themes were also drawn from a codebook based upon my literature review and theoretical framework, which had been continually revised over time. Moreover, thematic analysis can fragment stories with the messiness and complexity of lives frequently being erased (Clarke et al., 2015). Through combining both thematic and narrative analysis, I therefore sought to capture the complexity and intricacies of individuals' lives, whilst also identifying some overarching themes.

In line with the analysis approach, I chose to combine a thematic writing style along with that of a narrative approach. I soon however became aware of the difficulty of maintaining the complexity of each individual's life, while also presenting a series of clear, recognisable overarching themes. While I could have chosen to present the finding chapters as individual case studies to allow greater engagement with individual context and to maintain the richness and complexity of individuals' life stories, I felt that it was important to represent a number of voices, especially given that very little academic scholarship to date has sought to examine the experiences of disabled people engaged in anti-austerity activism. I also felt it was important to highlight the diverse range of experiences amongst disabled people. In order to navigate this, I experimented with using various ways of presenting and analysing the data, chapter 5 and 6 drew more upon a thematic writing style, while chapter 7 and 8 used a combination of thematic and narrative writing approaches. These approaches in combination, helped to capture the overarching themes while also presenting detailed, nuanced accounts that demonstrate the complexity of individuals' lives.

4.8 Research dissemination

Efforts were made to disseminate the research findings to wider audiences including all key stakeholders. Along with publishing the research findings in the form of a doctoral thesis, the research was also disseminated at several national and international academic conferences, student lectures/seminars and in the form of research publications (under review). Research participants were also provided with a short written summary of the research findings, made available in a variety of different mediums e.g. audio and easy-read.

4.9 Limitations of the research

This thesis and its methodology have some clear limitations. First and foremost, the main limitation of this research is its choice of terminology. Through only recruiting those who defined themselves as disability ‘activists’, this research is likely to have overlooked other activist practices, whereby individuals do not so readily define themselves as activists. Individuals may, for example, prefer to be identified as a ‘campaigner’, ‘advocate’ or ‘lobbyer’, due to activism’s frequent association with militant, public, direct and/or violent acts. It was much more likely (perhaps due to the phrasing of recruitment materials), for individuals engaged in protest and direct action to come forward and request to take part. Similarly, some may not have seen their actions as significant enough or equitable to be understood as activism and so felt unable to identify as an activist. Further research is therefore required into the implicit resistant or political practices of disabled people who are neither associated with a disability activist group nor identify themselves as disability activists.

The research participants were also all white British or white Irish and predominantly within their 40s or 50s (19/27 participants). Further insights would therefore be valuable from younger activists, those who may not have had the same exposure to the history of the Disabled People’s Movement or be as familiar with the conceptual models which have conventionally underpinned the movement. Similarly, the experiences of Black and minority ethnic people are not represented in this study. Further research would therefore be of value in exploring the experiences of Black and minority ethnic disability activists, along with those with further intersectional identities, who may experience multiple forms of disadvantage.

Further to this, my thesis does not engage with the experiences of people who practised their ‘resistance’ within the ‘system’, such as those within government or sitting on advisory committees. While individuals working within these areas were contacted to seek their input and insights, I did not have sufficient space to engage with their accounts in any meaningful manner. Further publications from this research, may therefore focus on exploring the varying insights of participants working within rather than against the system.

Due to the financial and time constraints of this study, it was only possible to interview a small number of individuals (n=27) and so it was not feasible to explore the whole breadth of activist practices currently taking place. Disability activists inevitably engage in a much wider array of practices than those which are mentioned within this thesis. Further, it was much easier to engage in participant observation of public forms of activism (i.e. protest and direct action) compared to those which were private or liminal in nature (i.e. online activism, advocacy etc), potentially leading to a greater depth of analysis around public forms of activism. It should however be emphasised that this qualitative study does not seek to capture a representative snapshot but rather to explore the personal, everyday, in-depth experiences of those within the current context.

4.10 Conclusion

Through this research, I have sought to adopt elements of feminist, participatory, emancipatory and inclusive disability research. Working alongside disability activists, I have sought to adopt an inclusive methodology, which recognises and values both the voices and unique insights of disabled people. Through incorporating disabled people in various capacities throughout the research process (e.g. in the development of the research methodology and associated research questions), the research has sought to acknowledge disabled people as co-creators of knowledge and experts by experience (Grant and Ramcharan, 2007).

While echoing some of the themes of ‘emancipatory’ research such as the principles of inclusion and the need for research to bring about impact, the research does not perceive impact or the transformation of individual lives as the sole criterion of ‘good’ research (Stone and Priestley, 1996). The value or impact brought about through this research may be minimal, indirect and difficult to evidence. For some, the experience of being listened to was in itself of great value. In a world full of noise, dominated by the powerful and the elite, the impact of someone taking the time to express an interest in an individual’s life can be of infinite value, providing an individual with a sense of self-worth and accomplishment, particularly when one might regard their own life as mundane, trivial or of little importance.

This research has primarily been driven by my desire to give recognition to the actions and tenacity of disability activists during a time of austerity. Recognising and writing in my positionality (as a female disabled researcher) into the research has been incredibly important from the start, highlighting and making transparent (as far as it is possible) how this may have impacted upon each stage of the research, from its very first inception (serving as a motivating force behind the research) to the data collection, analysis and eventual write-up. While my positionality has inevitably influenced many different aspects of the research process, I believe that this should not prevent us from researching things which are of personal importance and meaningful to us. Our personal connection(s), passion and interest in the topic under study, is often what drives us and enables us to give such vast energy and enthusiasm to our research.

Chapter 5 Defining activism and be(com)ing an activist

5.1 Introduction

This chapter is the first of four that present and analyse the research findings. The aim of this first chapter is twofold, firstly, to explore how and why participants have become involved in activism and secondly, what they understand by the term 'activism'. The chapter will begin by outlining the perceived urgency of disability activism in response to austerity and how individuals' personal circumstances may have motivated them to become engaged. The chapter will also look at some of the key factors which may have aided (or hindered) participants in the process of engaging in disability activism. Following on from this, the chapter turns its attention to look at the different ways in which participants understand the term 'activism' - highlighting how they may correspond or differ to conventional depictions of activism as direct, militant and highly visible public actions (Kluge, 1982). In doing this, the chapter will set out the basis for the following three analysis chapters.

In order to contextualise participants' accounts, it is important that we first and foremost understand the circumstances in which participants engage in disability activism, it is therefore here that we begin.

5.2 Urgent disability activism in response to austerity

Austerity has significantly impacted upon the lives of disabled people across the United Kingdom (and internationally), with disabled people found to be facing the brunt of recent austerity measures (Cross, 2013; Duffy, 2013; Power, 2016). Austerity cuts in the UK (including the aforementioned reforms to key disability welfare benefits, the closure of the Independent Living Fund and reductions to adult social care) have led to increased poverty and isolation, reduced independence and a deterioration in mental health amongst disabled people (Cross, 2013; Ryan, 2019; UNCRPD, 2016).

Participants' accounts within this study reveal similar stories of hardship. Melanie at the time, found herself in acute debt, unable to pay for her carers after being forced to take out a loan from the council in order to make her property accessible. Rachel found herself homeless for several months with the council unable to provide her with accessible accommodation, due to reductions in social housing investment. Simon and Anna both found themselves in a continuous battle for access to the recently reformed welfare benefit 'Employment and Support Allowance' (ESA), unable to work and relying upon this benefit for their everyday needs. Both found themselves in a state of perpetual anxiety, fearful daily of the arrival of a brown envelope from the DWP (Department for Work and Pensions), requesting that they reapply or declaring that their application had been unsuccessful. They found themselves stuck in a continuous cycle of applying, being rejected, attending multiple tribunals, being successful and then almost immediately having to reapply again, as Anna explains:

> You don’t know where you are, you are [thinking] how am I going to survive if I don’t get this and it’s torture. It’s PURE TORTURE! You never know when you’re going to be assessed and it’s torture they put you through.

Meanwhile, Alex had undergone multiple battles in terms of accessing an appropriate care package for her deteriorating health conditions and Liz was facing increased barriers to education, with cutbacks and bureaucratic changes to Disabled Students’ Allowances (DSA), making it too complicated for her to access a personal assistant (PA) for her studies. The above examples demonstrate just some of the ways in which participants found themselves living in situations of increased hardship and precarity under austerity. This has consequently given rise to a series of different practices that have been associated as activism, including, for example, protest, the arts, online activism and advocacy. The desperation brought about by austerity caused people to be fearful of their futures and it is this fear that is explored next.

5.3 Emotion as a critical driving force towards engagement in activism

Engagement in disability activism in response to austerity, appears to be highly emotive and driven by strong emotional forces. Nathan’s activism, for example, was predominantly driven by a sense of fear, hearing of the possible reduction to his number of allocated care hours as a result of the proposed closure of the Welsh Independent Living Grant (WILG). The care and support provided through this grant was deemed as essential for Nathan to retain his current standard of living, as he recounts:

> In May 2015, I had a visit from a social worker. And she advised me that without the Welsh Independent Living Grant, my hours of care would be reduced from 86.5 hours a week to 31 hours a week. Now, I can’t cope on 31 hours, so I was panicking… I was in crisis. I was thinking oh my god I’ve got to get myself involved in the community more so that I become integral to the community. Therefore, the council would find it more difficult to take hours off me because I could argue well, I need to do this and that. So that was sort of my trigger, all from fear and the reality of what would happen if they removed my support.

Through the above quote, we can see how Nathan found himself in a state of heightened anxiety, fearful for the future and what lay ahead. Here we might draw upon Horton’s (2016) writing around anticipated futures, where he notes that the anticipation of funding cuts can be more troubling than the cuts themselves. For participants like Nathan, it was often the uncertainty of ‘not knowing’ which was most difficult to deal with. Nathan was of the view that he needed to become a more visible and prominent member of his local community in order to retain his level of care and support: he believed that in doing this, he would be able to gain greater public support and more people would be made aware of his situation. This particular situation was deemed by Nathan to be akin to the well-known phrase, ‘the straw that broke a camel’s back’ in igniting his activism. While Nathan (along with others) had been experiencing adversity for some time (both prior and post the onset of austerity), it was this particular point in time that Nathan felt ‘enough was enough’ and he decided to take action. Not all activists’ histories were however similar to that of Nathan’s. Others’ activism developed in more diverse ways, sometimes slowly and incrementally with many activists unable to identify a specific event or ‘trigger’ behind their activism.

Like Nathan, Rachel recounted fear as being a key driving factor behind her activism. Fear appeared to be a common feature emerging across most participants’ accounts (particularly amongst those who became involved in disability activism post the onset of austerity), seen as key in propelling individuals into action. Rachel’s account, in contrast to Nathan’s, illustrates how her activism was driven by a more detached experience of hearing about the hardship of others and then relating it back to her own *potential* situation.

> I can remember the particular point I think it was. Basically, it was an article in a newspaper that had come up… it was a release of figures from the government stating how many people had died after being denied Employment and Support Allowance. And so obviously me being on ESA, it’s something of interest anyway... I was reading about that going... is that going to affect me and how’s it going on sort of thing… And that’s when I’m going, what’s going on. How is no one ranting and raving and kicking up such a fuss about it? And so that’s when it got me to kind of [engage in activism].

Rachel notes here how reading a newspaper article about the number of suicides which took place as a result of work capability assessments, triggered her activism. It was often said to be easier for participants to act or speak out about the injustices being faced by others (in similar situations) as opposed to that of their own. This may in part be due to the way in which society, values and honours masculine attributes such as independence and autonomy (Connell, 1987, 1995; Gill et al., 2005), making participants not want to narrate themselves in a position of need.

Rachel’s activism was however underpinned by both a sense of fear and urgency, aware that she could be called in any day and re-assessed for ESA – she in effect, could be next in the firing line.

Both Rachel and Nathan’s accounts demonstrate a sense of urgency regarding disability activism around austerity, a need to quickly and proactively prevent or minimise any further damage. Emotions were deemed as crucial in instigating action. Beyond that of fear, feelings of grief (over what had been lost), anger and injustice were also deemed as key in driving participants to engage in activism. While all participants shared a sense of injustice, anger was most apparent in the accounts of those engaged in more masculine, militaristic forms of protest and direct action (Coleman and Bassi, 2011). Adams (1987: 10) has suggested that 'like the spark that ignites the fuel in an engine, anger is the stimulus that initiates action'. A sense of anger became particularly apparent within Anna's account. Anna, while having been involved in both disability and mental health activism for a longer period, had become particularly involved in protest and direct action around changes to disability welfare over the past five years.

> Anger, the anger drives you, the adrenalin drives you. When you’re out there, you’re pumped up, you’re scared shitless, you’re anxious. I get anxious. But when I’ve been attacked on a bus and I’ve been attacked on a protest, I go back out there and think fuck you, you’re not going to beat me. I’m getting back out there and carrying on. And when you’re with people who feel the same as you, you get strength from other people. You all feel the same way against the government. You’ve all been hurt by them and you want to do something about it… They are culling us in large numbers, and you can’t take that lying down. Each death is personal, each eviction is personal, each person going hungry is personal.

Feelings of anger were therefore deemed as central in both igniting and sustaining Anna’s activism. Activism for Anna was about fighting back. Klar and Kasser (2009) have suggested that engaging in some form of action may help to temporarily relieve some of the anger and negative side effects brought about through such injustice. Anna’s account appeared to echo this:

> It kept me focused because I so wanted to get justice for other people who are in a worse situation than me. I've turned the anger into action and without that action, I would have killed myself four years ago.

We can see here how anger is often inherently intertwined with feelings of grief. Anna’s involvement in activism had given her a focus and an outlet to externalise her feelings - rather than internalising them which would have potentially been damaging for both her mental health and sense of self. Anna’s engagement in activism had therefore served as a means of sustaining herself during a period of heightened adversity. Activism provided Anna with a sense of hope, that another way (or better world) was possible. Hope appeared to play an important role across all participants' accounts, as 'a positive motivational state' (Snyder et al., 1991: 287). Without a sense of hope, activism would neither be instigated nor sustained.

5.4 The changing nature of disability activism in response to austerity

The sense of anger and injustice felt amongst disability activists who had become engaged in disability activism since the onset of austerity, was similar to the accounts of more longstanding disability activists. However, what differed was the sense of fear and urgency underpinning more recent forms of disability activism in response to a particular threat, austerity. Longstanding disability activists such as Claire, Liz, Mary and Lisa, who have been involved in the Disabled People's Movement since the mid to late 80s, explained how their activism had not initially been motivated or underpinned by this same sense of urgency and/or fear. This was said to be largely due to the lack of rights disabled people had during this period (mid to late 80s), they had not known, or experienced an alternative beyond institutionalisation, segregation and social exclusion (Campbell and Oliver, 1996). Participants such as Claire, Liz and Lisa spoke instead of how their activism had been motivated by a gradual yet growing sense of frustration and resentment towards how disabled people were being treated by wider society. Lisa for example spoke in great detail about her experiences of everyday discrimination and segregation during the 1970s and 80s:

> I was packed off to residential special school when I was very young. I was 16 months. Left two days before my sixteenth birthday and very, very weighed down by internalised oppression... I left school, came back home to a family and a community that didn't know me. I didn't really know them… I [then] went to mainstream college, it was just horrific because I had no sense of how to interact with non-disabled people my own age, because I'd been entirely segregated before. But I must have had a sense of wanting to do and be something different because I left college thinking I've got to find a job… I remember going to the jobcentre, being told that people like me didn't really work but what that did I guess was keep reinforcing the sense of otherness, the sense of difference, the sense of not wanting to be a disabled person, desperate to fit in.

Childhood experiences have been deemed as playing a significant role in shaping an individual's life course along with one's values and beliefs (see Maynard, 2018). Here we can see Lisa's resentment towards how she was treated and socially excluded as a child. However, her experiences of social exclusion and segregation were not solely confined to childhood but extended into young adulthood and beyond. It is interesting to note how Lisa at the time was told that someone disabled like herself could not work. In stark contrast, today welfare reform has meant that nearly all disabled people are forced into work regardless of whether they have the ability, support or resources. For Lisa and other participants who had been involved in the Disabled People's Movement pre-austerity, their activism had often been driven by a culmination of experiences, which had very slowly and gradually built up a sense within them that they needed to both challenge and resist discriminatory structures and the way in which disabled people were being treated by wider society.

Longstanding activists who had become involved in disability activism pre-austerity expressed some concern and ambivalence towards current forms of disability activism in response to austerity. In particular, there were concerns that it may simply be serving as a form of firefighting. Mary, for example, questioned whether current activism in response to austerity, was simply about returning to the status quo (i.e. focused solely upon getting benefits and support reinstated), it had in her eyes, lost its vision, its radical edge. Disability activism was no longer seen to be about imagining an alternative. However, the desperation in participants' accounts (such as that of Nathan's), demonstrate the perceived importance and urgency of such forms of activism, as a means for survival. Living in situations of extreme hardship and precarity, fire-fighting was often seen to be the only option available to individuals.

In describing the activities of the Disabled People’s Movement, Beckett (2005) engages with Ellison (2000, para 7.3) notion of ‘defensive forms of engagement’. Ellison (2000) notes that there are two forms of civic engagement – proactive and defensive. Proactive engagement refers to actions, which seek to secure new citizenship rights. Meanwhile, defensive engagement is understood as the practice of:

> ….. those lacking access to relevant power networks who find themselves engaged in efforts – perhaps to maintain a status quo, or to develop new arrangements – simply to preserve existing interests and entitlements (Ellison, 2000, para 7.3).

Defensive engagement is seen as being a reactive attempt to seek to hold onto and reassert existing citizenship rights (see Patrick, 2017). In the current context, it is plausible that disabled people due to a lack of power and resources are only able to engage defensively. Disabled people continuously have to actively defend themselves against the erosion of their rights.

5.5 Be(com)ing a disability activist

Along with being driven by strong emotional forces, being in contact with other disabled people appeared to be pivotal in each participant's account, often helping them in the process of identifying as disabled and recognising the everyday injustices they faced. Thus, the coming together of disabled people often resulted in consciousness-raising and a synergy for action. Contact with other disabled people gave individuals the opportunity to share experiences and to recognise that the discrimination or injustices they faced, were part of a larger, collective and structural issue rather than that of an individual one. In doing this, they would also often come to question the legitimacy of individuals and structures who had authority over them. Here we might draw upon the scholarship of Hanisch (1970), wherein she argues that the congregating of women to share stories of oppression and mutual injustice, should be conceptualised as a political act as opposed to solely that of therapy, as it involves highlighting and unsettling existing patriarchal power relations. In this case, there was an unsettling of ableist structures and norms.

Several participants’ transcripts reflect on the significance of other disabled people (as role models) in encouraging and motivating them to become politically active. Reflecting upon the emergence of the Disabled People’s Movement, these spaces of exchange have historically been situated in welfare institutions such as mental health ‘asylums’, day care centres, residential care homes or special educational needs schools. These were the few likely places in which disabled people came into contact with one another and were not necessarily sites which emboldened individuals or ignited challenge (Taylor-Gooby, 1991). Disabled people were for a long time an invisible minority and very often invisible to each other (Scotch, 1989), for some this remains the case, particularly in the context of increased personalisation, the closure of community care services, day care centres and Disabled People’s Organisations (Cross, 2013; Ryan, 2019). Personalisation should be recognised as a positive change, in providing disabled people with greater choice and control over their lives and enabling individuals to live independently in the community. However, it can also have the unintended side effect of closing down spaces of encounter between disabled people.

Social contact amongst disabled people has traditionally been and to some extent still is highly structured by welfare organisations (Acheson and Williamson, 2001), with individuals often not meeting other disabled people in any other setting (ibid 2001). It is therefore unsurprising that the origins of the Disabled People’s Movement along with its early actions emerged largely from the congregating of individuals within these institutionalised care settings. Disability activists were often reliant on these spaces and the staff within (i.e. as accessible spaces for meeting and also due to them providing transport etc.) for their mobilisation (ibid 2001). A number of the longstanding disability activists that I interviewed, similarly spoke of getting involved in the movement through meeting other disabled people while at institutions such as special education schools and mental health services. With the gradual closure of such institutions and the increasing personalisation of social care, it is particularly interesting to explore how more recent and younger disability activists have come about engaging in the movement and finding other politicised disabled people, in the absence of such spaces. One route appears to be through university, as both Rebecca and Sophie spoke of encountering disability activists while at university who sought to recruit them and provided them with models of activist behaviour. It should however be recognised that the university is rather a privileged and exclusive space, which will not be accessible to all. Social networks and online communities have also been integral in recruiting individuals, with activist networks often encouraging and supporting people to engage in public forms of protest.

Along with being in contact with other disabled people, identifying as disabled was deemed to be another important part of participants' accounts. Becoming comfortable with the identity of disabled can for some, be a long and difficult process (regardless of whether an individual was born with an impairment or became disabled later in life), with some individuals indeed never reaching this stage. This is largely thought to be a consequence of stigma and the common association between disability and personal deficit (see, for example, Brisenden, 1986; Goffman, 1963; Oliver, 1990 on the 'medical model of disability'). Becoming comfortable with the identity of 'disabled' appeared to often involve redefining what it means to be disabled (Devlieger et al., 2016; Waldschmidt, 2018). This is likely to involve identifying as part of a minority group who experience discrimination, social exclusion and multiple barriers to participation in everyday life (Acheson and Williamson, 2001). Such an identity is in stark contrast to a medicalised self-identity, whereby an individual identifies as a victim of personal tragedy and misfortune. In practice, however, it is unlikely that these distinctions will be so definite, with many individuals experiencing both simultaneously.

Chris, who is CEO of an independent living centre in the South East of England was one of those who identified with the above narrative. He noted how during his childhood he had limited contact with other disabled people and actively sought to distance himself from the label disabled. It was only when Chris joined a peer support organisation during his 20s for people with similar impairments that his opinions and perceptions began to be challenged. It was here that he was first introduced to the social model of disability and began to understand that the problems he faced were not individual but structural and shared by the wider collective. One could liken this to a raising of consciousness as identified in relation to class by Marx, whereby the attention of a group is focused on a specific condition, which is deemed to precede action (Borland, 2008;

Hanisch, 1970). Chris's narrative further emphasises the integral value of feeling a part of a community, in which others have shared similar experiences to himself: 'There was a certain strength in talking to people who I could relate to'. Identifying as disabled however took a long time for Chris, as it did for several of his fellow activists. Nevertheless, this process of self-identification was deemed by most participants to be a necessary step and juncture before individuals could engage in disability activism.

To summarise, within this first half of the chapter I have explored some of the key ways people spoke of coming into activism. These stories were varied and complex but I have drawn out some key threads and different routes into activism. Often these involved the importance of emotions such as fear, anger and resentment in driving people into action, and emphasised the urgency of the current situation, with many finding themselves in situations of increased hardship and precarity. Contact with other disabled people was also deemed as pivotal in most participants' accounts. In the second half of this chapter, I will now be turning my attention to the multifaceted ways participants defined 'activism'.

5.6 What is activism?

In terms of the actual practices understood as characterising activism, participants had a range of different views and experiences. The term 'activism' is widely used yet highly debated, with scholars alike drawing upon a wide spectrum of different definitions and understandings (Martin et al., 2007). As a term which emerged in the mid-1910s, it is generally understood as being underpinned by agency, having the capacity to act, along with make or change history (Jordan, 2002). Gitlin (2003: 5) notes how, 'It reminds us that the world not only is, but is made'. Activism is therefore understood as the action of fighting for rights or change, it can be reactionary along with progressive. Although not the only form of activism, direct action (consisting of proactive actions that are often militant, public and direct in nature) or as Kluge (1982: 212) terms it the 'immediate on-the-spot struggle', has been seen as central to most definitions of activism. Direct action has been seen as fundamental to every social movement's successful battle for rights (Campbell and Oliver, 1996; Mellor, 1920; Wallerstein, 1990). Such understandings of 'activism' can be seen across a variety of dictionary definitions of the term, which understand it as direct and often militant action in order to bring about political or social change (Oxford Learner's Dictionary, 2019; Collins English Dictionary, 2019; Cambridge English Dictionary, 2019).

Corning and Myers (2002: 704) however, provide one of the most tangible definitions of activism, seeing it like Abrahams (1992) as the 'behaviour' of advocating for a particular political issue or societal change, through a variety of different methods from beginning a petition, writing a letter, to engaging in forms of direct action or civil disobedience. The broad nature of their definition creates a space for a variety of different forms, practices (along with spaces) and modes of 'being an activist' to be recognised.

Throughout this research, I did not want to impose any particular understanding of activism on participants. Instead, I actively sought to ask participants how they understood activism and whether they associated with this term. The majority of participants understood activism as any action which sought to bring about change, as is illustrated in the following quotes:

> Activism, I think is anything that is about getting social change, whatever level that is, whether that's for an individual… [or] a group of people (Claire).

> Fighting or working in some way to make a positive change… I quite like the word because it implies a sense of agency and action and energy (Anne).

Along with influencing change, participants' accounts also emphasise the importance of activism as a means of information sharing, connection, drawing attention to often overlooked or hidden issues:

> Activism is like campaigning, raising awareness to a wider audience. You can't really be an activist if you're the only one who knows about it (laughs) (Rachel).

> To me it's raising awareness, it's making things that are unknown or misunderstood to the general population better understood - whether that's through social media or through a campaign or a protest... Successful activism for me is seeing change, it won't necessarily be immediate, it might be incremental (Sophie).

While every respondent understood activism as acts that highlight a particular issue and bring about social or political change (similar to Corning and Myers' (2002) definition), there was greater discrepancy and disagreement surrounding what acts participants understood as constituting activism. For Darren and Simon, activism could only be associated with the more visible, militant and direct actions, like that articulated by Crossley (2003); Tarrow (1998); Thoburn (2008) and Wallerstein (1990), whereby activism is seen to be rooted in radical action, civil disobedience and protest. However, the idea of rebellion and risk are masculine ideals (Atencio et al., 2009; Holt and Thompson, 2004), it is therefore perhaps not surprising that it was two male participants who held this view. Darren is an active member of a prominent UK disability anti-austerity protest group, a campaigner for the Labour Party and a member of his local trade union for disabled and unemployed people. Darren told me:

> If you're going to talk about the archetypical features, it has to be in some way confrontational and against the everyday… Disrupting the everyday and challenging the power structures of the everyday.
>
> I was talking to a teacher and she said: "Well I kind of feel like I do my activism in the classroom." And to me, that was the extreme limit... I kind of thought "that's not enough". Nothing against teachers, left-wing teachers but you know, I just thought, this is not enough, this is not [activism] you know…

While noting here the perceived importance of confrontational forms of activism, Darren also gestures towards direct action being a 'perfect standard' of activism. Bobel (2007: 147) uses the notion of a 'perfect standard' of activism to refer to the mentality and outlook that activists are often expected to hold i.e. that of constant and relentless dedication. However, we could expand upon this to include the practices that are most recognised and valued amongst activists. For Darren, this was an engagement in risky forms of protest or direct action. This view was also echoed during participant observation at disability protest events, with activists often perceiving riskier forms of action such as protest and confrontational acts as being the most pure, valuable and effective forms of activism.

Activism appeared to be valued more by Simon and Darren if it involved some degree of personal risk. Simon, as a fellow member of the same prominent UK disability anti-austerity protest group, associated activism solely with more masculine, public, vocal and antagonistic acts e.g. civil disobedience, protest and direct action. Simon for example spoke of how activism for him was about:

> Rebellion, rebellion (laughs), yes rebellion… It's rebellion and also fighting for your rights and fighting for things we all deserve.

While not advocating for the sole use of direct action or protest, Rebecca similarly placed a particular emphasis on public forms of activism saying:

> I think an analysis of the kind of different ways that are useful for challenging injustice [is helpful but] you should be prepared to kind of do the placard thing (laughs) as well, but not everyone does.

In line with changes in scholarship around activism (see Askins, 2014; Horton and Kraftl, 2009a; Pottinger, 2017), the vast majority of participants (except for Darren and Simon) saw the need to recognise activism as comprising of a variety of different forms, far beyond solely the public and the visible. Sophie, a young disability activist who had only recently become involved in campaigning around changes to Disabled Students' Allowances (DSA) and funding for ME (Myalgic Encephalomyelitis) research, perceived the notion that protest and direct action were the most valuable forms of activism as being incredibly ableist, as she recounts:

> I think people who argue that it's not real activism unless you're protesting or if you're in a group are really ableist to a certain extent.

Alex similarly echoed this view, noting:

> It's really important that we recognise that activism has so many different forms. There can be in-house arguments between different arms of activism, saying well you should do it this way, you should do it that way, that's bad activism, that's good activism. We're a really diverse community and for our people to be able to join in, all of our people to be able to join in, we have to have as diverse ways of joining in as possible.

Alex here emphasises the importance of both opening up and acknowledging a variety of avenues through which individuals may engage in activism - mindful of how disabled people may have varying needs, abilities and strengths. Recognising this diversity is seen as essential to ensuring an inclusive movement. Alex suggests that every act of resistance (regardless of how small or supposedly insignificant) should be recognised as having value and importance, chipping away and contributing towards change. Private, small-scale, everyday acts according to some participants such as Alex, also count as activism and have the potential to bring about incremental yet significant change - this finding is echoed elsewhere by Martin et al. (2007). Research by Askins (2014), Horton and Kraftl (2009a) and Pain (2014b) similarly acknowledges that engaging in activism extends far beyond that of the 'grandiose, the iconic, and the unquestionably meaning-ful' (Horton and Kraftl, 2009a: 14), it can be identified in smaller, more intimate encounters. Judith draws attention to the wide array of acts (often private, mundane or small-scale) which she believes comprise activism:

> Well, I think activism comes in different forms. There are those who feel that direct action is the best way forward, to get out on the streets doing protest, through breaking the law, through petitions *et cetera*. Then there's the activism through what I call negotiation through committees and then there's the activism in writing and the arts. So, we have different facets to our movement.

Judith's account draws attention to the variety of ways (albeit not exclusively) in which individuals may engage in activism, be this through the arts, writing, protests, petitions or committees. Despite enduring hierarchies of activism (as mentioned above by Alex) operating within some circles of the Disabled People's Movement, the majority of participants' accounts highlight the need to broaden understandings of activism to ensure that as many people as possible can participate and that it becomes an inclusive activity. Liz similarly drew attention to how forms of activism often work in conjunction or parallel to one another:

> Each of these different forms of activism work in conjunction with the other. Also, sometimes they open doors to the others. So yes, I think it's really naïve when there's an assumption that there are right ways of doing it or certain ways are ok and certain ways are not relevant. There's a complete package.

Jessica further expanded on this point, when saying:

> Often people feel bad for not being people who are chaining themselves to stuff. But you need a mixture, a whole load of skills and personalities to make campaigning and activism work. Because if you have fifteen people that only want to hold the microphone or the megaphone, then you're not going to get anywhere… So, it's a collective activity that you kind of have to appreciate everyone that's part of it and I wouldn't be able to do the kind of activism that I do, without the likes of DPAC. Because DPAC enable me to seem reasonable in the context of politicians that are terrified of disabled people. Equally, I make Liam (a friend and fellow disability activist) seem reasonable because Liam is willing to put up and shut up a lot more than I am. So often, Liam and I will go into a meeting and I will say something that puts people's backs up and then Liam will back me up and then it seems more reasonable.

Jessica makes clear that a variety of different approaches and personalities are required cooperating with each other to bring about change and make activism successful. This appreciation for different practices under the banner of activism is further explored through the following chapters. Chapters 6, 7 and 8 will explore the variety of forms and spaces in which disability activism is currently taking place - from the small-scale, private and intimate to the large, public and visible, along with anything in between.

5.7 Conclusion

This chapter has explored what participants perceive as activism along with their various routes into it. Engagement in activism may not necessarily be underpinned by clear triggers or spurred on by a specific event but rather be ignited by a build-up of events (or issues), which may culminate in prompting an individual to call out such injustice. The chapter has further drawn attention to how current activism in response to austerity differs from that of disability activism in the past, being underpinned by a real sense of fear and urgency. Further, it highlights how some participants associated activism solely with engagement in public forms of protest or direct action. Nevertheless, there is a growing recognition amongst other participants of the need to embrace alternative forms of activism, to ensure a larger and more inclusive movement in response to austerity. This chapter, therefore, serves as the basis and background for the following three chapters.

We now move to the second findings and analysis chapter, the first of three that will explore the spaces in which disability activism is currently taking place. The focus of this first chapter will be on public forms of anti-austerity activism such as protest and direct action.

Chapter 6 'Actions speak louder than words'[9]: Public spaces and forms of activism

> The placards were ready, and the megaphone was switched on. Each individual stood in a line and faced the oncoming crowd. They were braced and they were ready. The scene was tense, I felt the anger and rage of those raising their voices on the megaphone. There was a sombre mood. This was no fun and games, this was serious. (Participant observation 14th July 2017 at a protest about disability benefit cuts, outside the opening ceremony of the World Para Athletics, Queen Elizabeth Olympic Park, London)

As chapter two noted, the Disabled People's Movement first emerged in the United Kingdom during the 1970s and 80s, inspired by the civil rights movement in America (Campbell and Oliver, 1996). The movement became known for its engagement in protests, marches and acts of civil disobedience (e.g. sit-ins and road blockades) to bring about awareness of the injustices being faced by disabled people (e.g. discrimination, inaccessible transport and institutionalisation). As a population group, largely excluded and marginalised from wider society, these acts were intended to increase the visibility of disabled people in the public sphere, to have their voice and concerns heard and raise awareness of the barriers they faced to inclusion. This chapter will draw upon the accounts of activists who are (or have previously been) involved in disability protest and direct action, to explore how these actions have been adopted in the context of austerity. The chapter will highlight the value of public protest as an avenue for activism, highlighting some of the key tactics and strategies deployed as part of this approach and some of its critiques. The vast majority of participants in this study had been involved in some form of disability protest or direct action (n = 21/27) and as mentioned in the previous chapter, a small number of participants solely associated 'activism' with these approaches.

Protests have typically been regarded as high intensity, fast-paced and fast-moving (Harvey, 2012; Routledge, 2019), relying upon numerous bodies occupying and moving through a particular space in tandem. The ideal activist has been conceived as a mobile person (most likely that of a young, non-disabled man), who can respond quickly and defiantly to changing obstacles and demands (Coleman and Bassi, 2011). Disabled people in contrast often experience numerous barriers to physical mobility accompanied by limited social and financial resources, restricting their ability to travel to, engage and keep up with protests and direct-action activity. Despite

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[9] Disability activist, 15th February 2018 during participant observation at a disability activist gathering in London.

these barriers disabled people nonetheless do protest, but little academic work has explored the manner in which they do this.

The key themes that therefore emerge in this chapter include how disability activists have actively sought to adapt their actions and spaces of protest to accommodate for a wide variety of bodily capacities. The disabled body will also further be analysed as a potentially valuable vehicle within disability protest and direct action. The body serves as a central part of protest and direct action as an argumentative force, which has largely been neglected within analyses of protest in social movement studies (DeLuca, 1999). Theories of social movements have largely overlooked the role of the body in collective action (Gamson, 1997; Taylor, 1998). The experiences of disabled people serve as a useful case for understanding the agential potential of the protesting body, with the body serving as either a vehicle through which to convey a message or as a message in and of itself (Sasson-Levy and Rapoport, 2003; Tyler, 2013). Since the body is at the centre of relatively new identity-based movements (e.g. LGBTQ+, Black Power, disability), it is important that we understand both its role and purpose in protest (DeLuca, 1999).

Along with critically analysing the role of the disabled body within disability protest, the chapter will also consider the role of emotions in motivating, sustaining and at times prohibiting protest and direct action. The chapter will add to the limited existing literature on disabled people as political actors, along with the evolving shape of the Disabled People’s Movement at a time of austerity. In doing this, the chapter will challenge conventional understandings of protest and direct action as spaces that are occupied by non-disabled bodies and which are underpinned by masculinist and ableist assumptions (i.e. the common conceptualisation of protestors as individuals who are prepared to stand up and put their bodies on the line) (Coleman and Bassi, 2011). The chapter will also further critique existing scholarship that fails to consider the disabled body in its valorisation of public spaces of activism (Della Porta and Diani, 2015; van der Heijden, 2014).

6.1 Early experiences of the Disabled People’s Movement

Many participants in this study were involved in the initial establishing of the UK Disabled People's Movement and its early protests and direct action. During the 1980s and 1990s, protests organised by the Disabled People’s Movement were predominantly around segregation, a long-standing issue that had become ingrained into society through societal attitudes and unrelenting environmental barriers. Claire, Elaine, Judith, Liz, Lisa and Mary all noted what an exciting period this was for disabled people. Liz Crow who is now in her 50s and a disability artist-activist felt that it was important that she be named in this study, to both raise her profile as an artist-activist and also to gain greater visibility of her work. For this reason, I have not replaced Liz's name with a pseudonym. Liz initially became involved in the Disabled People's Movement during the late 1980s, having experienced institutional discrimination while at school and university. She recounts:

> The very, very first thing I did… was in relation to social security. There was a big march organised by disability organisations in London to Elephant and Castle [the location of the then Department of Health and Social Security] to demand changes in benefits. I don't know how many of us there were, many hundreds… it was big [and] extraordinary that, that number came out. It is hard to convey how physically difficult it was for that number of disabled people to come to a single place.

Living in Bristol at the time, Liz expressed feeling isolated and removed from the growing Disabled People's Movement which was (and continues to be) predominantly centred in London. During this time, there were no wheelchair-accessible public buildings in Bristol in which disabled people could meet. There were also very few means for disabled people to connect or come into contact with one another unless they had met while in segregated education or at a rehabilitation unit (as was the case for many individuals who were originally at the forefront of the Disabled People's Movement). As a result, these initial protests and direct actions were said to be exhilarating, providing Liz and others, in their own words, with a great sense of joy, community and belonging. They also allowed for a focus on the hidden barriers that were facing disabled people, as Liz went on to say:

> It was an extraordinary, extraordinary time actually. In terms of building community and having a public presence in creating a representation of disabled people that was completely unknown in history. And being able to go out there and both confront non-disabled people with the reality of the extent of our exclusion but also potentially, educate and bring people around to aligning with us.

Similar to that of scholarship on LGBT activism (DeLuca, 1999; Fish et al., 2018; Pitts, 2000), Liz illustrates the importance of visibility in public protest, as a means of ensuring that wider society encounter difference – especially that of different bodies, along with hopefully being unsettled and educated around the social exclusions faced by these groups.

Claire, expressed a similar sentiment, noting how exciting and extraordinary activism was during this period, with disabled people beginning to be seen in the public arena. Claire is now 49 and has been a learning disability advocate for several years, having experienced social exclusion and institutionalisation as a child with learning disabilities. The barriers disabled people faced to social inclusion were therefore not only environmental but also social and attitudinal. She spoke of how her first engagement in disability protest had been attending a protest about the problematic representation of disabled people as objects of pity and charity in the media:

> My first protest was to stand outside whatever the London regional station was at the time with Mike Oliver [a leading figure within the Disabled People's Movement] and everybody else, you know, with all this music… I came down with a placard and I was standing there, thinking this is my first direct action and I've never looked back since (smiles)... It [was] great to be amongst disabled people who were angry, knew about rights and not charity.

These protests, therefore, created a greater public presence and visibility of disabled people, with individuals actively seeking to both challenge and reclaim their representation. Protests also served to create a space in which (politically active) disabled people could connect, interact, come to know one another and tell their own story on their own terms, in doing so, speaking back to dominant media discourse. The Disabled People's Movement as seen through Claire's quote has conventionally been seen to be based upon pride, focussed upon strength and justice, rather than charity and pity.

6.2 The role of protest in the Disabled People's Movement today

In contrast to the earlier experiences, more recent protests in response to austerity have exerted a greater sense of urgency, actively seeking to expose state violence. For numerous disabled people, austerity has brought about unbearable hardship, pushing many into a state of crisis. This was indeed the case for the majority of participants, who expressed how difficult life had become for them as a result of austerity (see section 5.2). There have been instances where disabled people have been pushed to suicide as a result of unrelenting welfare reforms (Malik and Domokos, 2012). Two participants in this study confided in me that they too had been close to attempting suicide as a result of austerity reforms. As a result, activists have had to step up, with austerity posing as an immediate threat to the lives of participants and that of disabled people more broadly. Consequently, the focus of recent forms of disability protest and activism, expressed by participants, has been more around the crux of being able to survive, with protests being organised quickly and haphazardly as an urgent response to ongoing reform. These protests are often framed as matter of life or death, with protestors for example, frequently chanting and displaying banners with slogans such as, 'Cuts Kill' or 'No more deaths from benefit cuts'. While some protests have been criticised for being too dramatic and scaremongering, for disability activists the urgency of the current situation is very clear and real:

> We are in a battle for the right to live, for the very right to exist. It's not just about benefits, it's about our rights as disabled people being eroded. (Anonymous activist quoted during participant observation at a Universal Credit protest, Westminster 18th April 2018)

Attaining visibility through protest and direct action remains an important part of the Disabled People's Movement today, with protest groups such as DPAC and Black Triangle amongst others actively seeking to utilise protest and direct action to raise awareness of the impact austerity is having on disabled people and their rights. Rebecca who is 41 became involved in DPAC in 2011 (a year after it was established) and now sits on the organising committee and is a spokesperson for the group. She has spent the vast majority of her working life on campaigns for user-led and self-advocacy organisations. Rebecca explained to me that founding DPAC was a conscious move to revitalise the movement, which she argued had experienced somewhat of a decline since the mid-1990s:

> When DPAC was set up, it was kind of a feeling that the disabled people's rights movement had lost its radical edge. So, the idea of DPAC was to get that back, to kind of remember how to chain wheelchairs together again and you know, block the street.

With the emergence and implementation of various pieces of disability legislation during the 1990s, including that of the 1995 Disability Discrimination Act and the introduction of the 1997 Direct Payments Act, disabled people's demands were seen by the public and government officials to have largely been met (Oliver and Barnes, 2006). The implementation of such policies and legislation served to stifle and forestall, more militant forms of activism for a period (Oliver and Barnes, 2006). Those who had lower levels of impairment decided to exit the movement, having had their needs largely met, leaving those with higher levels of impairment behind. It is only really since the closure of the Independent Living Fund and Disability Living Allowance, that there has been a re-emergence of more militant forms of disability activism.

DPAC has a very distinct style of protest, which usually involves utilising the disabled body as a vessel in their resistance, i.e. through chaining wheelchairs together and remaining in situ, serving as a form of disruption and refusal. The group has become renowned for its engagement in direct action in order to bring to light the challenges currently facing disabled people as a result of austerity cuts. Actions have included barricading the entrance to the House of Common Chamber with wheelchairs in 2017, the closing of Westminster Bridge in 2016 and chaining wheelchairs together in order to block the VIP entrance to the Conservative Party Conference in Manchester in October 2015. It was not uncommon during participant observation to hear the phrase 'are you ready to do it the DPAC way?' before group members took hold of their placards and positioned themselves in the centre of an oncoming crowd or sought to enter a private premises. DPAC protests have ranged greatly in size and scale with the smallest protest I attended consisting of around 7 individuals to the largest being around 30 people. While the group has factions across England and Wales, its largest, most renowned and well documented actions appear to have taken place in London and Manchester, due to DPAC members being particularly active within these areas and the organising committee being based in London. Protests are organised strategically and tactically around particular sites of oppression or decision making (e.g. government buildings, institutions or disability benefit assessment centres). Routledge (2019: 146) has recognised protest as a 'tactical performance' through which activists seek to both reclaim and reframe a particular space, challenging the meanings and feelings commonly associated with it. A number of protests, for example, took place in and around parliament, as one of the key sites of decision making in the UK for example the 'Lobby of Parliament for Independent Living' (18th July 2017) and the 'Universal Credit National Day of Action' (18th April 2018). With parliament (a supposedly democratic and representative site of decision making), being seen to have failed or ignored the voices of disabled people, becoming visible is seen as one of the only mechanisms through which disabled people can seek to have some sort of voice and claim their rights as equal citizens. These protests were therefore orchestrated to gain the attention of members of the public, the media and that of parliamentary members.

Along with being strategically located, protests and direct actions were often organised at a symbolic point in time or at short notice (e.g. as an urgent response to a policy change). This appears somewhat in contrast to disability protests that took place during the 1980s and 90s, which participants expressed did not expel this same sense of urgency. For many disabled people at the time, the daily discrimination and segregation they faced had become both normalised and deeply internalised (Goffman, 1963) - many could not imagine an alternative.

One of the protests that I attended, which was called at short notice, was a protest that took place outside Southampton City Council on February 15th 2017 about what were deemed to be unethical practices by the outsourced benefit assessment contractor -CAPITA. The protest was organised within the space of a fortnight, taking place after a whistle-blower shared with the Disability News Service[10] how CAPITA had put increased pressure on its assessors to reduce social care spending at the demands of Southampton City Council. It was therefore important that the protest take place promptly to shame both councillors and contractors alike. Liz noted both the importance and potential of protests in such instances:

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[10] Disability News Service is an online news outlet specialising in disability issues.

> If you’re dealing with an emergency, there isn’t time to have a conversation, you actually just need to get on with it and so that very direct, confrontational activism is almost certainly what you need there. But alongside that, you're still going to need to think about the long term.

The speed and temporality of such actions can, however, mean that they are largely responsive, potentially not as well thought through and serve largely as a form of fire-fighting. Nevertheless, they can also be an effective mechanism through which to increase short-term visibility of an issue in the public domain. Protests often have a particular temporality, rising momentarily, and then subsiding. Not only do protests take place at a particular moment in time but they can also disrupt time and space i.e. the presence of the disabled body in the road calls for the road user and observer to both pause and slow down (see Dean and Jones 2016 and Devlin 2016 on the reporting of a 2016 anti-austerity disability protest that took place on Westminster Bridge). The disruption of time and space similarly became visible through my field note observations from a direct action which took place on a major road beside the ATOS headquarters in London on 21st July 2017:

> Following an hour or so of protesting outside the main entrance of ATOS, we have now moved on and are blocking a nearby road in an attempt to gain greater visibility... When we arrived here, we stood at the pedestrian crossing and waited for the lights to change. Once the green man appeared, we started to cross and then to my utter surprise, we stopped and froze right in the centre of the road. For a moment or so there was complete silence as we positioned ourselves and our banners. A number of pedestrians stopped to point, stare and read our banners. All I could see at this point was the vast lines of cars which had accumulated in front of us, each stationary and still. The silence didn’t however last long, car horns are now blazing, drivers are shouting and swearing, the pedestrian crossing is ringing, and we are doing our best to chant louder and louder. There is so much noise around me, but somehow everything seems so still…

It could be said that in pausing, we stop the clock for a moment, notice our environment and potentially what a protestor is seeking to draw our attention to. The above field diary extract demonstrates this perfectly, signalling how momentarily, protests can pause time, forcing passers-by to stop and take notice.

Richard noted how important it was for disabled people to be both seen and heard in the context of an increasingly hostile environment towards disabled people:

> Disabled people have been shut off, cut out, pushed aside. They've been labelled with pejorative terms, scroungers, lazy, a drain on the resources of our country *et cetera*, *et cetera*, *et cetera*… as disabled people we have a right to be heard and we have a right to fight back.

Richard raises an important issue here, that austerity has not solely been about cuts to benefits but also about an ideological campaign against the receipt of welfare, which has been heavily reinforced by the tabloid media (Daily Mail, 2012; Slocan, 2010). As such, the battle for disabled people has not solely been about raising objections to austerity cuts but also about a wider battle to reclaim dignity and respectability. We might argue here that earlier representations of disabled people as objects of charity and pity have gradually morphed into objects of disgust due to their receipt of welfare (Clarke and Newman, 2012; Power and Bartlett, 2018). The nature of disability activism has therefore altered significantly in line with the changing context i.e. pre- and post-austerity.

Richard is 49 and has been engaged in disability activism since he became disabled after a motorbike accident during his 30s. Frustrated with the way in which he felt disabled people were being treated, Richard established a disability protest group (a faction of DPAC) in his own city, in the South East of England. Disability protest was not only about lobbying the government and the public but also about providing disabled people with a sense of hope, as Anna notes:

> We've got to be seen to be visible… resisting this government by any way we have, to give people hope that something can be done.

Anna who is 46, has been heavily involved in disability protest and DPAC since 2012, having lost two close friends through suicide as a result of disability benefit reforms. Protest was seen by Anna as a means through which disabled people could demonstrate that they are political actors and would not passively put up with such measures:

> When you do that banner job, when you occupy parliament, when you shut that road down, when you've stopped trains from leaving… it gets to the wider public. You've got to be seen to be visibly fighting back.

Visibility was deemed to be particularly critical to disability protest in response to austerity, as many of the issues currently facing disabled people may be invisible to the wider public (e.g. changes to disability benefits, welfare and adult social care). Along with using statistics around the impact of austerity cuts and individual stories, the visibility of disabled bodies further personalises the debate and gives a human face to stories of suffering. Thus, exposing the real lived impacts of state-sanctioned austerity (Butler, 2015c; Ryan, 2019) and the ways in which it can make life for some, unbearable or un-liveable (Malik and Domokos, 2012).

6.3 The protesting body

The body serves as a central component of protest and direct action, it is therefore important that we critically interrogate the role the body plays within such action. Protest and direct action were deemed by Rebecca and other participants as an important means through which disabled people could use their bodies to visibly express their objection to austerity policies and reforms:

> It's all about "We're still protecting the support of those who are most vulnerable" and when you've got people who look the stereotype of most vulnerable in wheelchairs out there campaigning then that's kind of visibly showing [this is not the case].

The disabled body in this instance is instrumental in carrying the political message of dignity and rights - the right to a liveable life. This was further illustrated through the five disability protests I attended in London from July 2017 to April 2018. During these protests, wheelchair users and those reliant upon walking aids and/or mobility scooters were prominent, often encouraged by protest organisers to take a position at the forefront of a protest. Their bodies here became central to their argument, in terms of demanding their treatment as full and equal citizens. Methods such as this were deemed particularly helpful as a means of creating images that attract widespread media attention. Roland Barthes (2007) has noted how some photographs include a 'punctum', a sensitive point in an image, which pricks, bruises and disrupts a particular viewer out of their usual viewing habits (see Cloke, 2013 on Ingrid Pollard's photography of black women in the British countryside). Through occupying this space, disabled people were visibly articulating and performing their right to equally occupy public space and be included within society. The visibility of certain bodies can be seen as an act of defiance, a refusal to be hidden away, marginalised and silenced (Campbell and Oliver, 1996; Cloke, 2013; DeLuca, 1999). Through making their bodies visible to the public, activists sought to challenge their exclusion from society and assert political identities and rights that had been withheld from them.

Individuals sought to challenge the common misrepresentation and public perception of disabled people as passive and agentless. Protestors decorated their wheelchairs and scooters (as extensions of their bodies) with banners, badges, stickers and placards, see photographs below (figures 2 -4):

Figure 2: Photograph of a decorated wheelchair at ATOS Kills Protest, ATOS Headquarters, London 21st July 2017. Source: author.

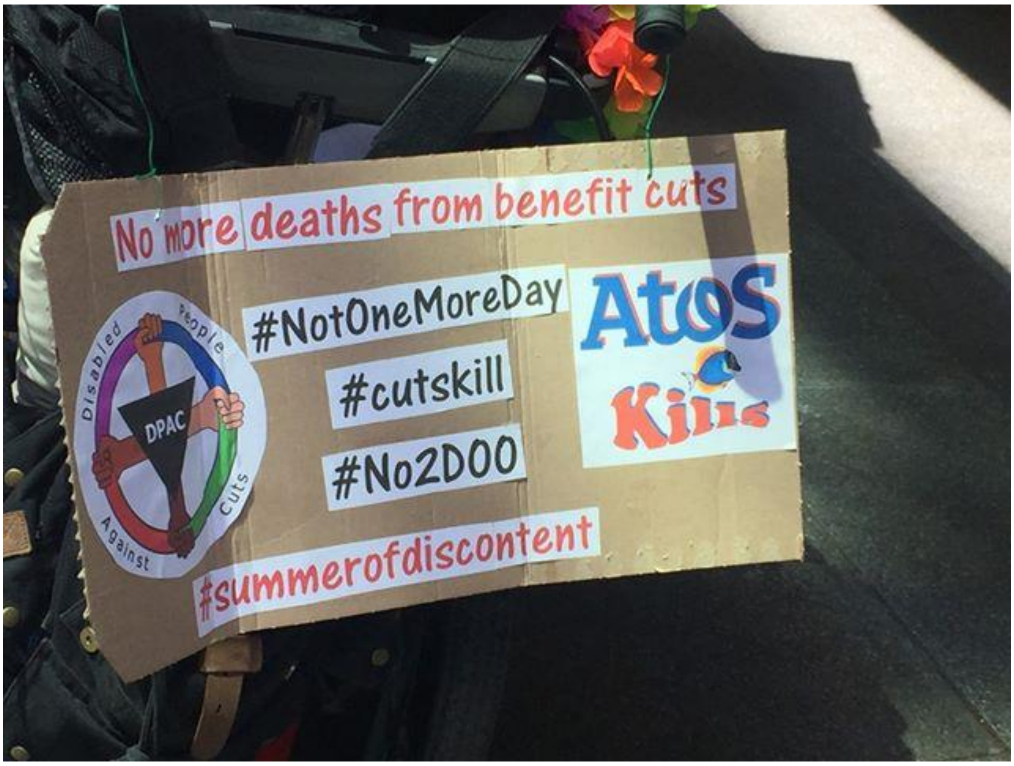

Figure 3: Photograph of a banner on wheelchair at ATOS Kills Protest, ATOS Headquarters, London 21st July 2017. Source: author.

Figure 4: Decorated walking aid at a protest against the removal of guards from trains, Department for Transport, London 20th July 2017. Source: author.

Journalist Francis Ryan (2019) documented a similar practice taking place as part of a protest outside the Department for Work and Pensions (DWP) headquarters in 2014 against the closure of the Independent Living Fund. In the 2014 protest, a protestor had constructed a makeshift cardboard prison cell, which was wrapped around their wheelchair. On the cardboard cell, were written the words: ‘Without support, we become prisoners in our homes’. Mobility aids can therefore be used as a further tool in individuals’ resistance.

Through drawing upon a relational approach (Andrews and Duff, 2019; Hall, 2019), we can see how the wheelchair, cane, or walking aid may be regarded as an extension of the body and as an instrument within resistance. Connections can also be made here to literature discussed in section 3.3 on the potential of the body to serve as an arena for resistance and self-expression (Carroll and Anderson, 2002; Featherstone, 1982; Gimlin, 2006; Twigg, 2007). The body can be utilised as a space to protest against normative codes and hegemonic identities. Little research has however explored how mobility aids, technological or assistive equipment can be personalised and used to further articulate one's identity, beliefs or values.

Importantly, not every participant had a visible disability. Some activists with poor mental health, learning disabilities and/or other invisible disabilities, noted how they often felt uneasy and ’out of place’ (Kitchin, 1998) occupying spaces of disability protest, fearful of how the public may perceive them, particularly at a time when narratives of benefit fraud are rife. Simon for example noted how he was often confronted during protests by members of the public, due to him not looking visibly disabled:

> You saw it on that [protest against CAPITA 21st July 2017, London]… when that bloke came up to me and he said to me, you’re not disabled. But my disability is invisible. I have anxiety and depression so I look like I’m healthy and strong but I’m not.

The man that Simon refers to here physically confronted him during the protest and sought to take his banner from him. Simon felt upset and infuriated as a result of this encounter. Such instances of prejudice were not uncommon; I myself received several comments from members of the public during protests such as ‘You look normal so what’s your problem?’ (14th July 2017, Queen Elizabeth Olympic Park). It is not uncommon for activists to develop strategies to manage this prejudice, as illustrated in an observation from a protest against the closure of the Independent Living Fund in and around the House of Commons on 19th July 2017:

> I walk alongside one of the young female activists whom I had met previously. She is very excited and jumps onto the back of her ‘walker’ and glides down the slope in excitement to the security area. I talk to her once we are in the queue inside the foyer and she explains to me that “I am going to sign to you. I know you won’t understand it but if I don’t, they’ll [security and police] think I’m a scrounger or faking it?”. This was a practice which she said she adopted regularly.

The above accounts demonstrate the difficulty of campaigning and occupying spaces of disability protest as an individual with an invisible disability. They also raise questions around who is perceived as having the right to represent or speak on behalf of disabled people. Many were as such found to be engaging in practices that might be understood as ‘inverse passing’. While ‘passing’ or concealment in disability studies has been used to refer to practices which disabled people engage in, in order to be seen as ‘normal’ and undifferentiated from non-disabled others (Gilson et al., 1997; Southwell, 2012), here within the above extracts we can see practices through which individuals conversely, actively seek to be recognised or acknowledged as disabled in order to ‘fit in’ to the disability activist community. While earlier disability protests, which took place during the 1980s were about creating a more powerful disabled identity, the welfare benefits system has created a system where disabled people are having to demonstrate their weaknesses rather than their strengths, for fear of being deemed 'fit for work' and/or ineligible for support (Burke and Crow, 2017). With the continuous circulation of discourses such as 'scrounger', 'skiver' and 'shirker', there is an ongoing fear amongst activists (particularly those with invisible impairments) that they will be deemed inauthentic or 'faking it'. Appearing too 'able' was seen by some activists as having the potential to undermine their argument i.e. their call for welfare and support. Moreover, activists for the most part, appeared to be policed more by the public and onlookers than by fellow activists. Most activists recognise that not every disabled person has a visible impairment, nevertheless, there is still an active push for those with visible impairments to be placed at the front and centre of protests, with these individuals seen to better represent the face of the movement, along with the undue hardship and inequality faced by disabled people. In order to feel more comfortable and to gain a sense of belonging/being ‘in place’ (Kitchin, 1998), some activists adopted strategies such as wearing t-shirts or clothing which indicated that they had an invisible disability, as seen in the below photograph:

Figure 5: Photograph of invisible disability t-shirt at a protest against the closure of the ILF, Westminster 19th July 2017. Source: author.

6.4 The disabled body: playing with notions of vulnerability

Through engaging in protest and direct action, many participants saw the potential to challenge perceptions about themselves as disabled people. Liz for example noted in relation to the 1980s protest around disability benefits:

> There was a march to Elephant & Castle [in the] late 80s… where the Department for Health and Social Security was. The idea was that we'd have a polite little march there, we'd hold our banners and we'd turn around and we'd go back again [to where we started]. We'd been issued with little notices saying 'don't forget your macs in case it rains' (laughs) and you know, that was the level of it back then and the inexperience of it. And we got there and there were enough of us who went "hell no! we're not going anywhere!" We just sat down at Elephant & Castle roundabout and stayed for a couple of hours, while a number of the organisers were saying 'please move', 'please move'. Because you know it was felt that reputations were on the line and it was just this sense amongst a number of us that if we didn't start to push a little more, that things were really never going to change. It was time to stop being the kind of disabled people we were required to be, of being polite and thankful and so forth.

In the above extract, we can see how this protest served as space through which disabled people could both perform and articulate their agency and autonomy. The protest had been coordinated by disability charities and organisations (which were largely run by non-disabled individuals), with the intention of being a relatively short and uncontroversial event, which sought to highlight some of the issues being faced by disabled people. However, by taking control of the situation by sitting down in the middle of the roundabout and refusing to move, disabled people demonstrated that they were frustrated with being controlled and told what to do. They sought to articulate their agency and autonomy as independent political actors by putting forward an alternative, autonomous, and courageous body. Liz continues:

> … We stayed there and it was really quite effective and the police didn't have any idea what to do with us, because they'd never come across disabled people doing that sort of thing before. They didn't know what to do in relation to our bodies back then, so we were able to do more with activism than a lot of non-disabled people.

Police officers were unsure of how to approach and/or breach disabled bodies like Liz's. This, therefore, gave them more time and freedom to perform their message. It provided activists with a sense of control and power, as Liz went on to explain:

> It was just this sense of us coming together that was quite magical and powerful, that refusing to move… and realising it was ours [disabled people in a position of power and 'owning' public space], probably for the first time, was really quite significant.

Similar practices can be observed within more recent disability protests in response to austerity, with wheelchair users often commanded to the forefront of protests due to police and enforcement officers often being unsure of how to approach the disabled body without inflicting harm. The vulnerable body here becomes a potential source of strength, similar to that outlined by Tyler (2013) on maternal protest and Hammani (2016) on women's protest on the West Bank, potentially allowing individuals at times to achieve more with their activism.

Where disability protest has however changed from that of the 1980s and 1990s (as outlined earlier by Liz) is that it conventionally was about presenting a courageous identity and of being able to take over public space despite impairment. While some of this remains, there is now a greater emphasis on highlighting one's impairment in order to remind both the government and the media that austerity measures and benefit cuts are unjust.

This practice of placing 'vulnerable' bodies at the front and centre of disability protests can be observed within the following photographs (figures 6 – 9), whereby wheelchair users (as emblematic of 'vulnerable' bodies) are found at the forefront of each protest:

Figure 6: Photograph of disabled protestors blocking a road during a protest against the removal of guards from trains 20th July 2017, Department for Transport, London. Source: author.

Figure 7: Photograph of wheelchair users blockading the House of Commons chamber door during a protest against the closure of the ILF, Westminster 19th July 2017. Source: participant - printed with participant's consent.

Figure 8: Photograph of protestors holding banners and blocking the road beside the House of Commons during a protest against Universal Credit, Westminster, 18th April 2018. Source: participant - printed with participant's consent.

Figure 9: Photograph of protestors in wheelchairs gathered in a circle in the central lobby of the House of Commons during a protest against the closure of the ILF, Westminster 19th July 2017. Source: author.

The imagery of protests whereby wheelchair and mobility scooter users are at the forefront of collective action is tactical, designed for mass media dissemination and increased visibility, with vulnerable and taboo bodies being placed at the centre of attention (Tyler, 2013). Alex who is a wheelchair user in her early 40s noted how she often played with the notion of vulnerability as part of her engagement in disability protest and direct action:

> Blagging my way into buildings and things is one of my little skills... when you're a disabled person it just throws people, doesn't it? They all do that whole, I don't know what to do thing. So basically, whatever you say, they believe you. That's my tip for life. That prejudice, it causes us so much harm but if you know how to use it on a protest, it can be really helpful (laughs).

Alex attests to how she can challenge common perceptions of disabled people through her engagement in protest. While disabled people are not necessarily inherently vulnerable, Alex notes how she and others, actively choose to play on their perceived vulnerability for a strategic reason (e.g. to challenge the government's harsh workfare politics) (Butler, 2016). This practice should therefore be recognised as agential with activists re-appropriating (or as Alex attests – weaponising) their bodies and stigma, as part of their activism (Butler, 2016). We can therefore see how perceived vulnerability and dependency can be used by disability activists as a source of strength.

Like other protest movements such as the LGBT+ movement, the body is front and centre of disability protests, as the protests concern its care, treatment, recognition and freedoms (DeLuca, 1999). Disability protests (like that of other social movements) highlight the freedom to be visible, to exist and to be seen as equal citizens (Campbell and Oliver, 1996). In their protest, the activists use their bodies to point towards the injustice of welfare cuts and stigmatisation. Through coming together these individual vulnerable bodies use their vulnerability to form a larger collective body of strength and courage (Butler, 2016; Hammani, 2016). Drawing upon this embodied collective strength, individuals make a claim to equal citizenship and articulate their right to access a level of care and support that enables them to live independently in the community.

6.5 'We sit, stand and roll with them in solidarity'[11]: How participation in direct action is shaped by individual bodies and austerity

Protests are typically conceived as being high intensity, fast-paced and fast-moving (Harvey, 2012; Routledge, 2017, 2019). As a consequence, disabled people often experience numerous barriers to participation. Mobility impairments along with a lack of financial resources may for example make it physically difficult for disabled people to arrive at a space of protest, let alone participate. Disability activists have however been proactive in seeking to adapt such actions and spaces in order to accommodate for a wider variety of bodily capacities. The health conditions and disabilities of activists may mean they require equipment when protesting e.g. foldable camping chairs, accessible taxis/bus to get them to and from places. They may also require supporters or allies to help them while travelling and demonstrating e.g. guiding individuals, providing sign language interpretation or acting as a walking support. Activists' disabilities were one of the main challenges that defined their forms of protests and resistance, with it being hard to convey how physically difficult it was for some individuals to attend such events. At times this meant slowing down the overall pace of a protest (despite the general resistance towards slowness in activism), to enable the full inclusion of protestors regardless of their bodily capacities (see Genz, 2016 on 'retiree rebels'). Protests would often be of a static nature (rather than consisting of a march from one location to another), allowing space for individuals to sit-down (when needed) and take

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[11] Anonymous disability activist, 14th July 2017 quoted during participant observation at a protest against disability welfare cuts, outside the opening ceremony of the World Para Athletics, Queen Elizabeth Olympic Park, London.

regular breaks. The consequences of not making a protest space accessible became evident in one protest which took place against the removal of guards from trains outside the Department for Transport's headquarters in London on 20th July 2017. Due to the limited available space outside the Department for Transport, there was not sufficient space for disability activists to sit down. As a result, some activists became both frustrated and distressed, due to having difficulty in standing up for long periods of time. One woman, in particular, had to ask others to support her to stay upright, as she was beginning to wobble and gradually losing the ability to hold herself. Eventually, a place was located for the woman to sit down, however she was clearly in some pain. She told me that her usual strategy was to arrive late at protests, so as to avoid having to stand for long periods of time. Through the above, we can see how difficult it can be for some disabled people to occupy spaces of protest without appropriate adaptions. In addition to this, it also highlights the ways through which the individual body is supported by the wider activist body, serving as a metaphorical example of how solidarity is enacted amongst disability activists within the space of a protest. It was not uncommon during the protests I attended, for at least someone to be tired or in somewhat pain. Having additional individuals for physical and emotional support was therefore essential. Tasks which would be easy for non-disabled protesters such as arranging or setting-up the site and creating protest banners would often take substantially longer for disabled protestors, as Richard notes:

> You're battling with yourself and your own problems. So, it's a harder ask, it's much easier for an able-bodied person to pick up a placard and go and do things like this.

Moreover, it was not always possible to access allies or personal assistants, as was illustrated in he protest against the closure of the Independent Living Fund in Westminster on 20th July 2017, which led to increased stress and tension amongst activists:

> One of the most prominent activists in the group suddenly interrupts us and expresses that "I'm fed up with this. XXX needs a PA (personal assistant). He is at exit 4 [of the tube station]. I now have to go and get him!" When another activist offers to go and collect him, she refuses and speeds off highly frustrated and aggravated with her walker to go and get him.

Disability activists were therefore often reliant upon one another for support in both accessing and attending protests. Non-disabled allies are particularly valued by protest groups, not just for their ability to provide physical support but also to increase the visibility of protests, as Rebecca notes:

> Because we know that we can't get disabled people out in large numbers it's very important to have those alliances with other groups that can come as well.

There were for example attempts to establish online solidarity initiatives where individuals could send someone else to attend a protest on their behalf. The presence of allies at protests were said to also relieve some of the concerns that individuals (with non-visible impairments) had around whether they looked 'disabled enough'. Through attending protests, I became aware of how being there was for many enough of an achievement, as illustrated in the following observation from a protest which took place on 14th July 2017 outside the opening ceremony of the Para Athletics (Queen Elizabeth Olympic Park, London):

> Eventually, we find the group and I was greeted by a number of individuals, many asking my name and where I was from. A woman began to dish out gold medals to each of the activists. As she gave a medal to each of us, she congratulated us, "congratulations, you're here! You've made it!" I saw that others were bending down for her to put the medal around their neck. I soon realise that this was a medal to be worn during the protest.

The symbolic presenting of the medal served to acknowledge how difficult it was for many disabled people to even get to/attend a protest and the challenges they may have faced in doing so. On a small scale (perhaps in comparison to other activists), I myself as a visually impaired researcher experienced at times somewhat difficulty and barriers to attending such protests, as illustrated in this participant observation from the protest on 14th July 2017 outside the Para Athletics:

> What will I do? If I can't see them and I can't hear them, I have no chance. I realise how difficult it must be for other visually impaired people to attend such protests. I think about how funny it would be to write a participant observation or report about being visually impaired and being unable to find the protest. As I begin to give up hope, I see a man heading in my direction with a DPAC t-shirt on. I literally jump to say "Hi, are you a part of DPAC? Are you here to attend the protest today?" He jumps in shock. He looks most surprised. I must have given him a right scare. To my relief, he says yes. I explain that I am also there to attend the demonstration but that I am visually impaired and am having great difficulty finding the group. He told me not to worry and "just stick by me". I realised that over the next week, I would have to make sure I was on time. Protests wait for no one. He explains that he had just seen the group, but got so engrossed in rolling his cigarette, that he hadn't noticed them leave.

The above observation shows the difficulty that I personally had in locating and participating within one protest as someone with a visual impairment. Here, we can see how the speed and temporality of protest can make them difficult for some activists such as myself to attend and keep up with. The intensity of such actions along with the poor physical/mental health of activists, also meant that it was not uncommon for activists to require breaks from their activism. Both Rebecca and Darren for example reflected upon how they had days when they had been unable to participate or take an active role in a protest, due to poor mental health as Rebecca says, 'sometimes I'll just say no, I'm not doing it. I can't do it today, someone else has to do it'. In such instances sustaining oneself and one's wellbeing was dependent upon taking a step back. For others such as Alex, this involved taking longer periods away from her activism when it all got too much:

> People talk about burn out and I think that's just different people's ways of working… I probably do that thing people call burn out now and again, every so many years I have to take a bit of a break for a while. I find that suddenly I can't cope with talking to people all the time because I have mental health problems. I have to take a bit of downtime and then I just come back when I'm ready.

Sheppard (2018) has reflected upon the importance of taking a step back and strategically managing one's energies, as part of her research with individuals living with chronic pain. Pain was something which was often very present within the everyday lives and practices of activists, however, it was a feeling which was rarely discussed within spaces of protest. There appeared to be a tendency amongst activists to either avoid discussing or to keep silent about any pain they may be experiencing, confining this to the space of their homes. Sheppard (2018: 61) noted how for participants in her study, visibly expressing pain was often condemned and seen as transforming individuals into 'objects of horror'. Further, individuals greatly feared being criticised for failing to control their pain. While there could be seen to be value and comfort in discussing experiences of pain (as something from which many cannot avoid, as a central part of their lifeworlds), there appeared to be a substantial amount of social pressure upon individuals to stay quiet and not to express one's experience of impairment and/or chronic pain.

Practices of resistance had to be adapted in new hybrid ways, due to the often-deteriorating health of activists and their limitation in capacity, social capital and time. Disability protests in response to austerity have recently deployed similar practices to those exhibited within the Millions Missing campaign, which sought to highlight the lack of financial resources invested into research around ME (Myalgic Encephalomyelitis). The campaign has consisted of hundreds of protests taking place across the world. As part of these protests, a large number of empty shoes are laid out in a public space alongside the stories of those affected by the illness. Through this approach, individuals were able to engage in protest (through displaying their accounts) while simultaneously not having to be present or leave the space of their homes. Such an approach was particularly helpful for the thousands of people who are bedridden with this illness. Disability protests in response to austerity have at times embraced a similar approach with disabled people attending protests by proxy. An example of this which I witnessed was where activists held placards displaying pictures of those who supported the cause but who were unable to attend or participate due to ill health, as seen in the below photograph:

Figure 10: Photograph of a placard with a cartoon image on it of a woman stood holding a banner. The photograph illustrates how protests can be attended by proxy. Protest against Universal Credit, Westminster 18th April 2018. Source: author.

The activist pictured above took it upon herself to attend the protest on another disabled person’s behalf, with the individual being too ill to participate. Such initiatives were grassroots and small-scale, being driven by one or two key individuals who freely offered to attend protests on others' behalf. Similar examples include the practice of sharing the personal accounts of those who are unable to attend. This is common practice at disability protests, where often those most severely impacted by austerity are unable to attend such events or may not have the capacity to advocate on their own behalf.

Another way in which disability activists have sought to radically adapt their activism as a result of bodily constraints is through the embedding of social media and the internet as part of their protest, a theme more fully explored in the following chapter. Through doing this, individuals were able to virtually participate without being physically present. Along with coordinating disability protests through social media platforms, activists often sought to live stream or document protests online. By engaging in such tactics, it was hoped that protests would gain wider visibility and enable the inclusion of those who are unable to participate in protest due to disability, ill-health or lack of financial resources.

Numerous participants spoke of being unable to participate in vocal and visible forms of protest due to lack of financial means, dwindling care packages or fear of repercussion. Lisa who is in her early 50s has been involved in various forms of disability protest and campaigning since the mid to late 90s (predominantly around the topic of inclusive education following her own experience of attending a special educational needs school during childhood). She expressed her personal concerns and reservations around engaging in conventional forms of disability protest today due to her deteriorating health:

> Kind of this sort of really in your face protest feels really beyond me now because physically I don't feel that I have enough body strength to stand, to cope in a quick-moving demo which they often are. I'm much better if I can rock up to one and speak from the platform or something, because you can do the same job just in a different way.

Lisa is regularly referred to as one of the figureheads of the disability movement as a notable successful ex-Paralympian who is regularly involved in campaigning. She is not however alone in sharing reservations around engaging in protest at an older age. Like Lisa, many activists chose to engage in protest for a limited time, while they had relatively good bodily capacity. Activists often chose to transition to alternative forms of activism later in life, when they felt unable to participate in protest any longer due to deteriorating/ill-health. Along with deteriorating health, the emotional energy required of disability activists engaged in protest can often be exhausting and prohibiting, as Liz notes:

> I think one of the things that shifted with the work I’m doing now, is a realisation that doing forms of activism that are perpetually angry is exhausting and unsustainable. And

> it isn’t just that… I can feel angry about lots of things but there are certain forms of activism where it’s almost written into it that you wear that anger at all times and that’s work that isn’t actually necessary.

Liz felt that engaging in protest and direct action was not something that she could sustain both physically and emotionally for a long period of time, she instead sought to find forms of activism which were less emotionally and physically demanding, as she went on to explain:

> I realise I can't sustain it… I can't imagine ever not being an activist but then it's going back to the breadth of forms of activism. If you subscribe to the idea of it being very broad, then anybody can be an activist at any stage of life with any sort of responsibilities, impairments *et cetera*, *et cetera*. It doesn't exclude anybody if you have that broad form… it's possible to find a form of activism that takes better care of the people who are active within it, which historically activists have been very poor at doing. So, the classic thing is that somebody works very hard at it and they burn out. And they may come back to it later or they may go into a different phase of life. But as a movement you lose people who were INTEGRAL to it and as a movement, you can't afford to do that (laughs). And I don't like the idea of self-care, it's kind of the latest jargon, isn't it? But that idea of figuring ourselves into our activism is really, really important. We aren't just the tool to it and that really needs to be built-in.

Liz, therefore, articulates the need for us to work ourselves into our activism, and to find forms of activism which take better care of ourselves as individuals. Brown and Pickerill (2009) note the importance of emotional reflexivity to ensure activists' personal and collective sustainability and to prevent 'burn-out' (see also King, 2005). While emotions such as anger and fear can be incredibly valuable in igniting activism, they can unintentionally lead to poor mental wellbeing amongst activists. Brown and Pickerill (2009) argue that supportive spaces are required to work through the emotions and ensure activists' sustainability. For Liz, ensuring her sustainability and mental wellbeing involved transitioning into art-activism as an arena in which she could slowly and gradually process her emotions, while also not requiring the physical strength nor the speed, required of protest and direct action. I will turn to consider the various ways in which disability activists have utilised art-activism in the next chapter.

6.6 Emotions in protest

Along with considering the function of the body in protest, it is also important that we consider the role of emotions. Protests serve as spaces of intense emotion, with emotions often recognised as being crucial in both motivating and sustaining activism (Goodwin et al., 2001; Jasper, 1998;

Wilkinson, 2009). As I have previously noted in chapter 5, disability activism in response to austerity has been driven predominantly by strong personal emotional forces, such as that of anger, grief and fear. Public protest in comparison to other forms of activism (e.g. online activism and the arts), appears to both demand and draw upon the emotion of anger as part of its performance. Protestors are often expected to express anger as part of their activism, highlighting their outrage and animosity towards the issue at hand. Activists who were engaged in public protests often spoke about getting themselves into the right emotional mindset, in advance or during a protest. Within these spaces, traditionally masculine gendered performances were required (Coleman and Bassi, 2011), as activists sought to compete with each other to see who could be the loudest, most daring or attract the most attention, as seen in this extract from an observation taken at a protest outside the opening ceremony of the World Para Athletics 14th July 2017, Queen Elizabeth Olympic Park, London:

> I wondered if perhaps the group were appearing too aggressive and unapproachable through their loud, vocal and angry proclamations. There was one activist in particular who even scared me. I realised quite quickly that she was the leader and that there was no way I wanted to get on the wrong side of her. The woman must have bones of steel. As she stood there with her bent stature, walking stick in one hand and microphone in the other, her loud and fierce voice shook me. One could not but listen, her power, strength and determination was clear. No one was going to stop her. Those approaching drew quiet, as her voice stifled the laughter and filled the surrounding area. She was clearly having an impact…

While some activists rose to this challenge, for others this was much more challenging. Some participants spoke about experiencing fear as part of their activism. While fear can be the spur that compels someone to engage in activism, it can also curtail and place limits on the kind of activism a person can engage with. Richard for example, while engaging in activism because of fear (i.e. about a future without welfare and government support), his activism was also curtailed by fear (i.e. what would be the potential repercussions of his actions). Richard noted how he actively sought to distance himself from the limelight when engaging in protest:

> Simply because I'm a claimant… when we did the demonstration at the Guildhall, everyone was like "come on XXX, you've got to….". I said no, I'm a claimant... I'm happy to be there but I'm not happy to be pushed into the limelight so to speak, because you know I don't want that attention, because I might in two weeks' time be called in and they'll say "ohhh! Tick, tick, tick. Weren't you at that demonstration, didn't you wave a

> placard at me?". "Yes, that's right". So, as a claimant it's limited. I think a lot of people are frightened of doing these things…. they understand that they are in the firing line.

Richard feared that being publicly visible engaging in protest could endanger his access to disability benefits and/or social care. He sought to distance himself from the forefront of protests and used an alternative name when engaging with the media. He said that this practice helped him to 'cope with [it] internally and not freak out too much'. Richard was not alone in experiencing such feelings of fear around engaging in public protest, as seen in this observation from 19th July 2017 at a protest about the closure of the Independent Living Fund in Westminster:

> Another woman approaches me and asks if I am part of the group. She had been trying to find us, but the lack of banners and things made it particularly difficult for her. She seems to be at some unease, not knowing anyone there and tells me that she is worried about having her benefits taken away as a result of taking part.

Instead of perceiving certain emotions as solely a resource or motivating factor behind individuals' activism (Hercus, 1999; Goodwin et al 2001), we must also recognise how other un-planned and unanticipated emotions may arise as part of/through one's activism such as fear (see Martin et al., 2007; Wettergren, 2009). Fear is an emotion which many activists experience but rarely is it discussed (especially amongst those engaged in protest and public forms of activism), serving to both motivate and silence many disabled people. Richard, as a result, found it somewhat easier to engage in online forms of activism, which allowed him to remain relatively anonymous, adopt an alternative identity, and be less fearful of the repercussions of his actions.

Moments could however be observed when activists actively sought to subvert dominant emotions such as those of anger or fear through the injection of humour. Humour has been seen to make the practice of engaging in activism more enjoyable, attractive and empowering (Haugerud, 2012). Relief theories have conceptualised humour as a release mechanism, as a means of both dealing with and relieving feelings of fear (Morreall, 1987). Humorous practices initiated during protests included the mockery of politicians such as group dances to 'She's a liar, liar' (anti-Theresa May song, UK Prime Minister 2016-19) (20th July 2017) and the use of phrases such as 'Don't let Theresa see you moving the table – she'll tell you you're fit for work!' (21st July 2017) or 'Don't get too comfortable there Theresa, we'll evict you' (18th April 2018). Humour appeared to be greatly drawn upon during protests, in order to lift the spirits of protestors and to both amuse and gain the attention of the public. Humour can also help convey political messages to the public in a way which is more palatable (Duncombe, 2007).

Emotions are generally seen as a resource or motivating factor behind individuals' activism, along with that of a tool that can be drawn upon as part of one's action. It is important however to both complicate and advocate for a more nuanced relationship between emotions and activism. Emotions should not solely be seen as a motivating factor or the result of engagement in activism but rather as being constantly in flux; activists simultaneously experience a myriad of emotions (some of which may be difficult to detect), making it perhaps unhelpful to identify a specific emotion such as anger or fear as a sole trigger, 'resource' or motivating factor for one's activism.

Along with considering the role of emotions in both motivating and prohibiting activism, it is also important to recognise the emotional solidarities which can be brought about through participating in such spaces. While it is important not to romanticise protests and their transformative potential, many participants spoke of engaging in disability protest as being a positive experience, helping to both lift their spirits and enable them to feel part of a community. There was said to be a certain value in being physically present alongside other disabled people facing similar things, as Richard notes:

> It's not just about the activism. I don't think it ever is. I didn't take up my scuttles again simply because… I think it's because I needed to have people there to feel safe, to feel that the worst impact of all of this would be in a sense absorbed by the solidarity and support of the people in the group. That's very true, I've made some very close friends from all of this fight, the last seven years. And you know, people that are a great support network, who've become you know carers really (laughs) in some ways.

For Richard, his engagement in disability protest had given him a sense of community and a vital support network. Richard went on to note how for many disabled people like himself, disability protest communities had helped to fill part of the gap left by the closure of disability services and institutions, by providing individuals with a sense of community, form of social activity, interaction and a sense of purpose:

> That's the little bit of social life we've got, you know… it's filled the void (pause) that was created by austerity and the closing of places like [mental health day centre/drop-in service]. And you know, other day centres and places like that that've closed.

A sense of community and care amongst activists was evident across most protests that I attended, with hugs and gestures of affection, being a commonplace feature upon arrival and departure. This is not to say that every individual found it as easy to develop friendships, interact or engage with the protest community. My observations also highlighted moments of in-fighting, disagreement and internal fractures, perhaps driven by the often stressful and highly tense environment.

Participants' accounts demonstrate that activism is not only about getting a message to an external/wider public audience (*external activism*) but also about building a sense of community and belonging internally (amongst disabled people - *internal activism*). I have proposed the terms *external activism* and *internal activism* in order to convey this. While *external activism* entails raising awareness and visibility to the wider public, *internal activism* focuses on raising consciousness, building a sense of community and associated support structures, as Liz notes:

> It's not only for changing things out there but also for changing things in here, like internally and building community… [This] is as important, because without [it] it's very hard to make a substantial change

Alex echoed this point around the importance of building community and a sense of identity amongst disabled people, by saying:

> The more we're out there, the more we're visible and saying to each other, this is who we are, this is what we look like, this is what we give a shit about, the more our strength is built inside and it's so important!

Alex is in her forties and is a prominent disability activist within her city in North West England, she is involved in a local coalition for disabled people, a member of an anti-austerity disability protest group, an advocate for local disabled people and engaged in the arts (as a means through which to challenge public perception and build a sense of culture and identity amongst disabled people). For some activists such as Darren, engaging in protest was said to have helped sustain him. He spoke of how engaging in disability protest had provided him with a new identity, a sense of purpose and self-worth:

> It's realising that there are ways to strike back and say "Okay, my type of person is not appreciated, you don't want me around for various reasons or I'm an inconvenience," and discovering your own reasons to exist, reasons why you should exist, things you have of value.

Anna similarly noted, how engaging in the protest group DPAC had helped to sustain her and keep her going, providing her with a sense of purpose and an avenue through which to channel her energies:

> I never thought I'd say this, if it wasn't for finding that group [DPAC], I wouldn't be here now. I'd be dead. DPAC in a lot of ways kept me alive these five years. The activism

> saved my life… literally it kept me going. When I feel really crap, I get myself out there thinking I've got to do this. It's like we're all on a mission really.

Engaging in protest communities are for some activists (like Darren and Anna) seen as life-saving, providing a means of rebuilding shattered worlds and of finding new solidarities and networks of support. Further, it gave them a crucial sense of purpose, a drive and meaning to their lives at a time when all seemed to be lost.

6.7 Conclusion

This chapter has shown how disability activists use public spaces and forms of activism such as protest and direct action to highlight the insurmountable impact of austerity cuts (as forms of state violence) on the lives of disabled people across the United Kingdom. Anti-austerity protests are framed around survival, as matter of life and death. Participants' accounts highlight the importance of visibility, to be both seen and heard speaking out about the injustices they (as disabled people) currently face, with many of these going unnoticed by wider sociey.

Protests can provide disabled people with an opportunity to articulate and perform their own agency. This chapter has however drawn attention to the role of the disabled protesting body in recent anti-austerity protest, as a valuable vehicle through which disability activists have sought to convey their message. Through drawing on their bodies and corporeal vulnerability, activists have sought to demonstrate the injustice of welfare cuts and stigmatisation. By coming together these individual vulnerable bodies used their vulnerability to form a larger collective body of strength and courage. Bodies can however also be sources of pain and discomfort, so they had to be carefully managed, looked after and configured into activism. This at times meant, slowing down the pace of a protest and taking time to rest, recover and care for one another.

Along with the use of the body during protest, the chapter also highlights the role of emotions. Emotions such as anger, fear and grief, were seen as key in motivating, sustaining and sometimes also in curtailing public forms of activism. Many participants spoke of the emotional solidarities which participation in protest brought about. There was said to be a certain value in being physically present alongside other disabled people who were facing similar things and felt the same way. The support structures provided by protest communities were highly valued and for some, it was around these networks that their social life solely revolved. Participation in protest was seen by some participants to be life-saving, providing them with meaning and a sense of purpose at a time when they felt deeply lost and abandoned.

Participants' accounts however also reveal the need to embrace alternative forms of activism (those which are private or liminal in nature) that may be better adapted to individuals' abilities. While disability activists have actively sought to adapt spaces of protest in order to make them more accessible, it is difficult to convey quite how mentally and physically difficult it can be for some disabled people to reach such spaces, let alone participate. The following two chapters will therefore turn to look at alternative forms of activism, those which are taking place in liminal and private space.

Chapter 7 Liminal spaces and forms of activism

Some bodies may be too tired, exhausted, worn out or unable to engage in public forms of protest, while others might be too afraid to make themselves visible. This does not necessarily silence individuals but rather forces them to slow down and engage in forms of activism that are less visible or do not rely so heavily on the use of the body. This chapter will foreground the experiences of activists who are engaged in what I term liminal forms of activism - those which exist in-between the public and the private sphere including, for example, online activism and the arts. All forms of activism to a certain extent blur these boundaries between public and private. However, for the purposes of presenting the research in a way that seeks to explore the role of place, this was the clearest way to delineate between these different types. The forms of activism outlined in this chapter offer new ways of doing activism, often from the space of the home, without a focus on visible bodies on the street. Further, they highlight how activism may operate at a variety of different speeds, from the fast-moving and the immediate to the slow and the gradual.

Activism has typically been presented as a public, visible, ‘spectacular’ and antagonistic practice (see for example Anderson, 2003; Mitchell, 2013; Tarrow, 1998; Thoburn, 2008). Feminist scholars have however argued that this conceptualisation of political activity paints a partial and distorted picture of political action (Abrahams, 1992; Pain, 2014b; Riemer, 1986). There has been a growing trend amongst geographers to broaden understandings of activism to comprise that of the often overlooked, modest, everyday acts of kindness, kinship and creativity (Askins, 2015). This thesis, therefore, seeks to explore other forms of activism that exist (and other spaces in which activists occupy) beyond the public sphere, building upon work by scholars such as Hall (2011) and Askins (2014, 2015). In contrast to the previous chapter, these forms of activism are not (predominantly) reliant on the body and physical strength as a vehicle for its message. Thus, having the potential to open up a number of new possibilities.

The chapter will begin by exploring the use of online activism amongst disability activists in response to austerity. Despite some isolated exceptions (see Ellis et al., 2015; Pearson and Trevisan, 2015; Trevisan, 2017b, 2020) the study of online disability activism is still very much in its infancy. The internet may serve as an emotional and relational outlet and a valuable platform through which individuals can speak out and engage in activism. Furthermore, virtual spaces may be of value in connecting isolated people and building support structures (Obst and Stafurik, 2010). The second half of the chapter will then move on to explore the use of another form of liminal activity, that of art activism. Art, like online activism, is often not reliant on the visibility of the body or its physical strength and so can provide individuals with a degree of anonymity and freedom of expression.

7.1 Social media and the rise of online disability activism

Early work on cybercultures was quite utopian, seeing virtual space as democratic, fluid and open (Gray, 2001). Social media and online communication platforms have been heralded as effective mediums through which one can potentially transcend the body along with physical differences, space and place (see Boler, 2007; Gray, 2001). Gray (2001: 188) claims that ''[o]n the Net, race and gender distinctions dissolve'. Users are allegedly given the opportunity to establish new identities, putting conventional understandings of identities as fixed and static into question. Users are provided with opportunities to ‘move beyond the constraints of the usual social markers of ethnicity, class, gender, age and ability’ (Boler, 2007: 150). A utopian, globalised world is depicted where you can be whoever you want to be. As another cyber-theorist puts it:

> The greatest freedom cyberspace promises is that of recasting the self: from static beings, bound by the body and betrayed by appearances, Net surfers may reconstruct themselves in a multiplicity of dazzling roles, changing from moment to moment according to whim (Stallabrass, quoted in Wakeford, 1999: 170).

With disabled users potentially no longer constrained by the physical marker and restrictions of the ‘disabled body’, social media has frequently been heralded as a highly liberating platform amongst disabled users (see Barak and Sadovsky, 2008; Bowker and Tuffin, 2002, 2007; Moss et al., 2004). Research by Seymour and Lupton (2004) suggests that such avenues can be used effectively to both overcome and dismantle the binaries of ‘able’ and disabled. There have however been numerous critiques of such utopian visions of cyberspace, with some scholars such as Boler (2007) arguing that one can never truly transcend the body in online communication, as users will invariably always enquire about others positionality to interpret communication and confirm their identity. While optimism for the transformative potential of online media may not be the same today as it was twenty years ago - online platforms can provide users with promises of anonymity (and associated safety).

Online communication platforms have increasingly become avenues to express oneself, expand peer-networks and gain mutual solidarity and support regardless of geographic distance and other physical/environmental barriers (Anderberg and Jönsson, 2005; Trevisan, 2017b). Further, they can be used to express a political voice, convey discontent or stimulate debate and resistance. Online platforms have been used to supplement and work in collaboration with other forms of activism (e.g. protest, direct action and the arts), while also serving as a means of activism in and of themselves (Barker, 2012; Barnes, 2007; Kitchin et al., 2013). Take for instance the use of online initiatives such as Twitter 'storms' and virtual protest pages, which seek to blend online and offline forms of action. Online activism can be a relatively quick way of sharing information to a wider audience, perhaps not requiring the same amount of planning or co-ordination as more conventional forms of activism.

According to Pearson and Trevisan (2015) online activism has provided disabled people with a useful avenue to acquire visibility and air their voices in a public arena, often challenging government policy, public opinion and the antagonistic stereotyping of disabled people (see also Goggin and Noonan, 2007; Thoreau, 2006). This has been facilitated through either posting on Facebook, Twitter, online blogs or discussion forums. Social media further has the potential to provide people with opportunities to connect, discuss and self-organise outside of charity or advocacy organisations (Trevisan, 2017b).

This chapter will look at two discrete forms of online disability activism, that which is more overt and public (i.e. publicly accessible blogs and social media campaigns) and that which is more subtle, hidden and proceeds with 'not too much fuss' (Horton and Kraftl, 2009a: 15), such as the development and utilisation of online support communities. In doing so, this chapter will illustrate how people are using online platforms to speak out about the impacts of austerity and support one another in the process of 'getting by' under grave and profound austerity cuts.

7.2 Social media as an information source and resource for awareness raising

Online activism through platforms such as Twitter and Facebook has become central to recent disability activism in response to austerity (see Pearson and Trevisan, 2015). The majority of participants (n = 17/27) engaged in online activism through the form of occasional 'liking' and sharing of Tweets, Facebook posts, articles or videos. Anne, for example, is in her early fifties, lives in Scotland and has been involved in both disability and mental health activism for the past 20 years, working for a DPO, coordinating national disability campaigns and engaging in activism through her creative writing and social media:

> I spend a lot of time online, commenting and sharing stuff and supporting people…. I do it quite strategically in that if I was just to post loads of stuff around benefits or other things I'm active around, a lot of people would turn me off. So, every now and again I post something particularly important.

Terms such as ‘slacktivism’, ‘clicktivism’ and ‘armchair activism’ (Gremigini, 2016; Lovink, 2011) have widely circulated over the past ten years, often trivialising and mocking the online actions of individuals such as Anne, engaged in what is deemed as 'lazy' forms of activism through, for example, the posting and sharing of issues on social media from their homes. These practices are often criticised and undermined, seen as acts which make individuals feel good about themselves, rather than bringing about any change (Gremigini, 2016; Lovink, 2011). Participants, however, disagreed with these popular criticisms of online activism, noting how they were underpinned by ableist assumptions, that to be at home, not moving but rather doing things online, could not be deemed as activism or bringing about change. This view further serves to uphold the notion of the ideal able-bodied activist, who is mobile and takes to the streets (Coleman and Bassi, 2011), as Adam further explains:

> I’m aware of things like armchair activists and clicktivism but that’s very dismissive and I think quite disablist because there are people who can’t leave the house because of their impairment... They are housebound but they have a computer and an internet connection.

Adam is in his early forties and has been involved in disability and mental health activism over the past 10-15 years. Adam currently lives in a large city in the North West of England and frequently engages in online activism. While Adam sought to critique and disregard the notion of ‘armchair activists’, other participants such as Alex sought to reclaim the term. Alex told me:

> I just laugh every time I hear the phrase bum chair activist because most of my activism is done from my bed… have you got any idea what you can do from your bed if you’ve got a decent computer… oh my gosh, you can organise a protest, you can organise an entire campaign all from your bed.

Disability activists have frequently sought to reclaim terms such as ‘armchair activists’ and ‘armchair armies’ to describe their online activism (Pearson and Trevisan, 2015; Trevisan, 2017b, 2020). Alex illustrates here the potential of online activism in traversing various geographic scales and bringing about change. Whilst Alex stayed in place, remaining in her home, she could spur on an entire movement. Attention is drawn towards the connections between the private and the public, the individual and the collective, the local and the global (Gibson-Graham, 2002), noting how a single individual’s online actions, whilst at home, can galvanise a national or international movement.

Adam noted how he first became involved in disability activism, through online platforms, founding the War on Welfare (WOW) online petition[12], while he was experiencing a period of particularly poor mental health and living in a remote area in North Wales. Online platforms provided him with the opportunity to connect and build alliances with other disabled people, collaboratively coordinating a campaign despite geographic distance:

> The first thing I did was online because I was quite ill from how badly my health had got… I was one of the co-founders of the WOW petition. We used the government's own [online] petition system to get the debate and get some issued addressed. I was living in [a small town in north Wales] then, quite remote, it wasn't like a city I could go to and protest particularly.

Online petitions were one of the many ways through which participants felt greater public visibility could be gained of the issues facing disabled people and members of Parliament could be engaged. They were seen as having the potential to greatly increase the visibility of issues, which might otherwise go unnoticed. The Black Lives Matter protests, which occurred across the globe in May 2020 in response to the death of a black American - George Floyd lay testament to the potential of online platforms in raising international visibility of an issue (in this case police brutality and racism) and mobilising the public (Cheung 2020; Safi 2020).

During the course of this research between 2016-2019, I was invited to engage in numerous 'Twitterstorms' and 'Tweetouts', around the impact of welfare reforms on the lives of disabled people (#SummerofDiscontent #NotOneMoreDay #CutsKill 14-21/07/17), the misconduct of benefit assessments (It's time to put PIP assessments #OnTheRecord – 28/10/18) and against the introduction of Universal Credit (#StopAndScrapUniversalCredit - 22/09/18). Often these occurred in tandem with days of significance or organised protest. The following Tweetout was for example organised by DPAC in relation to the 2016 International Day of Disabled People:

> With people from all over the globe tweeting and looking at the hashtag #IDPD2016, this is our chance to tell the whole world what is happening in the UK – this is our chance to embarrass and shame the government over the atrocities they have perpetrated against us (https://dpac.uk.net/2016/11/)

Along with raising awareness to a wider public, social media was frequently seen as an information source, that could be drawn upon for individuals' activism. Rebecca, for example, was

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[12] An online petition and campaign launched in 2012 to challenge changes to the disability benefits system. The petition called for a cumulative impact assessment of the benefit changes, for the abandonment of Work Capability Assessments and for greater support to get disabled people into work.

involved in the Reclaiming Our Futures Alliance (ROFA) - an alliance of Disabled People and their organisations [13] , who brought about and provided evidence to the 2016 UN inquiry into the treatment of disabled people by the UK government (UNCRPD, 2016). Rebecca notes the value of social media in enabling the sharing of information and in providing critical evidence for the inquiry:

> The government was really angry about the UN outcome, they sent a very large delegation over of officials and I think they thought they had a chance to pull the wool over the eyes of the committee members. But because there were so many activists who are connected online in very different parts of the country, all doing their research, sharing information, it's a really good knowledge base to be able to [challenge the government].

For some, engaging in online activism was regarded as the bare minimum, as something which they engaged in when other forms of activism were not available to them or when other forms of activism had become too much, as Richard notes:

> I've had a rest. I've only been involved in as much as I've continued to maintain a local Facebook page and of course engaged in sort of online activism from Tweeting DNS stories to DPAC events and things like that. The sort of day to day bread and butter.

However, for others such as Sophie, who is in her early 20s and the youngest participant in this study, online activism was at times seen as simply too exhausting: 'I'm not as involved as I'd like to be… I think it's partly that I don't know that I'll have the energy [for it]'. There is often a presumption that online activism is somewhat easier and less exhausting (Gremigini, 2016; Pearson and Trevisan, 2015), however, this story shows that this is not necessarily the case. Online activism was seen by Sophie as emotionally draining and all-consuming. A small number of participants reflected on how it was difficult to set boundaries when engaging in online activism as it was something that one could constantly be involved in, especially as it was taking place from home, making it difficult to switch off and take care of oneself.

Beyond the use of social media for sharing petitions, news around protests, events and statistics about the impact of austerity on the lives of disabled people, social media has also increasingly been used for blogging and the sharing of personal accounts, as will be discussed in the next section. The following section draws particularly upon Rachel's account as the participant who was most involved in blogging. More of a narrative approach will be taken towards this

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[13] https://www.rofa.org.uk

section, as we can only really understand her reasons for engaging in blogging if we look at the full context of her story.

7.2.1 Social media as an emotional and relational outlet

Social media has increasingly become used as an avenue for storytelling, with disability activists frequently sharing stories of their own personal experiences of life as a disabled person in austerity Britain (see, for instance, the blog 'Diary of a Benefit Scrounger'[14] along with the ‘Spartacus welfare cut campaign’[15] and ‘The Broken of Britain’[16]). Through talking about personal circumstances and their everyday challenges, individuals can express the impact of controversial policy measures in an accessible way using everyday language that has the potential to draw individuals into political debates and provide the common ground for collective action (Benford and Snow, 2000; Bimber et al., 2005). Furthermore, online communities can help highlight how ostensibly private experiences are inherently political. Recent research has shown that disabled internet users are more likely than other users to engage in blogging and sharing their own content (Trevisan, 2017b).

While disability advocates in the US have long drawn upon individual accounts to bring about legal action against states or corporations (Trevisan, 2017b), in the UK the use of personal narratives as part of disability activism has been highly debated and disputed amongst the Disabled People’s Movement, with charities often using pitiful stories as the basis of their fundraising campaigns. Some activists have been concerned that focussing on individual stories may serve to deter away from the shared nature of disabled people’s struggle and oppression, presenting disability as a ‘personal tragedy’ as opposed to a social issue (Trevisan, 2017b: 382).

One activist, Rachel, in her early 30s, lives in London and has multiple disabilities (including physical, sensory and learning). She has become particularly active over the past five years in sharing her personal experiences of living as a disabled person under austerity online, through the form of her blog. Rachel has lived independently in South West London (her place of birth) for the past ten years, supported by a strong network of family and friends. Last year, Rachel, however, became homeless, after having to leave her council flat due to severe damp, which was significantly impacting upon her asthma (leading to hospitalisation on several occasions). With no one in her immediate family living in accessible ground floor housing (and the council not having

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[14] https://diaryofabenefitscrounger.blogspot.com
[15] http://wearespartacus.org.uk
[16] http://thebrokenofbritain.blogspot.com/

any accessible social housing available), Rachel had to move in with her ex-boyfriend's mother, in another London borough, sleeping on her living room floor. Away from her local area and support network, Rachel spoke of how she spent two months feeling isolated, unable to get around and continue her daily life. Studies such as Power and Gaete-Reyes (2019) and Ryan (2019) have noted how a growing number of disabled people are finding themselves homeless or living in inadequate and/or inaccessible housing due to reductions in local authority spending on accessible housing provision. In this instance, Rachel decided to turn to the internet for both support and as an avenue to speak out about the challenges she was facing.

For Rachel, the internet was deemed a quick and easy mechanism through which she could voice her opinions in a public arena. Due to being Deaf, face to face communication was not always easy for Rachel, often being slowed down by others' misinterpretations of what she was saying and vice versa. Face to face communication is often frustrating and highly anxiety-inducing for Rachel, having the potential to lower her self-esteem. Her communication difficulties make engaging in other forms of activism such as protest difficult. When engaging in such activities, she requires the support of someone else such as a Personal Assistant or close friend. Moreover, through blogging, she can engage in activism independently and can communicate faster and with greater ease. Along with being a more expedient and faster form of communication, blogging was also thought to be easier due to it being something which disabled people like Rachel could engage with from anywhere, and at any time of day, working around their personal routines. Typically, however, online disability activism fluctuates between short periods of intense activity (and resulting visibility) and weeks or perhaps months of relative silence. Online activism, for example, tends to mobilise around particular issues for a limited-time (perhaps occurring simultaneously with policy changes) as opposed to operating for the long term (Trevisan, 2017b, 2018).

While Rachel was homeless and experiencing deteriorating health and reduced mobility, blogging became Rachel's only avenue to speak out and engage in activism. Traditional spaces of activism such as protest and direct action were not accessible to her. Rachel, saw blogging as her outlet and her voice, helping her to overcome feelings of personal isolation through building community, and providing her with a sense of agency:

> The only thing that I had access to [at the time] was my blog and that was really my link to the outside world.
>
> It was my outlet, I've always been a diary writer since I was a child. I am more than happy to open out to people because I've got nothing to hide [and] I know that there are other people out there feeling just as isolated.

The two quotes above, show how important blogging can be in providing individuals with a means to speak out, overcome feelings of isolation, and enable individuals to know that they are not alone in facing such hardship. While Rachel continues to use social media and blogging as an avenue for her activism, speaking out about the lack of investment in accessible council housing, reductions in care and support and the closure of advocacy services, they were deemed of particular value while she was experiencing a period of particularly poor health and living in inaccessible housing. Not only was this practice deemed as being of personal value, Rachel saw her blogs as supporting other disabled people in overcoming similar feelings of isolation by making her (predominantly hidden and private) experiences of hardship visible to others. This was particularly apparent through the number of people who would comment on Rachel's blogs and get in contact with her, sharing similar experiences of hardship and feelings of both personal isolation and frustration. She saw her blogs as having the potential to foster community amongst individuals with similar experiences, who typically do not have the opportunity to meet and exchange their opinions. Rachel's blog has 10,000 different readers from as far as Canada, Australia and America, with each of her posts being read several thousand times. The internet is, therefore, a means through which Rachel can traverse both her personal embodiment and the confinements of the home, enabling her to spread her concerns, frustrations and anxieties around welfare reform (relatively quickly) to an international audience.

While for Rachel, blogging provided her with a platform through which to communicate her message to the public realm, as outlined in section 3.7, posting on social media can bring about several risks in the current environment of online surveillance (Van Dijck, 2013). In the current climate of austerity, disabled people find themselves constantly under scrutiny (Burke and Crow, 2017; Garthwaite, 2011), with narrow understandings of what constitutes a disability, how it should look and how disabled people should act (Grover and Piggott, 2010; Roulstone, 2015). Comments, photos and information shared via social media, have therefore on occasion been used to challenge disabled people’s entitlement to services and support.

Individuals have sought to resist such surveillance strategies by using fake names/pseudonyms on their blogs and discussion forums in order not to disclose their identities. Online platforms, therefore, provide a degree of anonymity that would not be possible in forms of conventional activism, whereby individuals make themselves visible and put themselves on the line and at risk. Online activism, therefore, has the potential to protect some of the most vulnerable activists. The anonymity that the internet can provide has enabled several disabled people like Rachel to speak more openly and vulnerably about the hardship they are enduring under austerity:

> You can decide not to put photographs of yourself up on your blog. People then don't really know who you are. You can choose a different name if you want. You know, have a pseudonym and it means that you're able to be as honest as you can be, because you are not as scared of what people see or what people think.

Rachel notes here how she felt comfortable in expressing her experiences online due to the anonymity that it can provide. Using pseudonyms online appeared to be a common practice amongst participants engaged in online activism, as Richard told me:

> I use my birth name online, my sort of official Christian name if you like, so I use my adopted name [normally] as my name but I always for public [activist] purposes use [my birth name]. Simply because I'm a claimant and it is a pressure… it's all sort of very cloakened out isn't it, so I use XXX online as a way of you know, keeping that name on the claim form out of the public eye (laughs).

The majority of participants told me how they used these alternative names online in order to resist surveillance strategies. Like many others, Richard and Rachel found great difficulty in juggling between these two different identities. This became particularly apparent when Rachel mistakenly signed the consent forms for this study under her 'online' name. Rachel told me how she consistently feared 'making a slip' and revealing her real identity online. She feared that being caught speaking openly against the system would put her personal benefits, care and support at jeopardy.

7.2.2 Online communities - Gaining access to a supportive community and informal support structures

Notwithstanding some of the anxieties and difficulties which surround online surveillance, online communities offer an important sense of community and a source of support for many disabled people. Most online disability support communities were seen to operate through closed groups on Facebook. While Twitter is generally understood as a public domain, often used by those activists who are more computer-savvy and politically experienced, Facebook is seen as a space for coming together, friendships and the building of community in ways that often blur the boundaries between the private and the public (Gerbaudo, 2012). While previous research into online disability activism has focused on collective action (Trevisan, 2017b, 2018), this subsection seeks to highlight the activism inherent in small acts of online connectivity and everyday conversation. The practice of establishing and maintaining online support groups was seen by the vast majority of participants mentioned in this subsection (Anna, Carol, Lisa, Darren, Simon and Rebecca) as a form of activism in itself.

Carol, for example, is in her 60s, lives in the North East and has chronic health conditions along with poor mental health. She engages in disability activism and advocacy largely through online mediums, such as through online support groups, one of which she established herself:

> Through my [online] support group which has been going quite a few years now, I've literally helped people get their money back, or helped them keep their money, by them understanding what they need to say when they're filling out the form, what information they need to include… My aim is to keep as many disabled people alive as possible through this brutal process because many of them just cannot cope…

These online groups serve as important, far-reaching support networks, providing individuals with access to valuable information and peer to peer support to help navigate the welfare system. This informal sharing of knowledge gives some degree of social capital to help people navigate a system that they deem to be increasingly bureaucratic and demoralising. Social capital is widely understood as the bonds and relations between people that can be leveraged for information, support and resource sharing. Social capital entered into academic and policy debates in the 1990s but has a lot longer history, deriving from the work of Hanifan (1916), where she used the term to describe 'those tangible assets [that] count for most in the daily lives of people: namely goodwill, fellowship, sympathy, and social intercourse among the individuals and families who make up a social unit' (Hanifan, 1916: 130).

These forms of solidarities, connections and knowledge transfer between disabled people, can be recognised as part of a new 'landscape of care' (Milligan and Wiles, 2010), or what might better be described as a new infrastructure of care, comprising of various components which have become fundamental to sustaining or enhancing an individual's living conditions. Online communities can serve as a critical component of this new infrastructure, as a space and source of care that has the potential to sustain people during a time of austerity. The retrenchment in public spending on social infrastructure (e.g. social care and services) brings about an environment whereby social capital is of ever greater importance. Power and Hall (2018: 311) argue that 'new spaces, relations, networks and practices of care and caring are emerging in difficult times, in unexpected and unconventional places'. Austerity can therefore provide an opportunity for the formation of new and adapted social support structures, along with that of relations of care, collectivity and interdependence (Hall, 2019; Hall and Jayne, 2016), with online platforms being one of the mediums through which this may take place. To date, research on disability and care has largely focused on care provided by professionals and/or family members, through top-down approaches or via co-production. Little to date has been written on reciprocal practices of care between disabled people, practices which have become of increased importance in times of austerity and are fundamental to the sustainability of the Disabled People's Movement (Campbell and Oliver, 1996).

Over the past three years, Anna has become heavily involved in maintaining and regulating a series of online support groups, having experienced the value of online support herself. The groups are particularly valuable in providing isolated disabled people with a sense of hope, belonging and communal support, as Anna says rather starkly:

> The Facebook groups are the lifelines for so many, it's all they've got. Without that support, they wouldn't be here. You're giving hope to others by setting up [online] workshops and peer to peer support to help people get through Universal Credit.

This view was similarly echoed by Lisa who said:

> [It gives you] the sense of being together, the sense of you're not on your own. You might be fighting an incredibly lonely battle at home, trying to hang on to support. But what you know is that you're not the only one facing it. That gives you some strength to keep on going, to keep resisting.

Here Lisa notes how the solidarity can increase individuals' determination and agency to continue. Burke and Crow (2017: 15) note that it is 'about solidarity with others [and] a bolstering of your own resilience'. Such online spaces and activities helping others navigate difficult welfare assessment processes should be recognised as being inherently political and as a form as *internal activism* (see Askins, 2015). Hall (2018) draws upon the scholarship of Hanisch (1970) to argue that the personal is not only political but also relational. She argues that 'togetherness and mutuality are a means of getting by within austerity, and of speaking back to it' (Hall, 2018: 250). Similar to this, the social media groups and online workshops, outlined in the above quote from Anna, provided individuals with a means of coming together, supporting one another and speaking out about their marginalisation. Here, like in Hanisch's essay, individuals are involved in sharing and making visible, hidden and marginalised experiences. In doing so, connections are made between their shared personal experiences and the broader political picture of structural injustices and violence (see also Dyck, 1995; Hall, 2018). Online communities also made it easier for individuals to see that the challenges they are facing are shared and part of a wider structural problem. For this reason, online communities also served as spaces from which further activism could be generated.

Coordinating and participating in online support groups was deemed by participants mentioned in this section as a form of activism, creating a platform through which individuals could speak out about the injustices they faced and provide support to one another, in an effort to resist austerity and its detrimental impact on disabled people's lives. Relationality, interdependency and connectivity, therefore, become both personal and political tools in austerity (Hall, 2018). While relationships built on care were evident across all the various forms of activism outlined in this thesis, it was in these online spaces where they were deemed to be particularly valuable. Within online spaces, activists were often said to be more willing to slow down, take the time to listen, support one another, and open up about their shared feelings.

Online activism is often quiet and potentially not even classed by some as activism (Gremigini, 2016). It is nevertheless, an integral part of contemporary disability activism in response to many threats including that of austerity, eugenics, COVID-19 and other issues that challenge disabled people's citizenship. My work thus contributes to existing scholarship that has sought to highlight how political action does not have to be noisy or disruptive but can be practised instead through 'banal, day-to-day practices' (Horton and Kraftl, 2009a: 16).

7.3 Performance, art and 'slow activism'

Like online activism, art activism can be an effective avenue for those who find face to face encounters difficult. The spatiality of art activism can be similar to that of online activism, lying in a liminal space somewhere between that of the public and the private, which can provide some degree of anonymity to those who engage in such practices. Individuals can both take time and use private space to construct their images, narrative and messages. Like online activism, art is often constructed in the private and then transmitted into the public domain. The following section will explore the unique space and temporality of art-activism, drawing upon several participants' accounts. Throughout this section I will advance understanding of the term 'slow activism' (Heim, 2003; Page et al., 2019; Robins, 2014), drawing attention to how art activism may operate at a different speed and temporality to conventional forms of protest, taking longer to both create and transmit messages, yet having the potential to bring about gradual, slower and arguably more profound forms of change. Further, the creative arts (e.g. painting and photography) can exist over a longer timeframe than temporary forms of protest and direct action, remaining in place until they are destroyed. The arts may therefore serve as a form of resistance which endures over a longer timeframe.

Art is thought to be uniquely placed, in having the potential to reach deeper levels and influence both the emotional and the cognitive (Shank, 2004), often encouraging the observer to reflect on their own lives and worldview, challenging their standpoint and introducing them to different perspectives. However, there appeared to be some uneasiness amongst activists with the notion of slowness in activism (see also Sparke, 2008; Thoburn, 2008), as was reflected in several participants' interviews. This was likely due to the urgent nature of the challenge to push back austerity, allowing little room for the recognition of acts that may bring about slower and more gradual social change. However, for every participant engaged in art activism, the arts were said to be an effective medium through which they could express themselves and share their ongoing concerns.

7.3.1 Art as an emotional outlet to a wider public audience

The arts can provide a medium through which individuals express themselves to a wider public, as Nathan found. Nathan, a 41-year-old man from Wrexham, North Wales, has a degenerative and life-limiting disease called Friedreich's Ataxia. This has led to him gradually becoming a wheelchair user and developing muscle weakness in both his arms and legs. He currently lives on his own with 86.5 hours of care a week paid for by the Welsh Independent Living Grant. I note the number of hours because every half hour of care is seen as fundamental to Nathan's independence and wellbeing. Nathan saw the arts as a medium through which he could express himself and articulate his personal experiences. Creative art was a particularly valuable medium for Nathan, as it need not involve speaking, something which Nathan has found increasingly difficult due to his degenerative condition. Nathan became involved in activism, following hearing about the proposed closure of the Welsh Independent Living Grant (WILG), which could see his hours of care halved. Nathan's activism has predominantly been through social media outlets and the arts. Nathan has asked me to use his 'real name', personal details and photographs, as he would appreciate greater visibility and recognition of his activism.

Nathan first became involved in the arts, when he was asked to participate in a project which sought to highlight the voices, experiences and challenges facing disabled people living in our society today, as Nathan explains:

> [Name of national disability charity] were doing an art scheme called postcards from the edges. They were encouraging disabled people to create postcards that illustrated how they felt as a disabled person in the twenty-first century.

Nathan saw this exercise as a helpful way to express himself and to process some of his feelings: 'I just thought, it's an easy way to get my thoughts and frustrations out of my head and onto paper'. From a young age, we are both taught and conditioned to see the arts as a safe place to express ourselves (Hall, 2013; Shank, 2004).

Nathan's postcards were largely around the themes of welfare changes, loneliness and a sense of abandonment, being some of the greatest anxieties within his life. Two of Nathan's postcards are reprinted below with his permission:

Figure 11: 'Help...' by Nathan Davies.

Nathan explains the postcard pictured above on the Postcards from the Edges website (www.postcardsfromtheedges.org.uk):

> 'Help…' is an expression of my exclusion and segregation from mainstream society as a result of my disability. I am represented through the isolated red dot that is outnumbered, ignored and isolated by the dominant yellow dots.

Figure 12: ‘Taxing Times’ by Nathan Davies.

The second postcard pictured here, in contrast, focuses its attention on the introduction of the ‘Bedroom Tax’ and how it would disproportionately impact on disabled people like Nathan, who would be pushed further into financial hardship and forced to count their pennies.

Nathan both designed and created these postcards from the space of his bedroom. The arts have served as a particularly valuable medium for Nathan to express himself and to gain a political voice, as they are not dependent upon him being mobile and leaving his home, which has become increasingly difficult due to cuts in his personal assistance and care hours. Moreover, this had not prevented Nathan from gaining visibility through his art activism. He spoke very proudly of the visibility he had gained through one of his postcards (the second postcard displayed above):

> I did one [postcard] and wrote 'no to bedroom tax' on my bed with 2p coins, that postcard appeared in the Daily Mirror… I think that was the start of my activism. It showed me that I could make a change, you know. That I could be listened to.

Here, we can see how visibility may be acquired from some of the most private spaces, challenging conventional binaries between public and private space. The visibility of his postcard in a national newspaper helped give him a sense that he was being listened to, further, it showed him that he could make himself heard even from the private and hidden space of his home. His most recent focus has been on the closure of the Welsh Independent Living Grant (WILG), an issue which is very close to his heart as a current recipient of the grant. Nathan has created a series of postcards on this issue (one of which is pictured below), which he has sent to various members of parliament. He has also sought to encourage people to take 'selfies' with the postcards and to share them on social media platforms, to further increase visibility of the issue.

Figure 13: ‘Save the Welsh Independent Living Grant’ by Nathan Davies.

Melanie has similarly sought to make the hidden, visible through her artwork. Melanie is in her late 50s, she lives in London and is a wheelchair user with both sensory and physical disabilities. While she used to work as a nurse, her degenerative condition has meant that she now relies on 24/7 support from her PA:

> I got disabled in ‘94 and it was a really, really hard thing to get my head around because I’d been a nurse before that. To suddenly be on the opposite side, needing support and care, feeling dependent and losing my independence was unbearable.

Melanie has experienced several cuts to her care and has been forced to live in inaccessible housing due to the council refusing to provide her with the equipment necessary to make her home accessible. Melanie is however keen to make the issues she is facing (along with that of other disabled people) visible and known. As she noted during an art activist event:

> We are like stardust – we must shine a light on the realities of this world. We must become the sharers of truth… knowledge is power, our ignorance is [the government’s] bliss. We must spread the truth until it is recognised. (3rd August 2019, Green Gathering Festival).

Melanie has created a series of art activist installations, her most well-known are 'Invisible' and 'Universal Credit: A Grave Issue'. The 'Invisible' installation consists of a wheelchair with a clamp and chain, along with an incontinence pad on the seat and a 'carer missing' sign on the back of the backrest. The installation seeks to show the impact of the removal of personal care and support on the lives of some disabled people, who are encouraged to use incontinence pads rather than relying on a carer, and prevented from leaving their homes due to the withdrawal of personal assistance.

Figure 14: Photograph of the art installation 'Invisible' as displayed at Green Gathering Festival, 2nd August 2019. Source: author.

Figure 15: Photograph of the back of the art installation 'Invisible' as displayed at Green Gathering Festival, 2nd August 2019. Source: author.

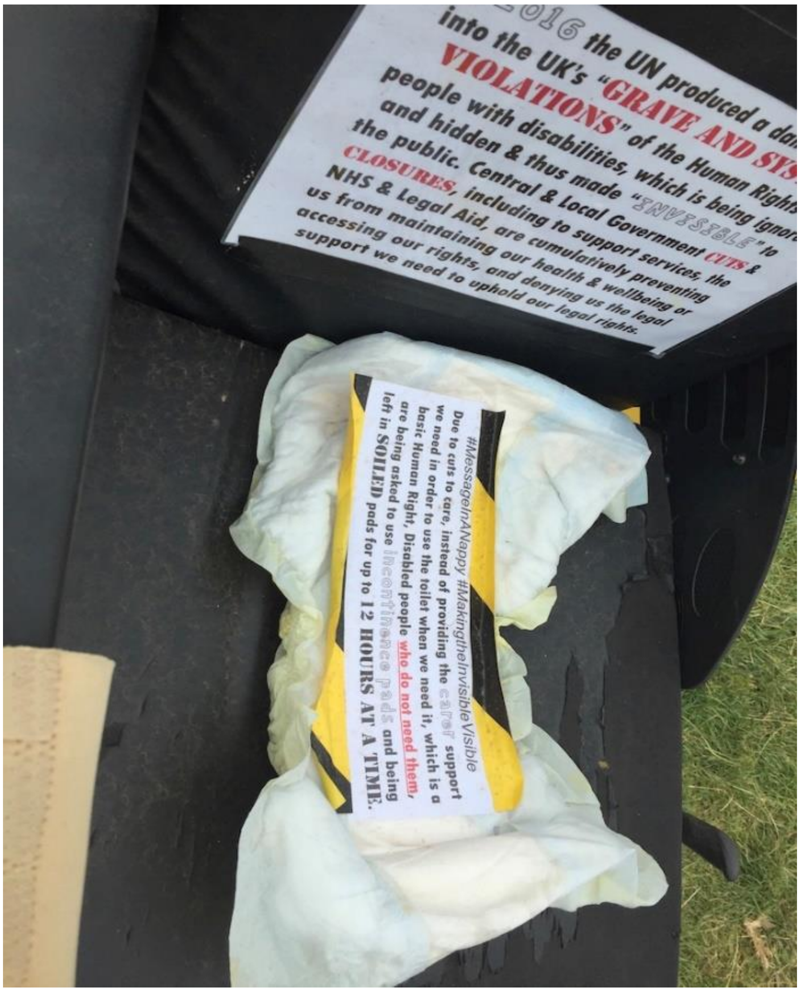

Figure 16: Photograph of a 'message in a nappy', displayed as part of the art installation 'Invisible' at Green Gathering Festival 2nd August 2019. Source: author.

Along with 'Invisible' another of Melanie's most notable art installations has been 'Universal Credit; A Grave Issue'. The installation consists of a wheelchair that is sat on top of a red and yellow slope. At the bottom of the slope is a grave which read 'RIP 10,600 and 2,380 All dead within 6 weeks after being found fit for work'. Around the grave are pictures and newspaper articles displaying the case studies of some of those who committed suicide or were found dead shortly after being assessed as 'fit for work'.

Figure 17: Photograph of the art installation 'Universal Credit; A Grave Issue' as presented at Green Gathering Festival, 3rd August 2019. Source: author.

The installation had been designed to illustrate how easy it is for a disabled person to die as a result of cuts to support and changes to universal credit. The barriers on the ramp illustrate the support structures that are being withdrawn or cut back.

Figure 18: Photograph from the side of the art installation 'Universal Credit; A Grave Issue' as displayed at Green Gathering Festival, 3rd August 2019. Source: author.

Both ‘Universal Credit; A Grave Issue’ and ‘Invisible’ seek to draw attention to issues which might otherwise go unnoticed and undocumented, as Melanie recounts:

> .. because once people can see what the problem is, then they can start thinking about how do we resolve it. The problems that disabled people are facing, are largely invisible to society and deliberately have been made so.

Melanie constructed both installations within the confines of her living room and with what she recounts as 'ample help and support from family and friends'. She notes how neither of these installations involves the use of the body in conveying their message or putting the body in view, thus providing her with a degree of anonymity. Melanie at times feared that revealing her identity and making herself visible might make her vulnerable to having her benefits cut further or even stopped: ‘I’m very conscious that I can and will be targeted by my local council, by the DWP…’. As noted by Richard in the previous chapter, fear of being identified and seen to be visibly challenging the government’ austerity reforms often curtailed individuals’ activism. For some activists such as Melanie, Richard and Rachel, they feared that being identified as engaging in activism may have a detrimental impact on their access to future care and support.

Individual stories exhibited as part of ‘Universal Credit: A Grave Issue’, call for onlookers to recognise the wider social and political landscape behind the individual stories and urge people to become an ally, instead of responding with sympathy (Hadley, 2019). A similar approach was adopted by art activist Vince Laws who has made poems out of a series of a hundred stories of disabled people who have died as a result of cuts to disability support (Laws, 2015). Laws' poems like Melanie's art installation, push spectators to simultaneously reflect on large-scale social issues and ideologies, at the same time as small-scale individual experiences.

Melanie's artwork also served another purpose, as she recounts:

> I thought, I can only talk a little bit, I get tired and things. And whereas if I created an installation, it could speak volumes without me having to actually speak.

Melanie's fatigue and deteriorating health were further reflected within my fieldnotes:

> From the moment [Melanie] wakes up in the morning to the time she shuts her eyes at night all that's on [Melanie's] mind is disability benefits, Universal Credit and how many people are suffering… I have come to see how [Melanie] is beginning to tire, wear thin and become increasingly ill due to the stress, pressure and weight she puts on herself. She tells me how she cannot do this forever and how she would like her exhibits to motivate others to replicate them in their own cities/towns. (Participant observation at Green Gathering Festival, 5th August 2019)

Melanie's art installations (particularly 'Invisible') were therefore designed to be easily replicable as she notes:

> Hopefully, other people would be able to duplicate it. Because it's just a wheelchair, a pair of shoes and all the information that's on it, I've got it in PDF form so anyone who wants to, I can send it to them, they can print it out and they can do it themselves. So ideally, I should have lots of 'Invisibles' in every town centre, so it becomes really visible.

While both Nathan and Melanie draw upon forms of art activism which do not require the physical use of the body to convey their message, another activist Liz sought to actively draw upon the disabled body and its representation as part of her art activism. Liz lives in Bristol and has been involved in disability politics in various ways for the past forty years. Due to being a mother and managing a deteriorating health condition, Liz is not as active in disability activism today as she would like to be. As noted in the previous chapter, when Liz was younger, she was very much involved in direct action. However, today, whenever she is able, Liz endeavours to campaign for disability rights through the arts and writing. Writing may be seen as a form of art, requiring creative writing skills and a degree of imagination, thus blurring and muddying the boundary between what does and does not constitute art activism (Ihlein, 2009).

Liz believed that creative arts help disabled people to use their bodies in a slower and more sustainably way than that of engagement in conventional forms of activism. Rest and slowing down have been conceptualised as central to any feminist crip utopian future (Kuppers, 2014), whereby notions of time are disrupted, making life less competitive, less frenetic, and more inclusive, giving everyone the opportunity to rest (McRuer, 2018; Samuels, 2017).

As a notable disability artist-activist, Liz Crow has produced several political art projects, primarily around the themes of disability, identity, austerity, survival and resistance. Her artwork has comprised of a variety of different mediums including film, live durational performances and art installations (see her personal webpage http://www.roaring-girl.com). One of Liz's most notable artworks has been *Bedding Out*, which has been discussed in the literature review (see section 3.8). The artwork embraced notions of slowness and stillness.

Figure 19: Photograph of bedside conversations during 'Bedding Out' by Liz Crow. Source: www.roaring-girl.com/work/bedding-out/

The overall aim of the performance was to draw attention to the usually hidden aspects of disabled people's lives along with challenging the ideology of benefit cuts, and the growing discourses of cheats, skivers and scroungers - as Liz explains:

> As somebody on ESA, I'm subject to all the crap of that… and one of the things that really struck me early on as abuse had started to increase, was the mismatch between people's view of us in public settings and the reality of our lives out of public spaces. For me, I know what I present [myself as in public space] isn't what I am, but this is what is visible. So, I don't look like somebody who feels ill or has difficulty and might not be able

> to work on a regular basis… or indeed might be grappling with discrimination all the time. It just felt very important to put that, in my case, bed life on top of the platform and say this is part of my life as a whole.

Liz was keen to highlight the realities and complexity of life as a disabled person, along with how the lived experience may differ from how a disabled person is perceived in public space. Liz sought to perform an invisible hardship that she and others struggle with daily in isolation (Kim, 2014). The performance, therefore, highlighted how some disabled people live their lives with incredibly stark public-private divides. Liz's artwork seeks to make the invisible, visible. This may therefore serve as a blurring of spaces - challenging the perceived boundaries between public-private space, with Liz playing on putting the private into the public.

Figure 20: Photograph of 'Bedding Out' by Liz Crow. Source: www.roaring-girl.com/work/bedding-out/

Hadley (2017, 2019) has noted that in the disability arts there has been a return to presenting disability in terms of pain and impairment, something previously shied away from. For Hambrook (2015), this shift is something that requires further and deeper discussion. Potential explanations for this include:

- Failure of the social model of disability to fully capture the diversity in the lived experiences of disabled people (which often feature experiences of pain, impairment and discomfort).

- A desire to speak to or challenge overcoming narratives - which proliferated around the 2012 Paralympic Games – potentially marginalising and stigmatising those who are unable to live up to these images.
- Disabled people's bodies have come under increased scrutiny under austerity, with increased eligibility criteria for disability benefits and support. Presenting pain and impairment can be a way of reminding the public of the challenges disabled people face in their daily lives and that the government has a duty of care towards disabled people (Hadley, 2017, 2019).

Liz's artwork arguably speaks to all three of the above. Her display of pain, impairment and exhaustion can be seen as a similar strategy to that of participants engaged in anti-austerity protest, as outlined in the previous chapter, and in Kim's (2014) writing about a crawling protest in Seoul to demand in-home care assistants. Like Liz, they drew upon their vulnerable and fragile bodies as part of their activism to highlight the injustice of government cuts.

While Liz's artwork often seeks to make visible the hardship brought about by welfare reform for disabled people, it was important to Liz that she did not give the impression that disabled people were inherently vulnerable. Through her artwork she has sought to illustrate that disabled people primarily become vulnerable through the withdrawal of support structures:

> 'Bedding Out'… had vulnerability built into [it]. Although different from the kind of vulnerability that's used to describe disabled people in mainstream media so much of the time… Nobody is intrinsically vulnerable or everyone is, because they are human. We are made so primarily from and by our circumstances, so if you remove my PAs, I am made vulnerable (laughs). You know, it's really simple. But I am not a vulnerable person. What I think I do in my activism is play/claim vulnerability.

Interestingly, Liz notes here how important it is that disabled people are not presented as inherently vulnerable as this denies and overlooks the structures which might lay at the roots of one's vulnerability (Titchkosky, 2007). The social model of disability (UPIAS, 1974a), the cornerstone upon which the Disabled People's Movement (in the UK at least) has been built, articulates that disabled people are not inherently vulnerable but are rather made vulnerable by social and environmental factors such as the provision of inadequate care and support.

The nature of Liz's performance enabled a space for dialogue and discussion between Liz and members of the public around issues such as changes to welfare, and the increasing rhetoric around skivers and scroungers. The discussion also extended from around the bed on to social media, with a continuous livestream capture of the event, and members of the public encouraged to join the conversation through Twitter using the hashtag #beddingout. The locus of change through this performance was therefore via small groups of people, who were invited physically into the 'bedroom installation' or who engaged within the online Twitter discussion.

Similarities can be drawn between Liz's art installation and that of Tracey Emin's renowned yet highly controversial art installation 'My Bed'. The piece was made by Emin in 1998 while she was living in a council flat in Waterloo.

Figure 21: Photograph of 'My Bed' by Tracey Emin as displayed in the Tate Modern. Source: https://www.tate.org.uk/art/artworks/emin-my-bed-l03662

The installation is of Emin's bed at the time, consisting of crumpled and stained sheets, strewn with cigarette butts, dirty underwear and empty alcohol bottles. The artwork provides a glimpse into her life at the time, which would ordinarily have been out of bounds, concealed and confined to the private space of her home. Similarly, Liz in 'Bedding Out' seeks to display her private life in the public sphere, opening it up to cross-examination and public scrutiny.

In contrast to the issues and barriers which faced disabled people in the past (e.g. inaccessible public buildings and transport), the barriers and injustices faced by disabled people today (i.e. changes to benefit entitlement and cuts to services) appear to be largely hidden and concealed from the general public. Liz, Melanie and Nathan were some of the many participants who told me that they thought current reforms fundamentally challenged disabled people's right to existence, and how difficult it had become to communicate something which was invisible and outside of most people's experience, as Liz notes:

> It isn’t a visible thing so that’s one of the things activism is doing that’s very important is trying to make it visible. But it’s hard to communicate a thing that is a) invisible and b) outside the majority’s experience. I think the really huge issues come down to our right to exist. And again, that’s invisible, it’s intangible, it’s outside most other people’s experience. Non-disabled people don’t think of themselves as having a right to exist because it’s never challenged for the most part.

Liz’s artwork along with Melanie and Nathan’s sought to make some of these issues visible, through bringing them into everyday public arenas, igniting conversations and increasing consciousness with and for members of the public. According to Liz, art can create an arena through which to generate discussion, propose new ways of thinking and introduce different perspectives (see Tostar, 2016). Art similarly can give both the artist and viewer space and time to think through various issues and formulate their own personal opinions. Engaging with the arts may therefore require some stillness, a slowing down and a deeper level of connection and contemplation, similar to that of engaging with pieces of memorialisation (Carpo, 2007; Goheen, 1997). This can, in turn, create a deeper, emotional response. It is not until we slow down, that we can truly engage on a deeper, emotional level with the artwork and understand its real human underpinnings and motivations. It is this along with the often slow and careful process of constructing artwork that I would term as 'slow activism'.

Liz’s art activism like that of fellow participants is deeply emotive, seeking to draw out and activate particular emotions in the observer. Shank (2004) notes how social justice movements have conventionally been known for their ‘cognitive communication styles’ that include irrefutable facts and figures. However, Shank (2004) and other scholars (Ariffin et al., 2016; Goodwin and Jasper, 2006; Huddy et al., 2015; Ost, 2004; Valentino et al., 2011) note an increasing turn towards the emotional, with feelings driving the politics of our world today. Liz’s account demonstrates that art activism can be an effective medium through which to access both emotional and cognitive pathways, often influencing the observer to change, challenge or reflect upon their standpoint, feelings, attitudes and/or behaviour towards a certain issue, through drawing out particular emotions (Porter, 2002). Not only this, but art has been deemed by participants in this study along with fellow scholars such as Porter (2002) as an effective tool in uniting communities and garnering a sense of solidarity and identity.

7.4 Conclusion

Within this chapter, I have sought to draw attention to some of the liminal forms and spaces of activism in which participants are currently engaged including online and art activism.

Engagement in online activism often took place within one's home but was then transmitted onto a public platform thus traversing the boundary between public and private. Similarly, art activism may often be constructed in private space but then later shared in public, challenging any supposed public-private divide. Previous scholarship on disability art activism has consisted predominantly of reflective accounts on personal artistic practice or analysis of news coverage and social media commentary on art activism (Crow, 2014; Hadley, 2019). This thesis, therefore, makes an original contribution by bringing together the personal experiences and opinions of multiple actors involved in disability art activist practices.

Both online blogging and art activism were often utilised as platforms for storytelling with individuals using such approaches to share their personal stories and accounts of hardship and suffering under austerity. The degree of anonymity which these platforms can provide appears to be critical in dictating how they are used, with individuals often feeling more able to openly express themselves through these mediums. Such platforms were deemed to be particularly valuable amongst those who were too afraid to publicly speak out against austerity measures due to fear of their benefits, care or support being cut as a result.

The forms of activism discussed in this chapter also brought about spaces and temporalities that were more accessible and inclusive of disabled people and their bodies. Neither art nor online activism necessarily relies on the body in order to convey its message. In contrast to protest and direct action, art activism often operates at a slower pace, creating both opportunities and spaces through which the disabled body might be built into its activism, in a slower and more sustainable manner. Art and online activism may as such serve as a reprieve and as an alternative from that of the physical exhaustion and energy-intensive nature of protest and direct action.

The following chapter will turn its focus to private forms of activism, those which have been integral in helping to sustain individuals and disabled communities under increasingly challenging circumstances.

Chapter 8 ‘Private’ everyday forms and spaces of activism

8.1 Introduction

> I thought of all the other invisible bodies, with their fists up, tucked away and out of sight (Hedva, 2016: 1).
>
> How do you throw a brick through the window of a bank if you can’t get out of bed? (Hedva, 2016: 5).

Engaging in public forms of activism is not an option for all disabled people, nor is it always necessarily desirable. Many disabled people do not, for example, have the capacity to engage in public forms of protest, due to ill health, isolation or insufficient support (Cross 2013; Hedva, 2016; Ryan 2019). Due to the nature of disability cuts and the loss or reduction in people's personal benefits and support, a small number of individuals in this research found themselves alone, neglected and with limited social networks. The shrinking support can affect the types of activism that a person can engage in. Two participants in this study noted how they were unable to partake in public forms of activism due to insufficient support. Moreover, while some individuals could not physically attend or engage in public forms of activism, for others this was more of an active decision. The most common reason for not wanting to participate in public forms of activism was the fear of being recognised and of making oneself open or vulnerable to repercussions. Some participants, therefore, decided instead to engage in more private and quieter forms of activism. Resistance amongst these individuals remains largely hidden and invisible to the wider public. Everyday private spaces are often overlooked as political spaces, for as Pain (2014a: 532) notes, ‘phenomena and events that are commonly viewed as public, political, global and spectacular continue to have wider appeal as subjects of study than the private and apparently mundane’. Hannah Arendt’s (1958) scholarship has also been prominent in upholding this, with her notion of the ‘Political’ as only constituting actions performed in public (see also Butler's 2011, 2015 use of Arendt's work to think about the space of the Political). This conceptualisation of ‘political’ is inherently exclusionary, as it suggests that an individual has to be physically present in order to be deemed as political. As a consequence, large parts of the population may be deemed as apolitical because of their inability to get their bodies into the street (Hedva, 2016).

With this study taking an interpretivist approach and participants seen as defining their own realities, this chapter seeks to highlight the variety of acts in individuals' everyday personal lives, which participants understood as constituting activism. While these acts may not solely reside in private spaces, they are inherently personal and largely go unnoticed. Private is therefore used to denote people's everyday personal lives, rather than not being seen. As has been discussed throughout this thesis, disabled people's partial citizenship and independence have also often meant forgoing any notion of privacy. The notion of private space is therefore not a concept that every disabled person will be able to relate to. It is for this reason that I have placed private in inverted commas within the title of this chapter. Along with drawing upon participants' experiences of engaging in everyday forms of activism, the chapter will further seek to challenge the conceptual binary between 'resilience' and 'resistance', through noting how participants saw their general meanings as inherently interconnected.

As already discussed, there has long been a perception in geographical literature on activism and radical geographies (particularly within urban neo-Marxist scholarship) that activism and forms of resistance must comprise definitive acts, which seek to directly challenge existing powerful and unjust structures (Hughes, 2019). Such scholarship has often been based on a particular idealised vision of the activist as male and able-bodied, with resistance comprising of taking to the streets (Coleman and Bassi, 2011; Routledge, 2017, 2019). The focus has therefore been on the public and spectacular rather than that of quieter everyday acts (Abrahams, 1992; Pain, 2014b). The assumptions implicit in this work therefore suggest that activism and resistance only take place in the public domain. Feminist scholarship has however been pivotal in critiquing this work (Abrahams, 1992; Askins, 2014, 2015; Hall, 2018) by emphasising the value of quiet, private, small-scale acts in both sustaining movements and as effective forms of resistance. It is, however, only relatively recently that some scholars have begun to recognise some of the quieter, slower, more subtle and mundane acts of 'getting by' and 'keeping on going', as acts of resistance (Pain, 2014a, b; Puar, 2017; Wilkinson and Ortega-Alcázar, 2019).

Wilkinson and Ortega-Alcázar (2019) for example, draw attention to the ways through which some young people in need of housing may withdraw, hold back and conserve their energies (as a form of passive dissent), rather than complying with the relentless demands to move forwards (and aspire for more) under austerity. While McRuer (2006) and Fish et al. (2018) draw upon everyday forms of resistance amongst queer and disabled people seen through the act of being open and embracing their identities in daily life, in doing so, confounding notions of compulsory heterosexuality and able-bodiedness which often govern our societies. With five participants in my study occupying space as sexual minorities (along with also being disabled), such studies are of increased relevance, exemplifying the multiple ways through which individuals may engage in activism through their everyday practices. Forms of quotidian activism are said to work alongside that of loud and explicit political actions, steadfastly chipping away at everyday societal codes and forms of governance The above scholars draw attention to everyday acts of resistance and survival such as ‘being seen’ (by e.g. social workers, the Job Centre staff, local authority administrators and local neighbours) and ‘keeping on going’, with survival being conceptualised as a crucial form of resistance. This work further disrupts normative visions of what acts count as activism, through opening up space to consider everyday acts of both ‘getting by’ and being seen in public as forms of activism.

In this chapter, I will draw upon the various ways through which participants saw themselves as being engaged in more private and everyday forms of activism, and the kinds of acts which were often deemed to be overlooked, trivialised, yet which enabled survival. Several key questions will be addressed within this chapter, including: what shape do ‘private’ and everyday mundane forms of activism take in response to austerity? What role do ‘private’ and everyday mundane forms of activism play in the lives of disability activists during a time of austerity? How might these acts provide disabled people with an alternative accessible means through which to engage in activism? And finally, to what degree are these practices acknowledged by the wider activist community?

8.2 Activism as slow endurance

For some activists involved in this study, activism did not merely mean engaging in confrontational or oppositional acts but was understood by participants as a form of slow endurance and desire to keep on going despite experiencing often extreme hardship and injustice. As Hedva (2016: 9) has noted: ‘most modes of political protest are internalised, lived, embodied, suffering and no doubt invisible’. Here, she is referring to how those who are not afforded positions of privilege within our society (such as disabled, black and transgender people), experience various forms of oppression that can incite great suffering. Individuals may as a consequence, live out an embodied daily protest, as they seek to carve out a space for themselves within society. The account of one participant, Robert, largely echoed this experience of engaging in an embodied daily resistance.

Robert is in his early 70s, lives with his wife (who is also his carer) in a city in the south-east of England. He became physically disabled during his early 40s due to severe arthritis. For Robert, disability activism was much more than solely campaigning, raising awareness and sharing with others his views and opinions around disbled and older people’s rights. Battling the welfare system and holding onto existing support had become a full-time job for Robert, continually having to justify himself and his impairment to social services, the local authority and the wider public. He found himself living in a perpetual state of anxiety with constant worry and fear for the future – a phenomenon associated with austerity more widely (Horton, 2016). Robert told me however that this had not prevented him from engaging in activism as he saw these very tasks of everyday endurance and his will to keep going in spite of on-going pressures as a form of activism in itself:

> It might be you as a disabled person at home getting on with your life when all the barriers are there to stop you, if that is your experience and you get on with your life. That actually is being an activist!

We might draw here upon Wilkinson and Ortega-Alcázar (2019: 157) recent concept of 'slow resistance', seeing Robert's actions 'as a form of politics that is not spectacular or public but instead often hidden, gradual and difficult to detect'. While relatively invisible, these acts of survival are far from insignificant. In contrast to Wilkinson & Ortega Alcázar's (2019: 164) use of the concept 'slow resistance' to refer to participants' active decision to 'retreat from the relentless drive to move forwards' under austerity, some participants in my study saw their desire and tenacity to plough on, while maintaining a positive visible disabled identity to be in itself a form of activism, resistance and self-care.

With this research taking an interpretivist approach and participants seen as defining their own realities, I will therefore argue that endurance during a time of austerity can indeed be seen as a form of disabled people's (slow) resistance and as an act of self-care. By keeping on going and not giving in despite punitive welfare reforms (targeted largely at disabled people), some participants saw this as an act of slow resistance, with individuals not allowing such reforms to knock them down or get the better of them - making them feel like a burden on society, an unworthy citizen or as insignificant. Robert, for example, noted that while he did not seek to resist or challenge austerity and the governing structures' micromanagement of the disabled and the poor (i.e. via the implementation of benefit sanctions and increased conditionality) (DeVerteuil and Wilton, 2009; Peck and Tickell, 2002), he saw his will to 'keep on going' in spite of such policies as a form of resistance in itself, as a refusal to be ignored and left behind. Such a viewpoint could be seen to both challenge and break down the conceptual binary between 'resilience' and 'resistance', seeing them both as being inherently interconnected. By engaging in endurance techniques ('keeping on going'), Robert is enacting a form of resilience, yet also that of resistance, ensuring that he is neither erased nor left behind.

As mentioned previously in the literature review, the concepts of resistance and resilience have traditionally been seen as somewhat oppositional to one another (Arampatzi, 2017; Brown, 2014; DeVerteuil and Golubchikov, 2016; Raco and Street, 2012). Resistance practices have often been perceived as transformative and striving for an alternative. Meanwhile, resilience has conventionally been understood as perpetuating the status quo and/or lacking transformative potential (MacKinnon and Derickson, 2012; Mould, 2018a). Scholarship has however increasingly sought to challenge these conceptual binaries (Arampatzi, 2017; Brown, 2014; Raco and Street, 2012), with DeVerteuil and Golubchikov (2016) arguing for a move towards a *critical* resilience, whereby resilience is envisioned as having the potential to maintain previous and alternative practices. Scholars have drawn upon the examples of grassroots community cooking collectives and work cooperatives, which are seen not only as helping people get by in the meantime but also about both enacting an alternative to austerity and securing a future (Arampatzi, 2017; Rakopoulos, 2014a, b). The aforementioned arguments around the repositioning of resilience as a form of resistance, are very relevant here to the experiences articulated by Robert and other participants, outlined within this chapter. By engaging in resilience practices such as those of self-care and keeping on going, participants such as Robert were able to ensure their ongoing survival and ultimately carve out a space for the continued presence of disabled people in society, at a time when disabled people are becoming increasingly isolated and marginalised. These practices of self-care may therefore be seen as co-constituting both those of resilience and resistance.

Like Robert, Jessica also told me how she saw her very existence as a form of resistance. Jessica is in her late 30s, lives in London and works for an international network advising on independent living. Jessica has been involved in various forms of disability campaigning from a young age, largely lobbying the government around issues of independent living and inclusive education. Jessica, however, saw her most powerful form of activism as being her tenacity to keep accessing mainstream spaces in uncompromising ways, to be both seen and heard proudly in public:

> When I talk about activism in a lot of the spaces that I’ve been in, my pure existence is a form of challenge to the status quo because I’ve been accessing mainstream spaces in an uncompromising way.

Jessica here is living the change that she wants to see, that is of the presence and inclusion of disabled people as equal citizens in everyday society. Existence, being present and 'keeping on going' may be seen as an act of resistance, which individuals engage in, either in the private space of the home or as Jessica notes, outside in public space. Care should however be taken here towards unreservedly defining the home as a private space. For some participants, the home was not seen as a private space, in part due to the constant flow of carers/personal assistants who cross the boundaries in and out of the home over the course of the day (see Twigg, 1999). Other studies have similarly, critiqued the notion of the home as an unreservedly private space, drawing upon the experiences of disabled people and/or the elderly living in residential care settings (Allan and Crow, 1989). Similarities can be drawn here to those who are in receipt of government assistance and as a consequence, lose their right to privacy. For some disabled people, receiving care and support has been said to involve forgoing any right to privacy (Burke and Crow, 2017).

Jessica spoke largely of the stigmatising nature of current media representations of disabled people (i.e. the rhetoric around ‘scrounger’, ‘skiver’ and ‘welfare cheat’ that has made disabled people increasingly fearful of public reaction), and how by simply ‘keeping going’ and being seen in public as a proud disabled woman, she was able to both counter and challenge some of these narratives. Jessica’s account may therefore illustrate resistance not only through her determination to keep on going but also through her tenacity to maintain both a visible and positive disabled identity. She highlighted the importance of disabled people being visibly present in society:

> I think having a disability in public space is essential because it’s kind of what we’re fighting for. The fact that disabled people aren’t visible in public space and the fact that it’s notable when they are, is an indication of where we still need to go, before we achieve an inclusive society… I don’t necessarily think you just need visible in terms of people campaigning, you need visible on a day-to-day basis. You’re going to the supermarket, you see someone who has a disability or you are going into a classroom and you know that your best friend has dyslexia. They are all kinds of visibility. But it’s not just about visibility, it’s also about disabled people being able to be in society and be open about having impairments.

For around half of the participants in this study, discriminatory representations of disability had in the past prevented them from claiming a politicised disabled identity. Jessica told me of how she saw recent media narratives around disability and welfare reforms as fundamentally challenging disabled people's citizenship and right to existence, and so 'keeping going', being actively seen in society and engaging in self-care were crucial strategies in challenging such narratives.

8.3 Advocacy; Supporting and sustaining one another

Activism was similarly deemed to be taking place in the space of the home, and outside through the quiet and unassuming practice of advocacy. A number of activists saw advocacy (particularly peer-advocacy, where individuals in similar situations come together and advocate for one another) as an important yet largely invisible form of activism, helping to support and sustain members of the disabled community during times of increased adversity. Advocacy has long been a central part of the Disabled Peoples Movement but has become of increased importance as of late, in the context of the closure of numerous Disabled Peoples Organisations (DPOs) and the gradual withdrawal of legal aid (see section 2.3.5). Advocacy was seen to have the potential to develop friendships, increase social interaction and mental wellbeing amongst disabled people. Alex was one of six participants engaged in advocacy (many more had over time been recipients of advocacy). She had been involved in various forms of unpaid advocacy (largely around securing care packages and independent living) over the past five years for autistic people living in her local community. Those whom she believes, are often left with no one to turn to for advocacy or advice:

> I end up doing advocacy for people that no one else will help… those who other people consider to be difficult clients. I go in and make sure the difficult clients get what the fuck they need…. It's not that the client's difficult, it's just complicated for them. All that's needed, is someone that's willing to take the time...

Here Alex refers particularly to the partial citizenship that autistic people experience, with their voices and concerns often silenced due to their inability to conform to standard social conventions of language and behaviour (Ahsan, 2019). Alex engages in advocacy via online platforms, through visiting various individuals at their homes (or residential care homes) and/or by accompanying them to various benefit and care assessments. Alex is very clear that her advocacy is part of her activism, as a way in which she can both challenge structures and ensure that every individual gains access to the services and support which they are entitled to as citizens. Advocacy is seen by Alex to be about ensuring that disabled people's rights are respected:

> I feel like I'm doing activism when I go out and support somebody through advocacy… For us, the immediate situations of risk, are in those [welfare benefits and care] meetings… We're being killed by being starved, we're being killed by being driven to suicide, we're being killed by not having the care packages we need. So, for us our frontline in that sense is those meetings, it's that advocacy... War is being done on our people in those quiet, quiet brightly lit meeting rooms while nobody watches.

Alex notes here the importance of advocates in attending care and benefit assessments alongside disabled people, situations in which individuals are at risk of losing access to their basic human needs and furthermore, means of survival. Alex compares the challenges that disabled people face today under austerity, to that of other social movements such as the Black Power Movement (Joseph, 2006). Alex noted that while Black people may face direct discrimination and injustice through the form of, for example, police brutality and prejudice (Cheung, 2020; McCurry et al., 2020), the frontline for disabled people in the UK is within these benefits and care assessments. It is within these spaces that the rights of disabled people are frequently violated (Barr et al., 2016; McCartney, 2012). Alex poignantly frames these assessments as matter of life and death, calling attention to the great repercussions that these assessments can have on both the lives and livelihoods of disabled people or more starkly, as Alex puts it - 'on disabled people's survival'.

Those made to undergo disability care and support assessments, experience increased stress and anxiety, fearful that they may not be deemed eligible for support. Individuals are expected to resemble what one activist, Melanie, terms 'the ideal disabled person – passive, submissive and dependent'. Individuals are forced to draw upon the medical model of disability and show evidence of their impairment in order to receive care and support. The assessment process as Alex remarks can be incredibly undermining and upsetting, causing individuals to feel differently about their disability and personal capabilities:

> I turn up and I help other people at their care assessments... as individuals it can be really hard to reinterpret ourselves in the ways that people want us to for these assessments.-We spend our whole lives trying to get away from that word ‘can’t’…

The role of an advocate in these situations according to Alex is to be present and when necessary, to hold the assessor to account. Alex went on to note that without anyone else being present during these assessments, the voices and rights of disabled people are often both violated and undermined:

> Most of it is actually just being there. It’s not even having any special skills, it’s turning up so that someone else is there to witness what’s going on… they take advantage of our people when we’re vulnerable, when no one can stop it. When we go in a pair it makes a difference and it’s stupid, it shouldn’t but it does.

Alex highlights how advocacy is not a spectacular, grand or public act but is instead, a small gesture of being present with one another. Alex notes that without the presence of another person at these assessments, disabled people become vulnerable. Connections can be made here to the principles of the social model of disability, which argues that disabled people are made vulnerable by situational circumstances, such as societal prejudice and a lack of adequate support. Without the presence of an advocate, the voices and concerns of disabled people were often felt to be ignored. Thus, further reflecting disabled people’s partial citizenship, with many not being seen or regarded as autonomous actors. Alex spoke of how accompanying someone to his or her assessment, had the potential to bring about immediate change, with the assessor knowing that someone else was listening and aware of what was happening, as she went on to say:

> I mean it's actually, it's so embarrassing, the amount of advocacy things I turn up to and I go to the meeting and [my physical presence means that] the problem's already gone.

The presence of an advocate in these situations was thought to help ensure that disabled people's voices were listened to and that any issues arising did not go unnoticed. Alex illustrates how simply being present as an advocate, can mean that problems get solved, with service providers aware that someone else is listening and holding them to account. This view was echoed by Anna and Simon, who similarly noted that without the presence of an advocate, family member or friend, the potential discrimination and wrongful conduct of some assessments would go largely unnoticed. Advocacy was therefore according to Anna, Simon and Alex, at times, about playing witness, increasing visibility of the injustices being faced by disabled people and ensuring that any violation or denial of disabled people's rights did not go unnoticed. Advocacy was therefore seen as a form of activism, in the sense that it helped raise the visibility of an issue, and to hold individuals accountable. Furthermore, by supporting disabled people to 'keep on going' and gain access to the support they were entitled to, advocacy was thought to enable disabled people's survival and ongoing presence within society, against a backdrop of welfare cuts, which sought to exemplify disabled people's partial citizenship and what participants deemed as a desire to further exclude them from wider society. Advocacy may therefore in a similar respect to the above section, constitute both a form of resilience and resistance, challenging a welfare system which was deemed by participants to be degrading and dehumanising. Advocacy may further constitute new, valuable networks and constellations of care through which some of the most detrimental impacts of austerity may be countered. These networks lay in stark contrast to those envisioned by neoliberal society, with its emphasis on notions of autonomy and independence.

Alex was inspired to become an advocate after receiving advocacy herself. The advocacy she received enabled her to gain access to services and support for herself and her (first) disabled daughter. The kind of support Alex received from advocates, included education around her rights, the support she was eligible for and how to best articulate her needs. Alongside this, Alex also received help with filling in welfare applications, and the presence of an advocate at disability benefit and care assessments. Alex felt a great duty to both reciprocate and give back the support and knowledge she had received:

> I think partly the reason that I do advocacy is that over the years, I've had other activists help me get my shit sorted, you know. Helped me get my care package and apply for benefits and helped me deal with that… I was really lucky to have all that help and now that I am more resourced, I'm trying to share that help with other people.

Here, we might refer back to the notion of interdependence, a key pillar of the Independent Living Movement. Disabled people's ability to live independently (along with that of the wider population) is brought about through relations of care and dependence upon others for knowledge and support. While the care that Alex both received and provided through advocacy was similar to that outlined previously in section 7.2.2 about online communities (in terms of providing a listening ear, helping individuals to articulate their rights and providing practical guidance/support), the relationship of care through advocacy was much smaller, operating only between two individuals. Online communities, in contrast, were much bigger, often drawing upon the knowledge, resources and care of multiple individuals simultaneously. The care provided through online communities was therefore dependent on individuals being willing to speak out and ask for support within the wider group. Advocacy, in contrast, was seen to be a much more private act, involving confiding in only one other individual. Greater time is often spent during advocacy, building a relationship and trust between the two individuals. For some participants such as Rachel and Sophie, asking for help online was felt to be easier than face to face due to its less personal nature. However, for others such as Alex, there was said to be a certain value in meeting someone face to face, particularly in terms of having someone physically present during welfare meetings and assessments – listening in and advocating on her behalf where necessary. Neither of these practices initiated by disabled people, are attempting to be public or spectacular but are instead seen as a form of *internal activism*, as a means to support individuals in articulating their rights and ensuring the sustainability of the broader movement and its people.

Here we might draw upon Tronto’s (1994) writing on an ‘ethic of care’. Tronto (1994: 101) suggests that ‘we need to re-think our conceptions of human nature to shift from the dilemma of autonomy or dependency to a more sophisticated sense of human interdependence’. Care has frequently been conceptualised as a practice which occurs in private and is often associated with the ‘vulnerable’ and the ‘needy’ (Hedva, 2016). Both providing and receiving care have often been understood as a weakness within our society, where the emphasis is on striving for independence and individualism (Dowse 2009; Wilton and Schurmans 2020). As Tronto (1994: 117) argues, ‘Society treats accomplishment, rationality and autonomy as worthy qualities, care is devalued in so far as it embodies their opposites’. Nevertheless, being ‘embedded in relations of attentiveness and responsiveness’ (Barnett and Land, 2007: 1067) along with that of a personal support structure, should be recognised as an important component of an individual’s resilience and resistance framework.

Alex in the quote above demonstrates how she has been both a recipient and a giver of care. While disabled people like Alex may not be financially productive (as a result of being unable to work), the care they provide is in itself valuable, even though it’s not financially remunerative.

Disabled people (particularly individuals with learning disabilities) are rarely recognised as contributing members of society (Power et al., 2016). Advocacy can therefore be a means through which individuals both give back and gain a sense of being valued as citizens.

The key message in Tronto's (1994) work is that the act of caring creates interdependencies and interconnections between people. These connections and positive support networks can help to both strengthen and nurture the self. While care and caring have typically been practices associated with women, Parton's (2003: 11) observes that 'care is central to everyone; it is not a parochial concern of women alone'. While no male participants in this study currently served as an advocate, many had been recipients of advocacy and performed care through other outlets such as through volunteering or supporting others in the activist community through providing practical support. This chapter, therefore, conceptualises self-care, care work and mutual aid as a quiet and often private form of activism, helping to sustain communities in the face of adversity. Previous scholarship has recognised the role of care and mutual aid in sustaining social movements and political action (Brown and Pickerill, 2009). However, rarely have caring practices been recognised as political acts or forms of activism in and of themselves (see Askins, 2014; 2015 for an exception). The feminisation of care (Finch, 1987; Graham, 1991; Milligan and Wiles, 2010; Thomas, 1993) has often meant that its political and activist role has been largely overlooked.

For Alex, advocacy was an incredibly important practice in the here and now, particularly in the context of the closure of numerous DPOs, which play a crucial role in providing independent, accessible advice, advocacy and peer support for disabled people (Connolly, 2017). Advocacy was seen by Alex as a bi-directional form of activism, whereby disabled people spoke out (to an advocate) about an issue, and the advocate would then either seek to resolve the issue internally or pursue it further. We can see here how both the advocate and the person they are representing may be jointly involved in the collaborative practice of activism. The above case study, therefore illustrates how informal and self-built support structures such as advocacy, can be critical forms of activism and resistance in both helping to challenge (and increase the visibility of) some of the injustices faced by disabled people, along with also educating individuals around their rights.

Like, Alex, Claire was similarly engaged in advocacy, predominantly for people with learning disabilities like herself. Her focus, however, was largely around independent living. She spoke about the growing number of people with learning disabilities, who are being admitted to Assessment and Treatment Units (ATUs) as opposed to supported living schemes, due to their high care and support costs. It has also been suggested hat a growing number of disabled people, over recent years are being admitted to care homes due to cuts to social care budgets (Brown, 2017). Claire's advocacy has therefore been largely focused upon supporting disabled people to leave these spaces, which she terms as 'Free our People' work:

> I do 'Free our People' advocacy work, working with people to get out of institutions… it involves going to meetings, explaining [to them their] rights, helping [them] to challenge things, so it's about…helping, in terms of going through the care act assessment, the care plans. Just doing what needs to be done.

While engaging in advocacy was seen by Claire to be both emotionally and physically draining, it provided her with a great sense of achievement and pride. This became particularly apparent when she told me about one individual whom she had supported in leaving a psychiatric hospital, and in gaining access to a supported living scheme in their local community.

A sense of care and duty underpinned Claire's advocacy. Along with supporting the aforementioned individual through her assessments, she had put together a care package for when she left the institution. This was a practice which she frequently did for those whom she supported. In this instance, she had asked members of the activist community to help in designing a wrapping paper for this care package. It was hoped that this would help provide the individual with a sense of support, a shared sense of injustice and a feeling of belonging. This was deemed to be particularly important at a time when many disabled people felt abandoned by the loss of countless community support services:

> This is what I've done... I was asking people to help design appropriate wrapping paper [to wrap some gifts in, when she is discharged from hospital]. I'll slip in there the UN Convention of Persons with Disabilities. Because every now and again she guesses whether there is a UN Convention for people with autism. I was thinking, you don't need to guess anymore, I'm going to put it in there (laughs) and you won't have to guess.

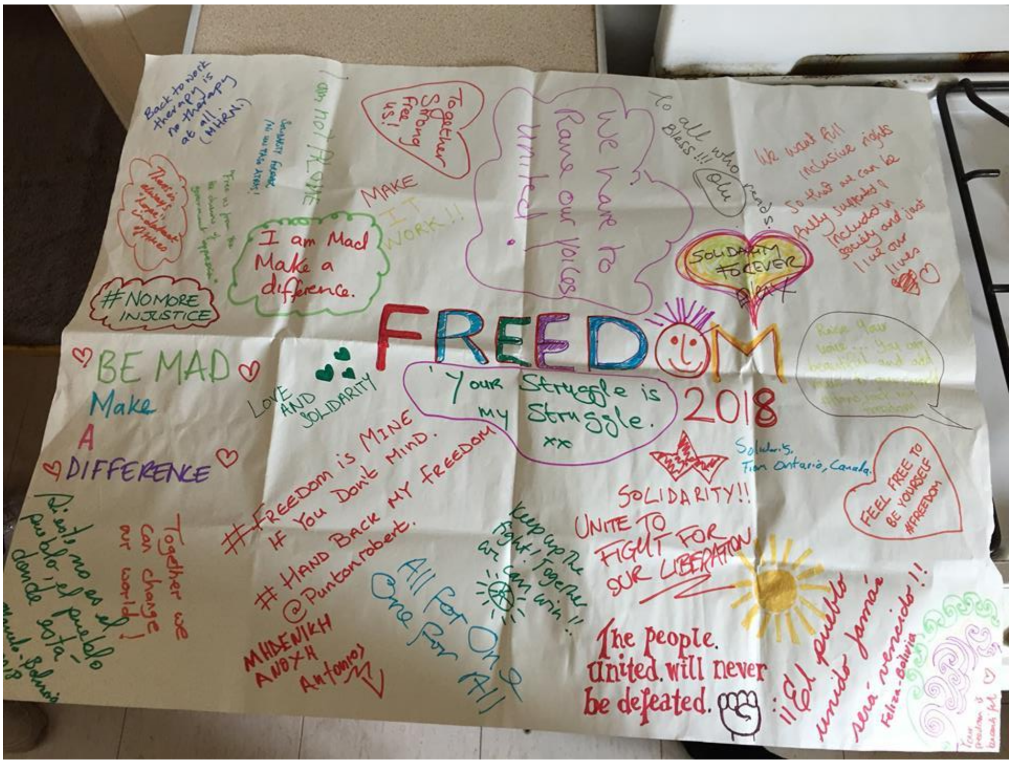

Figure 22: Photograph of 'Freedom 2018 – a participant's collaborative artwork. Source: author.

Here, we can see the close connections and relations of care Claire often builds with those whom she advocates for. Advocacy for Claire was about ensuring that individuals felt both supported and listened to, no longer alone or isolated. Claire did however share with me some of the emotional and physical challenges of undertaking advocacy work on her own. She consequently had a great desire to build up a larger support network of disability advocates.

Claire was not alone in expressing the need for a network of advocates. Carol similarly shared this vision and had been proactive in seeking to build a national network of disability advocates online:

> I'm trying to build up a hand holding grassroots network of people. So, we can have people across the country who can go along with the claimants and help them fill their form in or support them at work focussed interviews or sit with them while they have an assessment and things like that. There are people that do it but it's so fragmented, you need something like a national network, that's what I'm trying to do.

Carol saw the need for a more unified and succinct network of disability advocates - those who were able to provide individuals with face-to-face advocacy. Creating a national independent network for disability advocates that was not affiliated with any charity or governmental source of funding, was deemed by Carol to have the potential to be particularly valuable. The network would provide disabled people with a platform through which to find an advocate, but also simultaneously provide advocates with a network through which they could gain mutual support and provide emotional care to one another. The network would therefore work to fill in some of the gaps left by the closure of professional advocacy services, reductions in legal aid, and the closure of numerous Disabled People's Organisations (DPOs).

As mentioned in previous chapters, advocacy and bi-directional support networks have become a critical element of the new landscape and structure of care in austerity Britain (Power et al., 2016), helping support individuals to get by in an increasingly difficult environment - underpinned by increased disability benefit conditionality, the withdrawal of public and social services and growing public resentment towards disabled people (see Briant et al., 2013). Disabled people have, as a result, become increasingly reliant upon one another as avenues for (emotional and practical) support, accessible information and advocacy, as opposed to conventional, professional and top-down forms of support (Power et al., 2016).

With all of the above accounts (Robert, Jessica, Alex, Claire and Carol) drawing upon largely hidden and overlooked forms of resistance, there is evidently a need, as Wilkinson and Ortega-Alcázar (2019) argue, to be more attuned to quiet politics and to garner greater recognition of these somewhat mundane acts (Askins, 2014; Jupp, 2017), seeing them as crucial in the process of resistance, self-conservation and survival (Berlant, 2007). Acts of care, mutual support and survival (such as 'keeping on going' and 'getting by') have conventionally been framed as forms of resilience as opposed to that of resistance (Bracke, 2016; DeVerteuil and Golubchikov, 2016). This chapter has however sought to challenge this by showing how forms of care and mutual aid (which enable people to survive), might be reimagined as forms of resistance in themselves.

8.4 Conclusion

This chapter fundamentally raises the question of whether disabled people who are not actively engaged in anti-austerity politics but are instead focused on individually and collectively trying to 'get by' under a system that has arguably been built to 'break them' down (The Broken of Britain, 2012), could indeed be recognised as engaging in activism. The accounts of some of the participants in this chapter could be dismissed as apolitical and individuals could be accused of failing to resist, but perhaps there is something more fundamentally resistant and political in the act of 'just getting by' under a system, purposefully built to devalue, humiliate and degrade those who are deemed to be economically unproductive or inactive (Berlant, 2007). Might we, therefore, respond to DeVerteuil and Golubchikov (2016)'s call to break down the conceptual binary between 'resilience' and 'resistance', seeing them both as inherently intertwined.

In conclusion, this chapter has sought to highlight both the importance and potential of everyday, small-scale acts of activism. Regardless of their relative invisibility, such acts can be important for enabling an individual to ‘keep on going’, ensuring self-preservation and supporting one another to establish and safeguard their rights. The forms of activism mentioned in this chapter therefore have the potential to provide an individual with ballast and gradually challenge or ‘chip away’ at dominant structures or systems of governance. In contrast to other forms of activism discussed in this thesis, this chapter has drawn attention to forms of activism which need not necessarily be scaled-up in order to be effective. Activism has long been associated with an imperative to scale-up (to become bigger, louder and greater) (Gibson-Graham, 2002), with scaling up always inherently regarded as a positive thing (Kitchin and Wilton, 2003). This chapter has however exemplified how activism may be more diffuse, providing effective support to help individuals endure and keep on going, without the imperative requirement to become more active or scale-up. It can instead simply exist as a quiet, subtle and gradual act of resistance, endurance and self-care.

Chapter 9 Conclusions

9.1 Research questions revisited

The overall aim of this research was to explore how and why individuals had become involved in disability activism in response to austerity, along with consider the spaces and forms in which their activism was taking place. Biographical interviews provided activists with the opportunity to share in detail their experiences of engaging in disability activism. They were able to articulate their histories in their own words, and in keeping with the overall aim of the research – to explore individual routes into activism and the spaces in which activism is currently taking place. Individuals’ accounts are explored in detail and supplemented with participant observation garnered at various disability activist events, providing greater detail about the nature and forms of activism that people were engaged in.

The research sought to address four key research questions, which are discussed below:

Q1. What forms and spaces of disability activism are emerging and adapting in the context of austerity?

Austerity measures have posed a direct threat to the everyday lives and livelihoods of many disabled people, be this through cuts to individuals' care packages, personal finances or public and community support services. Many as a result have found themselves increasingly isolated, marginalised from wider society and pushed into situations of despair. The urgency underpinning the current situation becomes clear through each and every participant's account. However, while some have become vocal in their opposition to austerity, others have become increasingly fearful of the consequences of publicly speaking out against such change. Participants' fear often related to the impact that speaking out could have on their access to welfare benefits and support. As a result, some individuals sought to adapt their activism in order to preserve their anonymity. At times, this meant moving away from public forms of activism (e.g. protest and direct action) and turning towards the arts or online activism as often dis-embodied practices and spaces through which they could mask their identities, yet at the same time, draw widespread attention to the ongoing challenges brought about by austerity. Some individuals, therefore, felt more able to speak out due to the degree of anonymity that such platforms provide.

While some participants' accounts highlight the value of more liminal and private forms of activism, there was still a recognition of the ongoing need for public forms of protest. There was a sense among the vast majority of participants that disabled people needed to be seen visibly fighting back, providing other disabled people with a sense of hope. Some participants therefore did not fear the repercussions of being identifiable in protest but rather saw this as their moral duty. Moreover, there was also a recognition of the need to both engage and create space within protests for those who may have become increasingly isolated and housebound due to austerity with its cuts to personal finances and levels of care and support. Through, for example, integrating online forms of activism into protests (e.g. Twitter storms) and setting up initiatives whereby individuals could attend protests via proxy, activists were able to ensure that no one became prevented from taking part.

Different spaces invariably require different tactics and uses of the body, including the use of the disabled body as a vehicle within protest and direct action. The disabled body here is often actively mobilised and placed at the centre of actions, as a means of playing with notions of vulnerability and garnering greater media attention. Driven by the urgency and desperation of the current situation, activists engaged in public forms of protest were often said to draw creatively upon their individual ‘vulnerable’ disabled bodies as a means through which to convey their message. It was felt that through re-appropriating and playing with notions of corporeal vulnerability as part of their resistance, greater public visibility, understanding and support could be acquired. Through displaying the archetypical vulnerable body, participants felt that it helped them to illustrate that government cuts to social welfare were unjust, impacting upon some of the most vulnerable members in society. Participants noted how they were expected to present themselves in a similar manner during welfare and work capability assessments, emphasising impairment and vulnerability, and thereby conforming to what Melanie termed as 'the ideal disabled person – passive, submissive and dependent'. Access to essential social care and benefits was therefore seen as being dependent on conforming to this conceptualisation of the 'ideal disabled person'. The utilisation of notions of vulnerability as part of recent protest in response to austerity marks somewhat of a movement away from that of disability protests that were held during the 1970s and 1980s, which were orientated around presenting an image of collective strength.

Along with drawing upon the imagery of vulnerability, the use of individual stories as a strategic tool in activism has become increasingly commonplace in gaining greater media attention. These accounts often emphasise the vulnerability and fragility of disabled people’s lives and bodies in the absence of adequate support structures. The use of personal narratives has been recognised by some activists as a stark move away from the social model of disability with its emphasis on the social and environmental factors which bring about disablement. Activists have often worried that focussing too much on individual stories may detract from the collective nature of disabled people's struggle. Take for instance, the historical use of personal stories by disability charities for fundraising campaigns, which often undermined disabled people's sense of autonomy and resilience, turning them instead into objects of pity. Nevertheless, the use of personal stories as part of recent anti-austerity activism (driven largely by the urgency of the current situation) was generally thought of positively by participants as a valuable resource, in helping to convey the everyday and personal impacts of policy changes on disabled people’s lives.

Q2. What does activism mean to disabled people who seek to create spaces that challenge and transform the status quo?

Activism was understood by participants as a broad concept, consisting of a variety of different acts but which were focussed primarily around increasing the visibility of an issue and bringing about societal change. There was not seen to be one specific act which was deemed as constituting activism but rather multiple. For some their activism involved engaging in loud, public and confrontational acts such as that of protest and direct action. While for others it was seen through their engagement in the arts, online activism, advocacy and/or the more ostensibly private, quotidian and personal act of keeping on going in the face of a system which they deemed to be intentionally built to break them down. Activism was therefore seen as constituting a variety of different acts from those which were short and fleeting to those which were ‘lived out’ daily.

While many participants upheld protest and direct action as constituting the ideal and archetypal form of engagement in activism and/or of being an ‘activist’, there was a recognition of the need to broaden understandings of activism and to adapt activist practices in line with individuals’ bodies and abilities. Places of protest, for example, due to their fast-moving nature have not conventionally been seen as spaces appropriate for disabled bodies, but rather for those which are able, mobile and agile (Harvey, 2012; Routledge, 2017). This thesis has however shown how disabled people have sought to adapt these spaces and practices in order to accommodate and draw upon their disabled bodies as tools in their activism. There was a recognition of the need to create inclusive spaces through which all disabled people could participate regardless of their different bodies and bodily abilities. This at times, involved slowing down, drawing upon networks of interdependence, and incorporating spaces for both care and rest. Emanating from the accounts of activists, in chapter 7 I engage with the concept of 'slow activism', advocating for a slowing-down of activism, with the creation of spaces for rest, making the practice more inclusive and providing disabled people with a variety of means through which to express their resistance. Time and speed have long been understood by disability scholars and activists alike, as key factors leading to disabled people's exclusion and marginalisation. Disrupting notions of time has consequently become central to the Disabled People's Movement and crip culture (Kuppers, 2014; McRuer, 2018; Samuels, 2017), with rest and slowing down seen as central to any feminist crip utopian future.

Along with sharing a message to a wider public, activism was also understood by the vast majority of participants to be about raising consciousness, building community, morale and associated support structures amongst disabled people. In the process, helping disabled people to build up their sense of self-worth, persevere, resist and keep on going in the face of a system of structural change. Through participants' accounts that populate this thesis, I have proposed the terms *external activism* and *internal activism* to highlight and articulate this. While *external activism* entails raising awareness and visibility to the wider public, *internal activism* focuses on raising consciousness, building a sense of community and associated support structures. Both practices are deemed by activists as being equally important to the overall success of the movement. Different bodies, at different times, may, however, focus on both or only on one of these.

Due to the life and death nature of the current situation, there was a recognition of the importance and need for spaces which enabled individuals to support one another in keeping on going. Participants' accounts emphasised the importance of, for example, online spaces as platforms for the building of community and support structures along with the sharing of knowledge to enable individuals to preserve and resist some of the profound impacts of austerity on their everyday lives.

Q3. What motivating factors and experiences have encouraged individuals to become involved in disability activism?

Participants became involved in disability activism as a result of several different factors and experiences. Individuals' routes into activism were sometimes marked by key trigger points and other times were cumulative, more akin to the well-known phrase, 'the straw that broke the camel's back', with several issues or injustices building, eventually causing them to speak out and take action.

What each activist's account held in common, however, was the sense of fear and urgency that underpinned their current activism, with many finding themselves living in situations of increased hardship, precarity and with growing fear for the future, as Rebecca told me – 'We have no choice, the stakes have become too high'. Disability activism in response to austerity can be seen as a form of fire-fighting with individuals continuously seeking to regain their rights along with getting welfare benefits and support reinstated.

What participants’ accounts also held in common was the role of contact with other disabled people in igniting their activism. Through being in contact with others and sharing experiences, participants expressed gaining a realisation that the challenges they faced were not individual, but rather structural and shared. Thus, often moving participants away from a sense of self-blame and isolation to a shared sense of injustice. In the context of austerity, with a number of disabled people finding themselves isolated at home with limited support, participants' accounts showed how social media had become an increasingly important arena in igniting activism by providing disabled people with a platform to connect, share experiences, highlight injustice and become united in their resistance.

Q4. How might more personal or private forms and spaces of activism begin to challenge what critical human geographers traditionally perceive as ‘activism’?

Activism and political action have conventionally been understood by Marxist geographers as taking place in the public realm (e.g. on the street or in the square), with public space being seen as the key site of struggle and resistance. Activism, as a result, became associated with temporary, large, vocal and 'spectacular' acts of resistance generally undertaken by a collective body of privileged, male, able-bodied and mobile political actors (Coleman and Bassi, 2011).

Through drawing on participants’ accounts along with existing feminist literature relating to quiet and quotidian forms of activism, we may see how the demarking of public space as the sole arena of political action has increasingly become challenged. Participants’ accounts highlight how activism is taking place across a range of different spaces from the public to the liminal and the private. Some participants in this study, for example, understood activism as not only constituting of large, public and vocal acts but also those which were more private, understated and personal in nature, such as advocacy and caregiving. These practices have become of increased importance during austerity, serving as part of a new infrastructure of care, working to sustain individuals in the context of the closure of many support organisations and services. While quiet and passing with ‘not too much fuss’ (Horton and Kraftl, 2009a: 15), such acts should be recognised as crucial forms of self-care and resistance, helping people to keep on going in the context of an austerity programme which has arguably been constructed to wreck and dehumanise. For participants including Rachel and Robert, their tenacity to keep on going in the face of such injustice was in itself seen as a form of activism - as an outright refusal to be silenced, overlooked, victimised or left behind by wider society. Their personal activism lived out through the everyday further challenge conventional understandings of activism as inherently dramatic, momentary and event-based.

While these acts could, of course, be overlooked as apolitical or as constituting solely that of self-care or resilience, participants saw them as inherently agential and resistant. This thesis, therefore, challenges conventional Marxist understandings of activism; advancing a small yet growing body of feminist literature on quiet and quotidian activism, along with that which has sought to reclaim resilience as an intrinsic form of resistance, rather than being contrary to it.

9.2 Contribution

This thesis contributes to work in the fields of critical disability studies, social movement studies, geographies of disability and social and political geography. By providing insight into the experiences of disability activists engaged in anti-austerity activism, this thesis both builds upon and extends a small yet growing body of scholarship, exploring disabled people's role as activists and political actors. Little research to date has sought to analyse and bring together the various experiences of disability activists, relying instead heavily on autobiographical and self-reflective accounts of scholars' engagement in disability activism, along with that of media analyses of protest events. This research thus seeks to add to the existing literature by bringing together the experiences of multiple participants engaged in a variety of different activist spaces and practices. It also is original in exploring individuals' life courses and routes into activism, along with providing a geographically nuanced analysis of the spaces and scales at which individuals' activism is taking place. Furthermore, it both documents and analyses the unique nature of disability activism in the context of austerity, of which very little research has explored to date. In doing so, it further adds to the existing literature on the geographies of austerity in terms of exploring how disabled people are coming together to both respond to and resist austerity.

Drawing upon the theoretical framework of critical disability studies, I recognise the importance as Goodley (2011: 157) argues of 'start[ing] with disability but never end[ing] with it: disability is the space from which to think through a host of political, theoretical and practical issues that are relevant to all'. This thesis has clear relevance to fields far beyond that of disability studies, in, for example, expanding understandings of the role of the individual body in activism. Research in the field of social movement studies has to date largely focused on the collective body as opposed to that of the individual body. Through drawing upon both participant observation of protest events along with participants' accounts of engaging in activism, this thesis has highlighted the importance of considering the individual body in protest, with the body at times serving as a resource or being seen as a message in itself. Furthermore, there has been little research which has analysed the disabled body in protest. Through this study, I have thus sought to explore how different disabled bodies may engage in activism along with how we might make public forms of protest more inclusive and accessible to a wide array of different bodies.

Beyond expanding scholarship on the role and significance of the individual body in protest, this study has served to complicate understandings of emotions in activism. Social movement literature has largely analysed the role of certain emotions as a resource and/or motivating factor behind individuals' activism (Hercus 1999; Goodwin et al 2001). However, this study has demonstrated how other un-planned and unanticipated emotions may arise as part of/through one's activism (e.g. that of fear), having the potential to prevent or curtail it. Furthermore, participants' accounts also highlight the importance and value of emotional solidarities which can be brought about through participation in activist spaces –often ensuring the sustainability of their activism along with that of their personal mental wellbeing.

The study also contributes to the field of political geography by expanding understandings of activism and political space. Through drawing attention to more private, everyday and quotidian forms of activism, this study adds to a small yet growing body of literature on 'quiet activism'. In drawing upon participants' understandings of activism along with their accounts of engagement in quieter and more personal forms, this study both illustrates and advocates for a more inclusive conceptualisation of activism and political space- which are inclusive of a variety of different bodies and are not solely associated with public space. Furthermore, this study has shown how activism may not constitute a single and definable action or event but rather be seen as something which is lived out through the day to day, as seen through for example, individuals' tenacity to keep on going in the face of injustice. While such practices could be overlooked and seen as constituting solely that of resilience, this thesis has sought to add to existing literature which critiques the conceptual binary between resilience and resistance, showing how both concepts may be mutually constitutive.

9.3 Concluding thoughts

I conclude by returning to disabled people's partial citizenship status, as it is prominent within the conceptual framework that underpins this study and is further exemplified through participants' accounts that form the backbone of this thesis. The marginal status of disabled people in society has become particularly apparent during a time of austerity. Disabled people's rights in terms of Morris's (2005) three pillars of citizenship (self-determination, participation and contribution) have increasingly become undermined and challenged, with activists consequently having to adapt their activism in order to protect and maintain the previous gains of the Disabled People's Movement. The movement has consequently had to change its focus from securing new rights to largely reinstating those that have been lost. Nonetheless, there remains a deep-seated hope and longing amongst participants for a more inclusive future, as Anna recounts:

> A dream many of us have is a fully inclusive society. That we have the same rights as everyone else, that we are treated with respect and dignity and (voice quivers) treated as a person, not as a thing. That we don't have to fight for our services - they are there.

It is hoped that this thesis will serve as a resource for the Disabled People's Movement, in documenting the nature of disabled people's resistance in response to this particular period of austerity, as Melanie told me: 'If we don't write about it, our history will be forgotten'. Through giving both space and voice to disabled people and their varied experiences, it is hoped this thesis, and subsequent publications will serve as forms of activism in themselves. Being entrusted with people's personal stories, it is beholden on me to ensure that these are shared and documented in ways that are beneficial to disabled people's activism and the wider movement.

9.4 Areas for further research

There is evidently a need for further research in this area, with still very limited scholarship around disabled people's role as political actors or the evolving shape of the Disabled People's Movement today. Much of the literature on disability activism has historically and continues to be very UK-centric (see Berghs et al., 2019; Soldatic and Johnson, 2019 for some exceptions). Further research is warranted to explore the practices of disability activists from outside of the United Kingdom, who in some locations are similarly responding to austerity and its detrimental impact on disabled people's rights.

While this research sought to utilise qualitative methods including biographical interviews and participant observation in order to better understand the experiences and practices of disability activists, embracing more of a participatory approach such as that of Participatory Action Research (Banks et al., 2017) may have helped to ensure that participants were incorporated into all parts of the research, including in its write up. Being involved in the writing up of research about disabled people's lives has long been a key focus of the Disabled People's Movement, as the longstanding slogan of the movement implies - 'Nothing about us, without us'. The nature of the doctorate however dictated to what degree this was possible. A more participatory approach may have helped to ensure that the research findings and its eventual outputs were of greater benefit to individual participants. This research, therefore, points towards a clear need for further participatory research, working alongside disability activist communities to draw out and share knowledges in order to equip them in their resistance.

Lastly, disabled people continuously find themselves in situations in which they must justify their right to existence (from birth to death), as is implied within the title of this thesis. In the final writing up phase of this study COVID-19 came into existence and disabled people's lives were yet again challenged, often seen as being of lesser value, with some disabled people having ‘Do Not Resuscitate’ (DNR) orders applied to them, with little or no consultation (Hosali, 2020). Government advice was also frequently not made accessible, as seen through the absence of British Sign Language (BSL) interpreters at the UK Government Coronavirus daily briefings and the lack of easy read information made available to those with learning disabilities. Social media in this instance has yet again become a lifeline for some, helping to provide inclusive and accessible information, along with a means through to which to challenge and lobby the government. Research would be of value in exploring how COVID-19 has impacted upon disabled people’s citizenship and the strides and gains of the Disabled People’s Movement to date, along with what new and evolving structures of care and resistance might be emerging at times of crisis. With large parts of the disabled population expected to ‘shield’ and self-isolate in their homes, online spaces are yet again becoming of significant importance as spaces for activism along with the building of community and the sharing of knowledge and resources. As this thesis has shown, disabled people are political actors and their resilient practices and diverse forms of activism will no doubt adapt and respond to this changing context.

Appendix A Participant Profile Summary

NAME	AGE RANGE	GENDER	GEOGRAPHICAL LOCATION	DISABILITY	LENGTH OF INVOLVEMENT IN DISABILITY ACTIVISM[17]	SELF-IDENTIFIED TYPES OF ACTIVISM ENGAGED IN
ADAM	40-44	Male	North West	Mental health	10-15 years	Online activism, protest
ALEX	40-44	Non binary	North West	Mental health, learning and physical disability	10-15 years	Advocacy, art activism, online activism, protest, writing
AMANDA	50-54	Female	Midlands	Not disclosed	6-10 years	Online activism, protest

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[17] Some individuals had been engaged in activism for a longer period but had only recently become engaged in disability activism.

* - Indicates use of participant’s real name.

ANNA	45-49	Female	London	Mental health and physical disability	36-40 years	Advocacy, art activism, online activism, protest, sitting on committees, trade union, writing
ANNE O’DONNELL *	50-54	Female	Scotland	Mental health	16-20 years	Online activism, protest, research, sitting on committees, writing
CAROL	60-64	Female	North East	Mental health and physical disability	6-10 years	Advocacy, online activism, protest, research, writing
CATHERINE	25-30	Female	North West	Chronic illness and physical disability	1-5 years	Research, writing
CHRIS	40-44	Male	South East	Physical disability	16-20 years	Advocacy, online activism, research, sitting on committees, writing
CLAIRE	45-49	Female	London	Learning disability	41-45 years	Advocacy, keeping on going/being present, online activism, protest, research, sitting on committees, writing

DARREN	35-39	Male	London	Mental health	6-10 years	Art activism, online activism, protest, trade union, writing
ELAINE	40-44	Female	London	Physical disability	26-30 years	Campaigning, protest, research, sitting on committees
JESSICA	30-34	Female	London	Physical disability	16-20 years	Campaigning, keeping on going/being present, sitting on committees
JUDITH	60-64	Female	London	Mental health	30-34 years	Campaigning, protest, research, sitting on committees, writing
LISA	50-54	Female	London	Physical disability	21-25 years	Campaigning, online activism, research, sitting on committees, writing
LIZ CROW*	50-54	Female	South West	Not disclosed	31-35 years	Art activism, online activism, protest, research, writing
MARY	55-59	Female	London	Physical disability	36-40 years	Keeping on going/being present, protest, research, sitting on committees, research, writing
MATTHEW	50-54	Male	North West	Physical disability	10-15 years	Protest

MELANIE	55-59	Female	London	Physical and sensory disability	21-25 years	Art activism, online activism, protest, research
NATHAN DAVIES*	40-44	Male	North Wales	Physical disability and chronic illness	1-5 years	Art activism, online activism, protest, sitting on committees, writing
PETER	40-44	Male	London	Physical disability	16-20 years	Art activism, protest, writing
RACHEL	26-30	Female	London	Physical, sensory and learning disability	1-5 years	Advocacy, online activism, protest
REBECCA	40-44	Female	London	Mental health	6-10 years	Campaigning, online activism, protest, research, writing
RICHARD	45-49	Male	South East	Mental health and physical disability	6-10 years	Online activism, protest

ROBERT	70-74	Male	South East	Physical disability	6-10 years	Sitting on committees, keeping on going/being present
ROGER LEWIS*	55-59	Male	London	Sensory disability	6-10 years	Protest, sitting on committees
SIMON	45-49	Male	London	Mental health	1-5 years	Online activism, protest
SOPHIE	20-24	Female	North West	Chronic illness and physical disability	1-5 years	Campaigning, online activism, research, sitting on committees

Appendix B Photographs from activist events February 2017 – August 2019

Figure 1: Photograph of 'End The Capita Contract End The Theft!' demonstration, Southampton 15th February 2017. Source: author.

Figure 2: Photograph of a procession held during 'Who Killed Daniel Blake? – Sanctions Kill' demonstration, Southampton 30th March 2017. Source: author.

Figure 3: Photograph of placards outside the Job Centre during 'Who Killed Daniel Blake? – Sanctions kill' demonstration, Southampton 30th March 2017. Source: author.

Figure 4: Photograph of ATOS Kills protest outside the opening ceremony of the Parathletics, London 14th July 2017. Source: participant – printed with participant's consent.

Figure 5: Photograph of preparation for ATOS Kills protest, outside ATOS Headquarters, London 21st July 2017. Source: Author.

Figure 6: Photograph of Universal Credit Protest, Parliament Square, London 18th April 2018. Source: author.

Appendix C Participant Information Sheet

UNIVERSITY OF
Southampton

Participant Information Sheet (28/04/2017 - version 1.4)

Disability Activism in Times of Austerity

Name of Researcher: Ms Angharad Butler-Rees

You are being invited to participate in a piece of research. Before deciding whether you'd like to take part it is important that you understand why the research is being carried out and what it will involve for you. Please carefully read the following information and ask me if there's anything that's not clear or which you would like further information about. Take some time to carefully consider whether or not you would like to take part. If you decide that you are happy to participate you will be asked to sign a consent form.

What is the purpose of the project?

The project seeks to give voice to the experiences of disability activists. Over recent years we have seen an upsurge in disability activism, as a direct result of austerity measures which have disproportionately affected disabled people's lives. These measures have included for example, disability benefit reassessments, cuts to social care services and the 'bedroom tax'. Disabled people have not however faced such changes alone and in silence, instead many have united in resistance, joining grassroots campaign groups such as 'Disabled People Against Cuts', participating in street demonstrations or online campaigns. Individuals (rightly so!), want to voice their anger, concern and frustration at such policy changes. Little however is known about the lives of those involved in disability activism. This project will therefore draw attention to the forms of activism and resistance individuals are involve in, along with their individual experiences and motivations behind taking part.

Why am I being invited?

You have been invited to participate in the study because of your experiences of engaging in disability activism (or resistance). The project consists of 15 interviews with people who are currently involved in disability activism/resistance activities in response to austerity measures. I have selected a broad range of people who are involved in various forms of activism (or resistance activities) and who represent different groups of people in society (e.g. different genders, ages, ethnicities and geographical locations).

Do I have to take part?

It is entirely up to you to decide whether or not to take part. I will describe the study and go through the information sheet with you. If you agree to take part, you will be asked to sign a consent form. You are free to withdraw up to 1 month following the interview date and you do not have to give a reason for deciding not to take part. Simply inform the researcher (Ms Angharad Butler-Rees) in person or by email that you want to withdraw from the study and do not want to be contacted again. Once you withdraw from the study the data collected up to this point will be destroyed.

What will it involve?

You will be asked to participate in an individual interview. This interview will be arranged at a time and place that is convenient for you. In order to prevent any travel costs, I will always travel to you. The interview will take place in a space where you feel safe and comfortable. You will be asked by the interviewer where you'd like the interview to take place, this might be for example at your home, a local cafe or community centre. The interview will typically take an hour and a half (including time for giving consent), depending on how much you have to say about your experiences of being involved in disability activism. Generally one interview will be enough, however I may wish to contact you at a later date for a follow up interview (if you would like to participate further). This will allow me to ask any follow-up questions that I might have. There is however no obligation to participate in a follow-up interview or to answer any further questions.

What sort of questions will I be asked in the interview?

The interview will loosely follow a biographical structure, as we seek to piece together the various life experiences that might have led you to become involved in activism and which may ensure your continued involvement. The interview will begin by asking you to explain how you came about becoming involved in disability activism and what life experiences might have led you to this. Then we'll move on to talk about the forms of activism you may have been involved in over time, and your experiences of them. These might include traditional activist activities such as taking part in street demonstrations, lobbying, grassroots campaign groups, boycotts or more contemporary activities such as participating in online activist groups or media campaigns. Activism encompasses many different activities, you will be encouraged to talk freely about any activity that you have taken part in that you consider to be activism. There are no right or wrong answers, I simply want to hear about your own thoughts and experiences. Between you and the researcher you will draw a rough timeline of your involvement in activism. You will then, be asked to reflect on the role disability activism has had in your life and whether you would actively consider yourself an ‘activist’? The interview will be very informal with few set questions and lead mainly by your own experiences.

Will I be recorded?

All interviews will be recorded and transcribed (written up into a Word document). Recordings will be deleted once they have been transcribed. Only the researcher (Ms Angharad Butler-Rees) will have access to these transcripts.

Will my participation be confidential?

Every effort will be made to preserve your anonymity and confidentiality. Any information that I collect about you during the research will be stored safely in compliance with the Data Protection Act. All data will be carefully coded and saved onto a password protected computer at the University of Southampton. All findings will be anonymised, along with other information such as organisations, place names, and other people’s names. It will not be possible to identify you in any reports or publications relating to the research, unless you have stated that you’d like to be named within the research. I will also not tell anyone that you have taken part in this study.

Are there any risks involved?

There are no major risks involved in participating in the research. Your anonymity will be ensured (unless you request to be named in the research). The interview will be led by you and your own experiences, as such it is up to you what you decide to talk about. It is possible that at times you may draw upon experiences or memories that you find upsetting. I realise that your involvement in activism might be a direct result of enduring hardship or discrimination, and that austerity with its cuts to disability benefits and services might have had a further detrimental impact on your life. As such I will try my best to ensure that you feel comfortable, however if you do feel upset at any point then you are free to change the topic, take a break from the interview or to end the interview. I will also provide you with a list of support groups at the beginning and end of the interview, which you may contact if you so wish.

What are the benefits of taking part?

Participating in research can be an enjoyable experience, as it’s an opportunity for you to share your own opinions and experiences. You will also be given a £20 voucher for your willingness to give up your time. By taking part you will be involved in research which will help reveal both how and why disabled people are mobilising and resisting in response to recent austerity measures. It is hoped that the findings might lead to a greater awareness of disability activism and resistance today, as well as challenging common perception of disabled people as ‘passive’ and ‘powerless’ and drawing attention to the various life stories/experiences that have prompted individuals to engage in activism.

What will happen to the results of the study?

All findings will be published on the project’s website (in construction at time of writing). You will not be identified within any publications emerging from the research, unless you have requested otherwise. I will also send you via email (or post, if you do not have access to the internet) a summary of the research findings and a copy of your transcript.

What happens if something goes wrong?

In the unlikely case of concern or complaint, please contact the Research Governance Manager at the University of Southampton.

Phone: 023 8059 5058

Email: rgoinfo@soton.ac.uk

Further information and contact details

Ms Angharad Butler-Rees

Geography & Environment

University of Southampton

SO17 1BJ

Email: a.butler-rees@soton.ac.uk

Appendix D Consent Form

Consent Form

Disability Activism in Times of Austerity

Name of Researcher: Ms Angharad Butler-Rees

Ethics Reference: 25244

Postal Address: Geography and Environment

Shackleton Building (44)

University of Southampton

Southampton

SO17 1BJ

Email: a.butler-rees@soton.ac.uk

Please initial the boxes if you agree with the statements:

I confirm that I have read and understood the information sheet (dated 28/04/2017 version 1.4) outlining the above research project and that I have had the opportunity to ask any questions about the study. ☐

I understand that my participation is voluntary and that I have the right to withdraw up to 1 month following the interview date without any consequence. I understand that if I withdraw from the study the data collected up to that point will be destroyed. If I do not wish to answer any particular question, I am also free to decline. ☐

I agree to the interview being audio recorded so that my comments can be typed up and used as research data ☐

I understand that every effort will be made to preserve my confidentiality and anonymity, and that I will not be identified or identifiable in the publications or reports that result from the research. ☐

I agree for the interview data collected from me to be used in future research by the researcher. ☐

I agree to take part in the study. ☐

Name of participant (print name)	Date	Signature
________________________	________________	________________

Appendix E Photo Consent Form

Study title: Disability Activism in Times of Austerity

Ethics reference: 25244

Researcher name: Miss Angharad Butler-Rees

Postal Address: Geography and Environment

Shackleton Building (44)

University of Southampton

Southampton

SO17 1BJ

Email: a.butler-rees@soton.ac.uk

Please initial the box(es) if you agree with the statement(s):

I am happy for my photograph to be taken and used within the research and/or in any publications emerging out of the research, this might include, for example, journal articles, media articles, online blogs or book chapters. ☐

I understand that I may withdraw my permission at any time by contacting the researcher (Miss Angharad Butler-Rees). Once consent is withdrawn, the researcher will not use the relevant images again, but it is not normally possible to recall documents in which the image has already appeared. ☐

I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of this study. All files containing any personal data will be made anonymous.

Name of participant (print name)…………………………………………………

Signature of participant…………………………………………………………………..

Date…………………………………………………………………………………………….

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