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Reconciling the 'Private' and 'Public': Disabled Young People's Experiences of Everyday Embodied Citizenship

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Abstract

The body is the fleshy substance of citizenship. However, analyses of the body and of citizenship have remained largely disconnected, with limited intersection between the two. Traditionally, citizenship has been associated with the 'public' sphere and the body with the 'private' sphere resulting in the distancing of the body from citizenship in popular and scholarly discourses. This demarcation has resulted in the exclusion of particular groups of people from being able to achieve full citizenship based on corporeal difference. This thesis argues that the separation of the 'public' and 'private' spheres perpetuates the marginalisation of disabled people. Through developing the concept of embodied citizenship, this thesis offers a useful lens through which to view the experiences of disabled young people's everyday lives and to bring into focus the comingling of the 'private' and public' spheres.

Using data gathered from interviews with 18 disabled young people, with physical impairments, in Scotland, it explores the ways in which disabled young people negotiate their everyday lives. Thematic analysis of the data identified that participants' inclusion and participation in the 'public' sphere were explicitly bound to their experiences of the 'private' sphere. Participants' greatest feelings of exclusion were felt around everyday experiences often associated with the 'private' sphere such as intimate relationships, sexuality and toileting. Exclusion from these purportedly 'private' areas of social life resulted in negative impacts for participants' sense of self and psycho-emotional wellbeing, impacting on their engagement with the 'public' sphere, and thus their sense of full citizenship.

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To Mum, with all my love.

Author's Declaration

I declare that, except where explicit reference is made to the contribution of others, that this thesis is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

Phillippa Wiseman

21st March 2014

List of Abbreviations

CDS	Critical Disability Studies
CF	Cystic Fibrosis
CP	Cerebral Palsy
DDA	Disability Discrimination Act
DED	Disability Equality Duty
DLA	Disability Living Allowance
DPPI	Disability Pregnancy and Parenthood International
DWP	Department of Work and Pensions
GP	General Practitioner
ILF	Independent Living Fund
JRF	Joseph Rowntree Foundation
NHS	National Health Service
NKS	National Key Scheme
PE	Physical Education
PIP	Personal Independence Payments
SB	Spina Bifida
SENDA	Special Educational Need and Disability Act
SQA	Scottish Qualifications Authority
UN	United Nations
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UPIAS	Union of the Physically Impaired Against Segregation
WHO	World Health Organisation

Chapter 1. Introduction

Citizenship has been at the centre of the disabled people's fight for equality and at the centre of the disabled people's movement. Disability equality legislation such as the Disability Discrimination Act (DDA 1995, 2005), Disability Equality Duty (DED 2006) Special Educational Needs and Disability Act (SENDA 2001) and the more recent Equality Act (2010) have, at least on paper, recognised that disabled people should have equal access to participation in citizenship as their non-disabled peers. Historically, disabled people have been marginalised but have, in the last fifty years fought for greater equality and inclusion. Significant improvements, through the promotion of social inclusion, have been made to disabled people's lives. The Scottish Government's Disability Equality Outcomes Report¹ (2013) reaffirms Scotland's commitment to striving for equal citizenship and inclusion for disabled people. The 2013 Equality Outcomes report establishes that disabled people, particularly people with learning disabilities, still face numerous barriers to equal citizenship in comparison to non-disabled people; education, employment, housing, transport, social care and health were all highlighted as key areas of inequality for disabled people.

Disabled young people's lives, today, are built upon the lives of older generations of disabled people before them and the important achievements that have been made for disabled people through battles for equality and inclusion (Goodley 2010). Disabled young people, particularly those with physical impairments, are more embedded in mainstream social life than ever before. Disabled young people, in contemporary British society, enjoy greater access to community life, 'public' social spaces, transport, mainstream education and employment, although this is not to suggest that equal access to more traditional forms of citizenship have been cemented or fully achieved, as Shakespeare (2014) argues that the disability rights movement has negotiated a number of phases.

¹ The Scottish Government Equality Outcomes: Disability Evidence Review (2013) was published by the Scottish Executive. It looks at the equality outcomes for disabled people in Scotland as a way to develop tackling inequality.

Citizenship for disabled people has tended to focus on more traditional forms of citizenship associated with the 'public' sphere such as employment, 'public' provision, social care and education, for example (for examples see Oliver 1990, 1996, Barton 1993). There has been a limited focus on the 'private' spheres of disabled people's lives as being fundamental parts of their citizenship both within Disability Studies and Citizenship Studies. While 'public' citizenship remains a contested space for disabled people in the UK, there is very little focus on how 'public' participation intertwines with 'private' experience. Disabled people are likely to require additional levels of support in order to participate in 'public' life, for example personal assistance in dressing, bathing and toileting, a need for accessible homes, and access to accessible toilets (Bacci & Beasley 2000, 2002, Kitchin & Law 2001, Lister 2007). Limited focus into the 'private' realms of disabled people's lives and citizenship obfuscates full citizenship for disabled people (Morris 2005). The 'private' sphere has arguably been relegated to the 'back regions', which can have significant impacts on how we understand everyday citizenship for disabled people and this thesis aims to address this by exploring the ways in which the 'public' and 'private' comeingle.

The body has been a contested area in Disability Studies and has been relatively ignored in Citizenship Studies. The medicalisation of disabled people's lives and the fight for political recognition and equality led the disabled people's movement and Disability Studies to distance the body from the political goals of the movement; slogan's like 'Disabled by society, not by our bodies' (Shakespeare & Watson 2002) emphasise the gradual erasing of the body from discourses on disability through the emergence of the UK social model of disability. The body was understood as 'private' and personal and far removed from citizenship. While there has been much work that has brought the body back in to researching and theorising disabled people's lives (for examples see Hughes 2004, 2009, 2012, Paterson & Hughes 1997, 1999, Wendell 1996) a gap has remained in considering the embodied nature of citizenship in the context of disability and in Citizenship studies in general (Bacci & Beasley 2000, 2002). The bifurcation of 'public' and 'private' and disability and impairment shall be addressed in this thesis by exploring the everyday citizenship of disabled people from an embodied perspective.

Key areas of disabled people's lives remain underrepresented in political and social discourse and in Disability Studies. Sexuality, sexual citizenship and the sexual lives of disabled people have been given limited attention and have been given limited recognition as a significant part of citizenship for disabled people. Disabled people want to and do take part in meaningful intimate and sexual relationships and further still disabled people want to and do form families (Sanders 2010, Shuttleworth 2010). While these rights were recognised in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD 2006) and the United Nations Standard Rules on the Equalisation of Opportunities for People with Disabilities (1993, Rule 9), rights to sexuality (Shakespeare 2000) and parenthood (Malacrida 2012, see also Thomas 1997) remain unrealised and unrecognised for many disabled people as heteronormative able-bodied ideals surrounding sex exclude disabled people by constructing material, social and attitudinal barriers (Sanders 2010, see also Mollow & McRuer 2012, Siebers 2012 and Shuttleworth 2012). For example, the Scottish Government Equality Outcomes Review (2013) makes no mention of sex, access to sexual health or sexual health education in the report, nor is there any mention of disabled people accessing sexual or maternal health services. There has been a limited focus on how disabled people experience sexual citizenship, how they access sexual health and feelings towards sexual rights and sexuality and it is this gap that this thesis aims to explore.

Much of the equality that disabled people have achieved has been realised through the provision of state support in order to level the playing field for disabled people. Disabled people's benefits such as the Disability Living Allowance (DLA), the Independent Living Fund (ILF) and the 'Motability car hire scheme' have supported people in living independently, accessing personal support and care, support in getting to work and education for example. However, the UK Coalition government cuts to welfare reform threatens and removes the support that disabled young people have become accustomed to receiving in allowing them to participate at the level they are used to (Shakespeare 2014). The timing of this study meant that the cuts were only just beginning to impact on disabled people's lives and remains ongoing and as such there has been no significant piece of research looking at the impact of the cuts

on disabled people. This thesis will address the emotional and potential impacts of the cuts on everyday citizenship.

It was the aim of this thesis that it be led by the views and thoughts of the disabled young people that took part. This project emerged out of my own experiences as a disabled young person. Coming from a family with three disabled members, yet having had no experiences of other disabled people, and always taking part in mainstream education and social life I was keen to find out whether other disabled young people felt included in citizenship and what their experiences were. Drawing from my own experiences and through pilot workshops with disabled young people as part of an advocacy group it became clear that disabled young people's worries and experiences of exclusion were grounded in areas of life not traditionally associated with citizenship but that impacted greatly on their sense of self and inclusion, were important to their lives and interested them. This confirmed that these 'private' spheres were areas of disabled people's lives that required more attention. The research is grounded in the social model of disability through its focus on social relations; however it also looks beyond the social model in order to explore citizenship and disability from an embodied perspective. This research is concerned with the lived experiences of the young people who took part and is informed by their views, thoughts and feelings.

1.1 The research aims

The research aimed to explore citizenship in the everyday lives of disabled young people and the relationship between citizenship and the body and aimed to do so by exploring areas of citizenship that were important to disabled young people and how their citizenship was experienced. In order to explore this, the following research questions were identified:

What is important to disabled young people?

Do disabled young people feel included?

- Do they feel included by friends and family?
- Is it easy making friends?

- How are they treated by non-disabled people?
- Do they feel included in education
- Do they feel like they are able to participate in society?
- Do they feel equal?
- In what ways do they feel excluded?
- Do disabled young people feel they can go to the kinds of places they want to go?

Do disabled young people feel like they have rights to relationships or sexual rights?

- Is it easy forming intimate relationships?
- Do they have good access to sexual health education and information?
- Would they like more information?
- Where do they feel they can get information?
- Would they like to have children in the future?
- Do they think that there may be obstacles to having children?

How do disabled young people feel about the cuts to disability benefits?

- What kind of support do they access?
- What does this support enable them to do?
- How might the cuts impact on them?
- Have the cuts impacted on them?
- Do they feel valued?

Feelings about the self and their bodies emerged throughout interviews with participants and ‘sameness’ and ‘difference’ emerged as key themes in the data as it became apparent that participants had to negotiate feeling the ‘same’ (as non-disabled people) and simultaneously ‘different’ because of they felt about their bodies, this was at times a result of socially imposed corporeal norms and at times due to ‘impairment effects’ (Thomas 1999). It became clear that relationships with others, with social institutions and their disability benefits, for example, impacted on how they felt about themselves on a daily basis.

It emerged throughout the data that participants’ experiences of citizenship were inextricably bound up with their ‘private’ and personal experiences and feelings and were invariably experienced as embodied individuals and linked to

bodily practices. Therefore the 'private' and 'public' spheres emerged throughout the data and are referred to throughout the exploration of the data.

1.2 The structure of the thesis

The thesis consists of two literature chapters, a methodology chapter describing the methods used for data collection and why these methods were chosen. The thesis also consists of four data chapters and finally concludes with a discussion chapter that brings together the key themes in the thesis and presents the final conclusions. The structure of the thesis and chapters are outlined below.

Chapter Two: *Approaching disability* explores the various approaches to disability and locates the research within the UK social model of disability and also looking beyond it. The chapter focuses on the historical treatment and conceptualisation of disabled people and disability through exploring the 'individual' approaches to disability; it then discusses the emergence of the disabled people's movement and the genesis of the UK social model of disability. The chapter goes on to explore critiques of the social model of disability, in particular the disability/impairment bifurcation and looks at attempts to address this by discussing feminist approaches to understanding disability and the concept of psycho-emotional disablism. The chapter considers disability and youth in order to give insight into transition to adulthood and the exclusion that disabled young people face. Finally, the chapter looks at disability and sex and the exclusion of disabled people from sexual citizenship and how this can be used to analyse disabled young people's experiences.

Chapter Three: *The body and citizenship: bridging the gap* is the second literature chapter and looks at the sociology of the body as being founded on a series of dichotomous relationships. This chapter begins by considering the ways in which groups are marginalised based on bodily difference and the historical process of distancing the body from 'public' life. This chapter aims to bring together two, seemingly, unrelated paradigms in order to establish a theory of embodied citizenship through which to reconcile the 'public'/'private' divide that excludes groups such as, but not exclusively, disabled people, women, children and the elderly from full citizenship.

Chapter Four: *Methodology* focuses on the research methods and methodology that I employed. The chapter begins with a discussion of emancipatory research in feminist methodologies and the subsequent emergence of emancipatory disability research; it follows with a critique of the emancipatory disability approach as being a stalwart of the UK social model of disability and its limitations in developing functioning methodology. However, the utility of the emancipatory approach is its commitment to ending the oppression that disabled people face. The chapter then looks at the research design for this thesis by way of repeating in depth interviews with eighteen participants and a broadly grounded theory approach to the analysis. The chapter explores the ethical issues that arose during the research process and challenges the construction of disabled people as a homogenised group of vulnerable research participants. The chapter focuses on reflexivity and the role of the researcher throughout the research process.

Chapter Five: *Feeling the same, managing difference* is the first data chapter presented in the thesis. This chapter begins by looking at how participants felt the 'same' and how they constructed 'sameness'; this focuses on participants' relationships with friends and family as being integral to positive psycho-emotional wellbeing. The chapter goes on to look at participants' experiences of 'difference' and in particular participants' feelings of 'difference' in relation to intimate relationships. The chapter concludes by exploring participants' feelings about themselves in relation to clothes.

Chapter Six: *Sexual Citizenship: recognition and embodied experiences of sexuality* builds upon the narratives presented in chapter five and focuses, in more detail, on participants' experiences of sexuality in everyday life. The chapter explores participants' experiences of sexual health education in school, access to sexual health clinics and information. The chapter looks at how exclusion from sexual spheres impacted on participants' psycho-emotional wellbeing and feelings about their bodies. The chapter concludes by exploring participants' worries about the possibility of having children in the future and the potential obstacles they may face.

Chapter Seven: *Everyday Citizenship: the private/public divide* looks at how participants' accessed support in their everyday lives. The chapter begins by

looking at the role of toilets and toileting in participants' lives; this section explores the relationship between 'public' spaces and 'private' activities and looks into participants' narratives of inclusion and exclusion in relation to toilets. The chapter goes on to explore how participants accessed their homes, what adaptations they required and the process of getting them. The chapter reveals how participants who needed the most support experienced increased intervention from the state. The chapter ends by considering personal assistance and those participants who required the highest levels of support; this section looks at the way that daily life was shaped by this support and increased state intervention. The 'private' and 'public' spheres are considered throughout this chapter and how they comeingle in everyday citizenship.

Chapter Eight: *Facing the 'cuts': participatory parity and precariousness* is the final data chapter in this thesis and focuses on participants' attitudes, thoughts and fears about the proposed cuts to disability welfare provision. The chapter begins by focusing on the kind of support that participants got and how their independence was facilitated; this section looks at the role of families, state financed benefits and the 'motability car hire scheme'. The chapter goes on to explore participants' fears about how the cuts might impact on their participation in everyday citizenship. This chapter ends by looking at the relationship between citizenship and self-worth and the impact that proposed cuts have had on participants' sense of worth and belonging.

Chapter Nine: *Discussion and conclusion* is the final chapter in the thesis and presents conclusions from the research and a discussion of the key themes that emerged from the data analysis. This chapter highlights the importance of the 'private' sphere and the body in constructing an inclusive citizenship for disabled people and that recognises the everyday embodied nature of citizenship. This chapter focuses on the negative psycho-emotional impact of socially constructed able-bodied norms that serve to exclude disabled people from full citizenship and suggests that both paradigms of disability studies and citizenship studies need to consider the body. Future areas of research are suggested; in particular it is suggested that further research into the 'private' realms of disabled people's lives is necessary, for example: further research into disability, sexuality and parenthood should be undertaken in order to gain useful insight into experiences of disabled parents and disabled women and the barriers

to being and doing that they face. This chapter concludes that the separation of 'private' and 'public' spheres is not useful and in fact serves to exclude disabled people (among others) from full citizenship. A more holistic representation of disabled people's lives is required; by focusing on citizenship as an embodied experience it brings into view the way in which the 'private' and 'public' comeingle in complex ways.

Chapter 2. Approaching disability

This chapter aims to explore how disability has been theorised and understood across the social sciences. It aims to explore the development of Disability Studies and how disabled young people and the body have been contextualised. Through the exploration of the theoretical approaches and models that seek to understand disability this chapter will provide the context that laid the groundwork for this research.

The experiences, outcomes and treatment of disabled people have been impacted by numerous varied perceptions held about disability. This chapter begins by looking at the ‘personal tragedy’ or medical model of disability; it will explore the medical lens through which disability was understood and characterised. The second section of this chapter will go on to follow the theoretical and historical journey towards understanding disability within a social context. This section will consider the rise of the disabled people’s movement as it emerged with other minority and civil action based movements and organisations; the role of UPIAS (Union of Physically Impaired Against Segregation), disabled individuals and academics and the eventual emergence of the social model of disability will also be considered. The principles of the social model of disability frame and informed this research.

The third section of this chapter will focus on critiques of the ‘social model of disability’; the main critique of the social model will centre on the exclusion of impairment, the body and more experiential understandings of disability. This section will consider feminist critiques and the role of ‘identity’ in forming a more holistic approach to understanding disability. The chapter then moves on to look at youth and disability; this section will focus on transition and the exclusion of disabled young people from ‘youth activities’. Finally the chapter will examine disability, sex and relationships. This has been an area of disabled people’s lives that has been given limited attention, and this section will focus on the construction of disabled people as incapable of and restricted from sexual relationships.

2.1 The individual model

The individual model was the dominant way of looking at and understanding disability prior to the challenge made by disabled people in the late 1960s and 1970s (Goodley 2010, Roulstone et al. 2012, Shakespeare 2014). The individual model is characterised by approaches to disability and impairment that understands disability in relation to personal medical conditions of the individual body (Barnes 2010, Barnes & Mercer 2010). The relationship between disability and the medical paradigm is complex and varied. Certainly, the dominant discourse within Disability Studies has been one that locates medicalisation and personal tragedy as contributing to the disempowerment of disabled people (Oliver 1990). This section will explore medicalisation and ‘personal tragedy theory’ as a component of a wider ‘individual’ approach to disability. This section will consider these approaches and the treatment of disabled people as a catalyst for the disabled people’s movement and the emergence of the social model of disability.

Oliver claims that the medical model is underpinned by ‘the personal tragedy theory of disability’ (Oliver 1990, 1). The medical model refers to those diagnosed conditions or impairments that result in disability; thus disability is associated with the individual and is inherent in a body that cannot function properly (Barnes & Mercer 2010). Hahn described the medical model as serving to impose ‘a presumption of biological or physiological inferiority upon disabled persons’ (Hahn 1985, 89). It is this that has been challenged by the social model of disability. Oliver asserts that the location of deviance with the individual disabled person is reproduced in society’s treatment of disabled people as victims of a tragedy (Oliver 1990, 2); this then becomes the dominant social and political norm for understanding disabled people. As an individual problem, Oliver claimed, disability was to be managed through the medical treatment of disabled people and, socially, through welfare, as Oliver writes: ‘the assumption is, in health terms, that disability is a pathology and, in welfare terms, that disability is a social problem’ (Oliver 1996a, 30).

Oliver argues that the medicalisation of disabled people has resulted in the involvement of medical professionals in disabled people’s lives from birth until

death (Oliver 1990, 48). According to Oliver, the 'ideology of individualism' has produced a binary in which disabled people are the opposite of that which is able bodied and able minded and constructs disability as a medical problem, an individual problem and not a social one (Oliver 1990, 46). Therefore the social and medical response to disability was to attempt to rehabilitate, or at another extreme to cure, the disabled person or 'take care' and 'look after' disabled people within a system of social care which saw the removal of disabled people from communities into long-stay institutions. Disabled people became constructed as 'passive objects of intervention, treatment and rehabilitation' (Oliver 1990, 5) which cemented their exclusion and patronage.

Corker and Shakespeare argue that the 'personal tragedy model and medical models of disability are knowledge systems attributable to modernity whereby disability is classified within a 'meta-narrative' of deviancy and tragedy through which disability is located as opposite to 'normalcy' (Corker & Shakespeare 2002,2). Similarly, Oliver attributed the historical exclusion of disabled people to their relationship to capitalism and the means of production, which will be discussed in section 2.

Definition, labelling and classification became central to disabled people's lives. The process of classification came to establish whether or not they were suitable for state funded support (Oliver & Barnes, 1998). The process of definition and classification of disabled people was seen to alleviate deviancy whereby a person was classified as someone '*unable*' to work rather than '*unwilling*', through the compounding of tragedy the disabled person was disassociated from the feckless person who required welfare as a result of their refusal to work. Therefore disabled people were given a 'legitimate' status underpinned by medicalised notions of functional limitation (Oliver 1990, 3). The 1980 World Health Organisation (WHO) scheme became the source of classification for many health care professionals when classifying disabled people. The WHO scheme separated out a three-part framework comprised of: impairment, disability and handicap, which Oliver argues was in keeping with medical discourses of disability (Oliver 1990, 4). 'Impairment' referred the way in which the body functioned abnormally, disability referred to the inability to perform normal human activities and handicap referred to the inability to take part in normal social activities or roles (Oliver 1990 4, Barnes & Mercer 2010, 20). Certainly the

WHO classification system was focused on 'normality' and normal function. While the WHO scheme aimed to gain a fuller sense of a disabled person's experiences and health it located disability in discourses of health and functioning. Critiques of the WHO system lay in its focus on 'normality' and its failure to include the ways in which environmental barriers might impact on a person; rather than the 'handicap' classification being seen as disadvantage related to environmental barriers it was the individual's inability to overcome these barriers that became the focus and thus for activist scholars such as Oliver, the WHO system solidified the medical model as the problem remained with the individual rather than with society:

Ultimately their rationale rests upon the impaired individual and the social dimensions of disability and handicap arise as a direct consequence of individual impairments.

(Oliver 1990, 7)

The lack of inclusion of disabled people in their treatment and rehabilitation contributed to disabled people's exclusion. As Oliver and Barnes (1998) maintain, this lack of reference to disabled people themselves resulted in the expectation that they would passively accept treatment irrespective of how this might impact their lives. Oliver maintained that the role of the medical professional in disabled people's lives could be understood as 'the power theory of medicalisation' consisting of three components:

1. Superiority of medical knowledge
2. The medical profession was well organised
3. Interconnections between medical professionals and capitalist ruling elites

(Oliver 1990, 51)

Furthermore, medicalisation so dominated social discourse that words such as 'spastic' and 'cripple' perpetuated notions that disability resulted from impairment (Barton 1993, 237). In sum the foundation of the individual model

was that disability arose from impairment, and the barriers faced by disabled people were inherent to biological inferiority and failure (Finkelstein, 1993). The historical construction of disability as an individualised issue resulted in a social structure that failed to include disabled people, make necessary adjustments for impairments or solidify a range of services that worked with disabled people in overcoming barriers. As Goodley (2010) notes, a history of medicalisation restricted disabled people from being seen as ‘authors of their own lives’ (Goodley 2010, 8) and further presented them as biologically flawed which in turn limits visibility of an exclusion and intolerant society. As will be discussed later in the chapter, this has had far reaching consequences for disabled people in been seen as capable of living independently and capable of sexual relationships.

The ‘medical model’ has been at the centre of debate within both the disabled people’s movement and Disability Studies. More recently writers have challenged the existence of a medical model per se. As Shakespeare (2006, 2014) argues, while Oliver referred to the medicalisation of disabled people’s lives as an integral part of an individual model, he never located a ‘medical model’ that could be pinpointed and assessed. Arguably, the demonisation of the role of medicine and medical health care professionals obfuscates a prominent aspect of disabled people’s lived experiences. Every day disabled people access medical and rehabilitative services as a way to manage their impairments and empower and allow them to participate through pain management, bladder and bowel management etc (Shakespeare 2006). However, this is not to deny the system of patronage and control under which disabled people were unable to and restricted from taking control of their own medical decisions and journeys, a system that was actively challenged through the emergence of the social model of disability (Goodley 2010).

This section has explored the individual approach towards disability; it considered the medicalisation of disabled people’s lives and the exclusion of disabled people from social relations. This section of the chapter considered the claim that the medical model sought to disempower and oppress disabled people whilst also noting that recent work has challenged the limitations of constructions of the medical model thereby shedding light on the tension between medicine as being empowering to the individual and disempowering at

the collective level to disabled people as a group. The following section will explore efforts taken to challenge this individual approach to disability. Disabled people and the growing disabled people's movement sought to carve out a new landscape for disabled people that located disability firmly within society.

2.2 Towards a social model

The previous section considered an individual approach to disability, which located biological flaw and physiological limitations within the individual body. This section will explore the development of the disabled people's movement in challenging this dominant individual discourse of disability. This section will firstly explore the role of UPIAS in establishing an alternative framework for understanding disability through campaigning for fairer treatment and an end to discrimination. This section will subsequently map how the social model of disability emerged from this.

2.2.1 The role of UPIAS

The 1960s and 1970s were underpinned by a number of political movements of disadvantaged and minority groups in the UK. The political foundations of the disabled people's movement emerged through shared experiences of oppression and marginalisation with other minority groups such as African Americans, women's' liberation movements, gay and lesbian equality groups and wider minority ethnic and indigenous people's organisations that were active in the sixties and seventies (Roulstone et al. 2012, 3). Disabled people were not satisfied with the control over their lives by 'non-disabled' experts. Narratives, identities and experiences of disability were constructed without consultation with disabled people. Disabled experiences were being constructed for disabled people not by them. Thus there was shift in the political action to a 'grassroots' movement, whereby disabled people demanded a role in deciding their lives and challenging the traditional ideologies of the disabled person as a tragic, dependent and incapable creature (Barnes & Mercer 2004,1).

UPIAS was formed in the 1970s and was born out of dissatisfaction with other disability organisations at the time. Although UPIAS was not the only radical organisation emerging at this time, this section will focus on UPIAS and the

formation of the *Fundamental Principles of Disability* as it was arguably the foundation of the UK social model of disability. UPIAS was formed through the efforts of disabled activists Paul Hunt and Vic Finklestein who fought for the rights for disabled people to take control over their own lives and to live independently (Shakespeare 2014). UPIAS released the Fundamental Principles of Disability in 1976; this document was groundbreaking in its approach to disability; the Fundamental Principles argued that disability was a social condition that needed to be eliminated. It stressed that it was imperative that disabled people must assume control over their own lives and decisions (UPIAS 1976).

At the centre of the *Fundamental Principles of Disability* (UPIAS 1976) was an assertion that people were not disabled by their bodies or impairments but rather they were disabled by society, exclusion, and the barriers erected to prevent them from participating fully in society.

In our view it is society that 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. Disabled people are therefore an oppressed group in society (UPIAS 1976 cited in Oliver 1996, 34).

This was a revolutionary approach to disability: firstly it rejected previous theoretical and ideological approaches to disability namely that disability was a deviant status and that the individual was out with society's normal structures and functions due to their impairment. It firmly located disability as being in society. Furthermore, it established that disabled people were oppressed and 'recast disability as a historically contingent relationship in which people with impairments became a socially oppressed group, as has occurred with women, black and ethnic minorities, lesbians and gay men' (Barnes & Mercer 2004, 3). The emerging disability movement took measures similar to other minority or oppressed group such as mass protests and, famously, wheelchair users chaining themselves to London buses (Shakespeare 2006).

UPIAS made a critical distinction between impairment and disability; for them, impairment was defined as 'Lacking all or part of a limb, or having a defective

limb, organism or mechanism of the body' and disability as 'The disadvantage or restriction of activity caused by a contemporary social organisation...and thus excludes them from the mainstream of social activities' (UPIAS 1976, 3-4). Thus it can be seen that UPIAS and organisations of disabled activists sought to politicise the issue of disability by highlighting its inherent social and discriminatory nature.

2.2.2 The social model of disability

The UK social model of disability has been well rehearsed and well documented in Disability Studies (see Oliver 1990, Oliver 1996, Thomas 1999, Shakespeare & Watson 2002, Shakespeare 2014, and Watson 2012), however this section will provide a brief examination of the social model and the radical impact it had in approaching disability. The shift in focus in the location of disability, from the individual to the social, provided disabled people and organisations with political clout and legitimacy as disabled people became able to understand themselves as oppressed and discriminated against, and that this would only be eliminated if society were to change (Thomas 2002). Mike Oliver advanced UPIAS' fundamental principles in his 1990 work *The Politics of Disablement*; this manifesto called for a revolution based largely on materialist and Marxist principles. As Barnes maintains, the focus was on disability as a social creation and specifically a creation of the modern, industrial capitalist economy (Barnes & Mercer 2004, 3).

Laying the materialist foundation

Oliver approaches disability from a materialist Marxist theoretical perspective. He charts the relationship between disability and the rise of capitalism. He maintains that the drive in industry and the proliferation of industry excluded disabled people from the mode of production (Oliver 1990, 27). He argues that historically, disabled people became perceived as a social and educational problem as they were excluded from the labour market. This problem was solved via a removal and segregation from the community as disabled people were institutionalised into asylums and workhouses (Oliver 1990, 28-33).

Oliver argues that the ideology of individualism constructed the ideology of disability as the antithesis of able-bodiedness and able-mindedness; as such the disabled individual was constructed ideologically as an individual medical problem. This was underpinned by the disabled individual's relationship to production; as such the exclusion faced by disabled people from wage labour became the method by which they were socially controlled (Oliver 1990, 47). This control was carried out through the involvement of the medical community; as focus was on the body and the capabilities of the body to carry out work, the medical profession became preoccupied with the disabled individual (Oliver 1990, 51). Hence the power relationship between the medical community and the disabled individual was cast at birth and continued through life.

Oliver maintained that it was the rise of capitalism that resulted in mechanisms of social control and through this the proliferation of institutions such as workhouses, asylums, prisons and hospitals meant that disabled people were removed from their communities where families were no longer willing or able to support them (Oliver 1990, 33).

Thus a materialist or Marxist perspective argues that disabled people were excluded and controlled; subordinated by their exclusion from the labour market. As such the root of disability is not in the individual but in society's exclusion and discriminatory treatment of the disabled people and its construction of the disabled person as dependent and incapable. Thus, disability is the social creation of the 'institutionalised practices of society' (Oliver 1990, 83).

The UK Social Model

This approach to disability, known in the UK as the 'social model', was in stark contrast to the 'medical model' or individual approach to disability. Oliver asserts that 'if disability is defined as social oppression, then disabled people will be seen as the collective victims of an uncaring or unknowing society rather than as individual victims of circumstance' (Oliver 1990, 2). Thus, disabled people will be freed from the confines of the perception placed upon them that they are poor, pitiful objects of medical intervention and research; that they are destined to a life of dependency and incapacity and reliant on able-bodies and

charity. The social approach to disability became and remains primarily geared towards the emancipation of disabled people.

The social model asserts therefore, that society is at fault. Society creates disability and disablism. Society fails to take disabled people into account in social organisation through its failure to provide support and access and ‘the consequences of this failure do not simply and randomly fall on individuals but systematically upon disabled people as a group who experience this failure as discrimination institutionalised throughout society’ (Oliver 1996,33).

The social model has indeed been revolutionary in transforming the lives of disabled people and in changing the way in which disability is perceived as a social issue arising from the disabling barriers erected in and by society. As Shakespeare and Watson (2002) note, the social model of disability contains three important elements: firstly it grounds disabled people as a marginalised social group facing oppression, secondly it separates out the discrimination faced by disabled people from impairment and thirdly that disability is cast as the form of social oppression and not arising from impairment (Shakespeare & Watson 2002,10). As such the social model became a route through which to claim equal citizenship but was also transformative for individuals through its capacity to change the way that disabled people felt about themselves (Shakespeare & Watson 2002).

Since then, however, many have sought to establish a social theory of disability that includes impairment and an awareness of how it impacts on disability. Once established, a fear emerged that the social model has become static and fixed, unchangeable and domineering; ‘a litmus test’ for disability politics (Shakespeare & Watson 2002). Its representativeness of a true picture of disability has been challenged through the work of feminist disability scholars and through challenges to the efficacy of the disability/impairment bifurcation (see Crow 1996, Hughes & Paterson 1997, Thomas 1999, Shakespeare & Watson 2002 and Shakespeare 2006). However, Barnes argues that impairment is unique to individual people and as such it would be impossible to create a ‘social model’ of impairment as Oliver suggests (Barnes 1996, 4). Further he argues, that taking an approach to disability that focuses on impairment will create

negative cultural images of disabled people and bolster 'personal tragedy' theories (Barnes 1996, 4-5).

This section has focused on the rise and establishment of the UK social model of disability; it has explored the role of UPIAS and the disabled people's movement in establishing that disabled people were active in challenging the dominant social discourses of disability. The section also considered the revolutionary role of the social model of disability in disabled people's lives and changing the way that disability was approached. The social model of disability was the foundation for Disability Studies and has been a platform from which emancipatory disability research, conceptually, has taken off. However, while the social model's revolutionary principles have been recognised as valuable in exploring the social relations of disability, some have argued that it reflects a limited representation of the experiences of disability. The next section will explore these critiques in establishing the conceptual framework for this research.

2.3 Critiquing the social model

The success of the social model in shaping policy, legislation and equality for disabled people has lauded it as the 'sacred cow' of the disabled people's movement, and to some extent Disability Studies, which has resulted in limitations in forming critiques (Shakespeare & Watson 2002). However, in recent years critiques of the social model have emerged and these have centred around the dichotomisation between disability and impairment (Hughes & Paterson 1999), and the neglect of impairment at the expense of a focus on social barriers (Thomas 2001, Shakespeare & Watson 2002) and the gendered implications of this binary (Thomas 1999, 2003). By largely ignoring impairment, the social model has been criticised for homogenising disabled people's experiences, further it has been critiqued for its focus on physical impairment and its very limited engagement with learning disability or mental distress (Chappell 1997, Shakespeare 2006, Goodley 2010).

Shakespeare & Watson (2002) have argued for a complete abandonment of a 'strong' social model of disability while others have argued for a sociology of impairment that focuses on the social experiences of impairment (Hughes &

Paterson 1997, 1999). Further still there has been significant focus on other approaches and models that seek to understand and unpack the experience of disability and many others have been looking past the UK social model towards the Nordic relational model of disability, the North American cultural model and minority models of disability, for example (Goodley 2010, Shakespeare 2014). This section will now turn to the key limitations of the social model that have been addressed by authors within and out with Disability Studies.

2.3.1 Impairment and Disability

The social model has been critiqued primarily on the grounds that it does not adequately represent the lived experiences of disabled people through its failure to capture the heterogeneity of impairment and experience. One of the key ways that the social model has been criticised is through its reluctance to consider impairment as relevant to the experience of disability. The social model purposely rejects the notion that impairment and the body are connected to disability and social discrimination with Oliver, a key architect of the social model, going as far to say that ‘disablement has nothing to do with the body’ (Oliver 1996, 35). This lack of engagement with impairment has sparked debate and criticism among theorists’ scholars and activists.

The exclusion of impairment from the social model has a critical purpose; it serves to politicise disability and asserts that personal effects of impairment such as pain, fatigue and management of bodily functions are nothing to do with disability and the political goals that aim to be achieved. There is a fear that recognition of the biological aspects of disability will only serve to undermine the social model and the emphasis on social inequality; it would serve to bolster a medical approach to disability. However, impairment is a very real and impacting facet of what it means to be a disabled person. Herein lies the rub for many Disability Studies academics and for many disabled people (Shakespeare & Watson 2002; Morris 1991& 1996, Crow 1996, Patterson & Hughes 1997 & 1999).

Personal experiences of impairment have been one of the key criticisms of the social model. Academics who have challenged the social model have done so on the basis that the private lives of disabled people are often at odds with a social model approach. While the social model largely ignores seemingly private issues

such as chronic pain, sex, toileting and fatigue as 'apolitical' and 'private' it does not adequately capture the totality of experience (Shakespeare & Watson 2002).

Through its rejection of the 'medical' model and its disability/impairment dualism, the social model has succeeded in constructing impairment as a matter of biology and medicine and in so doing has excluded impairment and hence the body from politicisation and from part of the experience of being a disabled person, the body was conceived as separate from a person's identity and their self (Hughes & Paterson 1997, 326 see also Watson 2002). Williams (1999) and Hughes & Paterson (1997) argue that through this distinction, ironically the body was relegated to medicine. The disabled people's movement has followed in the same vein as classical sociological treatment of the body in that it is distinct and separate from society and is understood through a dichotomous relationship (Shilling 2007). However, disability and impairment are not experienced separately, as Hughes and Paterson argue that 'disabled people experience impairment, as well as disability, not in separate Cartesian compartments, but as part of a complex interpenetration of oppression and affliction' (Hughes & Paterson 1997, 329 see also Hughes 2002, 59).

Many actors within the disabled people's movement and disability scholars alike have argued for a 're-claiming' of the body for inclusion of impairment in documenting the true and whole experience of what it means to be a disabled person, and furthermore the assertion that impairment can be socially produced. For example, Liz Crow asserted that in order for the social model to be comprehensive and furthermore for disability to be comprehensive, the body had to be brought back in with an understanding that impairment can be disabling, and fatigue and chronic pain impacts on and shapes the world that we live in; that when there are no disabling barriers there will still be impairment and their effects (Crow 1996 see also Shakespeare 2006). Hughes & Paterson (1999) argue for a sociology of impairment and recognition of the impaired body as an embodied social agent as disability is not only experienced socially but through the body; exclusion from a venue, prevention from getting on a bus, information that is not accessible all impact the body just as impairment can be experienced socially through difficulty in communication or self-expression (Hughes &

Paterson 1999). The body is the site of a unique interplay of experiencing disability and impairment not separately but simultaneously.

Bringing the body back

Hughes (2002) argues that there are carnal norms that inform how a body operates in certain spaces; he argues that disabled people cannot relate to this as they have not been active in constituting this 'carnal order'. Furthermore, a sociology of impairment that is phenomenologically grounded asserts that there are assumptions based on the body that informs the way people relate to one another. Hughes maintains that this is most prevalent in 'embodied norms of communication' and thus disabled people experience exclusion based on carnal norms of able-bodiedness (Hughes 2002, 71). Moreover, Hughes argues, disabled people can experience their body as "an influential presence" in their confrontations with able-bodied people as impaired bodies are treated as such; thus any encounter becomes an encounter between a person and an 'object' as the body is objectified in these encounters (Hughes 2002, 71).

Mairian Corker and Tom Shakespeare (2002) argue that essentialist and reductionist approaches to disability are in themselves not useful.

Postmodernists and Poststructuralist theorists have offered critiques of these essentialist approaches to disability. Post structuralism operates on the premise that modernity is characterised by and founded on enlightenment concepts of knowledge, truth and dualist theories, which create meta-narratives. Corker & Shakespeare argue that the individual model is steeped in a meta-narrative of deviancy and tragedy and that this is in contrast to 'normalcy' and is therefore logically constructed as 'inferior' (Corker & Shakespeare 2002, 2). For postmodernists, modernity is key to the construction of social inequalities.

Poststructuralists argue that the subject is not an autonomous creator of their own world; rather they are part of a 'complex network of social relations' (Corker & Shakespeare 2002, 3). Corker and Shakespeare argue that it is important to deconstruct the ideologies and languages that refer to disability in order to understand the nature of the subject (Corker & Shakespeare 2002, 3). Poststructuralist approaches to disability aim to deconstruct theories around the construction of disabled identity and unpacking the normal/abnormal dualisms.

Poststructuralists have been critical of disability/impairment and explicate this as a Marxist totalising meta-narrative and is another example of reductionist thought (Corker & Shakespeare 2002, 15). However, the notion that the subject is not an agent in the creation of their world is problematic, it denies agency and renders the person as a passive subject unable to effect change, and could arguably be disempowering for the disabled person.

Corker and Shakespeare argue that disability is far too complicated to be explained by any one model or theory, and as such disability is the 'ultimate postmodern concept' as it transcends structure; it is varied, complex, experiential and is in a complex relationship with other forms of inequality (Corker & Shakespeare 2002, 15). Furthermore, post structuralism seeks to emancipate disabled people through researching the process through which disabled people can overcome their constraint by the social structure and can thus transform and overcome the social structure (Corker & Shakespeare 2002, 15). The risk involved in poststructuralist approaches is one of disaggregating disability to the point where there is no collective political movement and, as Patterson and Hughes assert, denies collective embodied agency (Patterson & Hughes 1999, 598). Similarly Shildrick (2012) argues that Critical Disability Studies (CDS) seeks to destabilise the notion of difference or otherness by accepting that 'all bodies are unstable and vulnerable' (Shildrick 2012). However this fails to capture the very real experiences of impairment that some people have, to be sure all bodies are vulnerable, volatile and unstable but to maintain that impairment is a product of constructed notions of difference obfuscates the lived reality of disability.

Simon Williams offers a 'third way' between a post-structuralist 'absent body' account and phenomenology's purely experiential accounts of the body. Williams offers 'critical realism' as an approach to explain embodiment and experience with particular reference to disability and chronic illness. Williams maintains that postmodernism, post structuralism and phenomenology do not necessarily offer a holistic view of the body (particularly in disability). He asserts that the body is more than what we experience of it in social terms and it is more than what society constructs it as; it has a real material foundation:

Humanity, in short, is never simply a 'gift' from society. We must not, therefore, conflate 'human beings' and their capacities with social beings. Here we return, once again, to the errors of post-modernism, post-structuralism and the like, errors that are effectively resisted by claiming that we are so much more than society can ever 'make' of us (Williams 1999, 807).

Critical realism, according to Williams, asserts that the social and natural world consists of three strata or domains: the first being the 'empirical' and that which we can observe, the second is the 'actual' or our experiences and events and the third being the 'real' which is the summation of the previous two- it is our mechanics and our experiences (Williams 1999, 805). It is this third that 'conflates' the ontological with the epistemological and there lies an analysis of the interplay between structure and agency.

Williams argues that critical realism allows for the recognition of the interplay or structure and agency through and across time allows for change, and allows for analysis of how structure and agency are shaped and in turn shape one another over time. Therefore disability is not seen as the product of linguistic categories or social discourse but rather is understood as a significant interplay between biological impairment, the structural or socio-spatial landscape, and through the agency of disabled people. Impairment is recognised as having an intrinsically biological foundation whilst also experienced in a social capacity. It therefore represents the holistic nature of disability and critically analyses the structural, experiential and biological facets of disability thereby recognising the validity and importance of collective embodied agency and 'the body' in disability (Williams 1999, 810). Disabled people are not mere passive receptors of social discourse and power, but actively construct the world they live in through their bodies.

Importantly, Williams recognises that many disabled people's impairments follow 'disease-specific trajectories' and that there is no homogeneity of experience between similar impairments never mind the wider disabled community. Therefore the body is the key to understanding disability without creating a sociology of impairment (or a social model of impairment to counter a social model of disability) and to build a sociology of disability that understands

the relationship between the body, disability and impairment as dialectic, as interrelated and interdependent (Williams 1999, 811).

Shakespeare (2006) argues that impairment is not pre-social it is in fact social and (albeit at times tenuously) can be socially created just as disability is; for example poverty and depravation are main causes of impairment particularly in the developing world (Shakespeare 2006, 35 see also Shakespeare 2014). He offers an approach that is grounded in an interaction between theoretical perspectives as well as 'intrinsic' and extrinsic' factors in disability (Shakespeare 2006, 55). This approach aims to be holistic in its understanding of impairment and disability as Shakespeare argues that 'Impairment is a necessary but not sufficient factor in the complex interplay of issues which result in disability' (Shakespeare 2006, 56). He draws on his and Watson's idea that disability is a continuum, which is unfixed and fluid (Shakespeare & Watson 2002).

This section has explored the disability-impairment divide and the role of 'the body' in understanding experiences of disability. By separating out impairment and disability and by excluding the body the social model has rendered impairment a private apolitical matter. By recognising that the body and impairment are crucial in representing the experiences of disabled people it allows the body to become a key part in understanding the everyday lived experiences of participation and citizenship. Establishing that all experiences are embodied forms part of the theoretical framework of this research.

2.3.2 Feminist critiques

Throughout the 1970s and 1980s disabled women felt excluded by both the male dominated disabled people's movement and feminist movements that failed to recognise disabled women (Morris 1991, 1996, see also Thomas 1999). As Bê (2012, 365) argues, disabled feminists posited themselves in two locations and felt it important to draw from both Disability Studies and the feminist research agenda. According to later feminist scholars this means that the social model of disability represented a white, male view of disability that primarily focused on physical impairment. In presenting a political model that sought to inform social change and remove social and political barriers for disabled people (Oliver 1996b), personal, seemingly, 'private' experiences were largely ignored.

Disabled feminist writers consequently took up the task of exploring the many ways in which the experience of disability was gendered these were areas of social life that had not been represented in Disability Studies. Further, disabled feminists at the time found that disabled women experienced disadvantage on top of that disadvantage faced by disabled men and non-disabled women and that there were not made visible through the current disabled people's movement or academic landscape (Bê 2012). The feminist dictum 'the personal is political' formed the basis of feminist disability research (Morris 1996,5). Disabled feminists were also critical of the impairment-disability divide so central to the UK social model of disability (as presented above); disabled feminists argued that this dualist thought reproduced the public-private dichotomy, discussed in the following chapter, that excluded women from political participation and equality (Bê 2012, 366, see also Morris 1996 and Crow 1996, Thomas 2001). Disability was cast as 'public' and a matter of political and economic concern while impairment was decidedly 'private', volatile and 'of no collective significance' (Bê 2012, 366).

In conjunction with reclaiming impairment, feminist disability writers have been critical in establishing the necessity for theorisation of and research into disability and the body. Wendell has crucially written about the 'othering' of disabled people on the basis of a rejected body (Wendell 1996). Wendell has also argued for a more nuanced understanding of impairment and the body that accepts impairment as having varying and diverse effects on disabled people and so calls for the inclusion of people with chronic and terminal illnesses in disability literature and research (Wendell 1996, 20). Further still, Rosemarie Garland-Thompson (1997) has highlighted how both women's and disabled people's bodies have been removed from the 'public' sphere and cast as irrational as she argues:

Many parallels exist between the social meanings attributed to female bodies and those assigned to disabled bodies. Both the female and disabled body are cast as deviant and inferior; both are excluded from participation in public as well as economic life; both are defined in opposition to a norm that is assumed to possess natural physical superiority (Garland-Thompson 1997,19).

This presents the gendering of private and public spaces and the relegation of personal experiences and the body to the 'private' sphere underlining how both women's' and disabled people's participation is limited on the basis of bodily difference. It presents the notion that citizenship and participation are 'to do' with the body and this forms a substantive theoretical focus of this research.

Feminist critiques of the social model have explored the lack of focus on experience and Thomas (1999) in particular has been critical of a barriers approach that was limited to external social or environmental barriers without considering how this impacted on self and identity. This led to Thomas' considerable focus on the notion of psycho-emotional disablism and impairment effects, which this chapter will now move on to explore.

2.3.3 Social relational model, psycho-emotional disablism and impairment effects

Carol Thomas challenged the existence of the impairment-disability divide through what she has termed the social relational model (Thomas 1999). Thomas' aim was to develop the scope of the social model through the social-relational approach; this is done in the first instance by directly linking impairment to disability and the subsequent social oppression and disadvantage experienced which she describes as 'an unequal social relationship between those who are impaired and those who are non-impaired, or 'normal', in society...so the concept of disability refers to the relationship of ascendancy of the non-impaired over the impaired' (Thomas 1999, 40). Thomas (1999) illuminated the ways in which the non-impaired body was cast as superior to the impaired body resulting in inequalities faced by people with impairments.

Central to the development of this framework is the concept of 'impairment effects'; although not necessarily constituting 'disability' in itself, impairment effects, according to Thomas, can be disabling through a process of 'othering' or the assumption that by virtue of having an impairment a person is incapable of particular activities - thereby constructing the disabling quality (Thomas 1999).

A further central concept within the core of Thomas' (1999) social-relational model (and subsequently developed by Reeve 2002, 2004 & 2012) is the notion

that not only are barriers erected to 'doing' but barriers but also 'to being' (Thomas 1999 see also Thomas 2004). Thomas suggests Disability Studies would benefit from moving on from focusing on the collective identity politics that underpin discussions on 'disabled identities' and move towards an understanding of 'selfhood' and how disabled people feel about themselves within their lived experiences (Thomas 1999). Thomas suggests that this can be done through the appreciation of the 'psycho-emotional dimension' of disabled people's experiences (Thomas 1999).

As discussed above, the disabled people's movement and Disability Studies in particular have paid much attention to the material and social barriers that disabled people face and subsequently how this has formed a legacy of social inequality and the 'othering' of disabled people. Thomas suggests a focus on the other dimensions of restrictions that impact on self and identity and 'the landscapes of our interior worlds' (Thomas 1999, 46). Thomas critically assesses the way in which 'socially imposed restrictions' have been constructed and argues that the focus on these restrictions should not be limited to the process of *doing* or what we are prevented from *doing* but also on what or who we are prevented from *being* and our feelings towards ourselves (Thomas 1999, 47).

Barriers to being are those social barriers that result in internally imposed restrictions, restrictions that disabled people place on themselves as a result of negative attitudes towards them, negative experiences and experiences that impact on a person's 'psycho-emotional' wellbeing:

'[F]or example, feeling 'hurt' by the reactions and behaviours of those around us, being made to feel worthless, of lesser value, and unattractive, hopeless, stressed or insecure'

(Thomas 1999,47)

For Thomas, these barriers to being form the basis of 'the psycho-emotional dimension of disablism which she describes as:

[T]he unintended or intended ‘hurtful’ words and social actions of non-disabled people (parents, professionals, complete strangers, others) in inter-personal engagements with people with impairments. It also involves the creation, placement and use of denigrating images of ‘people with impairments’ in public spaces by the non-disabled.

(Thomas 2007, 72)

Donna Reeve has also explored Thomas’ notion of ‘barriers on the outside, inside’ maintaining that ‘psycho-emotional disablism’ prevents disabled people from being the kinds of people they want to be (Reeve 2002) and that furthermore there are both ‘direct’ and ‘indirect’ forms of psycho-emotional disablism (Reeve 2012). Direct psycho-emotional disablism refers to that ‘invalidation’ felt by disabled people through their direct interactions and relationships either with themselves or other people through intersubjective confrontations (Reeve 2012, 81 see also Toren 1999). Reeve separates out ‘direct’ from ‘indirect’ with indirect being the structural disablism faced through, for example, a lack of access or structural exclusion (Reeve 2012, 82). As a heuristic tool this distinction helps us to distinguish between the immediately direct confrontations with others (through hate crime, name-calling, violence and staring for example see Rosemary Garland-Thompson 2009) and the less immediate structural barriers that evidence a lack of thought towards disabled people. However, it is necessary to stress the real feelings of inadequacy and the psycho-emotional impact of the latter which can often compound the idea that disabled people are in-valid or valued as lesser or less equal citizens (Kitchin 1998, Goffman 1978, Lister 2003).

2.3.4 Self and identity: Goffman and stigma

Psycho-emotional disablism, impairment effects and barriers to being are concepts that help to understand the impact that disablism can have on personhood, self and identity. This section will focus on labelling theory and Goffman’s notion of a ‘spoiled identity’ (Goffman 1969) in order to address the social model’s lack of engagement with self, identity and stigma. Exploring the notion of stigma highlights how inter-subjective relationships can have lasting

impacts on how a person might see themselves or internalise the discrimination of others.

Thomas highlights the shift in interpretative sociology to 'symbolic interactionism'. This primarily dealt with the meanings that were underlying in or a product of the interactions that took place between individuals and groups. These meanings were produced in and through the symbols and signs that are involved in these interactions (Thomas 2007, 19). Thomas explains that symbolic interactionists retained the view that illness was social deviancy; deviancy was a product of a social process of "deviancy creation" or labelling. Hence in order for behaviour to be deviant it must be categorised as such by someone in a dominant position (Thomas 2007, 20).

Central to Interactionist theory was Erving Goffman and his interest in the interactions between 'normal' and 'stigmatised' people in his 1963 work *Stigma*. Goffman argued that people with chronic illness and disability were stigmatised in the sense that they were discredited by whatever attribute it was that rendered them ill or disabled (Goffman 1969, 13). Goffman saw the chronically ill and disabled or rather the 'stigmatised' as agents in their own right, however their self-identity, emotions and biographies were still seen as entirely informed by their 'abnormality', 'deformity' or illness and subsequently by how 'normal' people reacted to and interacted with them:

By definition, of course, we believe this person with a stigma is not quite human. On this assumption we exercise varieties of discrimination through which we effectively, if often unthinkingly, reduce his life chances.

(Goffman 1969, 15)

What is important here is that Goffman recognised the discrimination that the 'stigmatised' face by 'normal' people; he recognised the social aspect of discrimination and how this impacted on identity and self. Goffman maintains that 'normal' people construct stereotypes through a 'stigma theory' in order to explain the inferiority, diminished status and danger represented by the 'stigmatised' person (Goffman 1969, 15-16).

Goffman focused on the interactions that took place between the 'normal' and the 'stigmatised' and how this impacted on the status and identity of both parties. While the 'stigmatised' person is self-conscious and highly aware of the impression he makes and the possibility that any mishap may be attributed to his differentness through the notion of a 'spoilt identity', the 'normal' person is at the same time acutely aware of his dis-ease and actions and how this will be interpreted by the 'stigmatised' person (Goffman 1963, 25). For Goffman, a 'spoilt identity' can be managed through what he describes as 'passing 'as 'normal'; this can be achieved by disassociating with the 'stigmatised' or only selectively revealing those attributes which are stigmatised (Goffman 1963). However, Goffman explicates that it is the 'stigmatised' person that will become more capable of managing this situation as they will be more used to experiencing these situations (Goffman 1969, 31).

These interactions become informed by symbols that convey social information. For example, Goffman argues that 'normal' people construct 'stigma symbols', the purpose of these symbols are to draw attention to the attribute of differentness and as such serves to devalue the person (Goffman 1969, 59). While Goffman clearly conforms to the idea of the deviant from the norm, he does accept the agency of the 'stigmatised' and the social discrimination they face and their subsequent need to manage their identities and presentation when interacting with 'normal people'. It is a step towards recognising discrimination and its social character, how often discrimination exists in complex interpersonal interactions with non-disabled others, but also, as Thomas (1999) and Reeve (2012) note in the lack of representation or visibility of disabled people in mainstream society.

This section of the chapter aimed to explore the key limitations of the social model of disability. It considered the role of impairment in understanding experience in everyday; it went on to look at the disability-impairment divide and considered the social character of impairment. The chapter moved on to consider feminist approaches to disability and critiques of the social model, which also challenged the dualistic construction of disability and impairment. Finally this section considered psycho-emotional disablism, impairment effects and Goffman's notions of stigma in symbolic interaction as useful tools for understanding the emotional impact of disablism on a person's sense of self and

identity. The chapter will now move on to explore the relationship between youth and disability.

2.4 Disability and youth

The previous section considered critiques of the social model of disability; it focused on the key limitations of the social model. The remaining sections of the chapter will consider the substantive themes that inform this research. This section of the chapter will focus on youth; it will begin by considering youth and youth transition within youth studies and sociological literature. It will explore the way in which youth literature focuses on independence and transitioning to adulthood and how, not only is this problematic for non-disabled young people, it is problematic for disabled young people. This section will then go on to explore disability and youth; it will consider the barriers that disabled young people face in achieving independence and the barriers they face in being able to take part in 'youth culture' or risky activities associated with being young.

2.4.1 Contextualising youth

Youth can be understood as the transitory point between childhood and adulthood; it is traditionally recognised as roughly spanning ages fifteen to twenty five. Barry argues that youth represents a denial of young people of the attainment of rights and responsibility and of status, she observes that one has 'entered a new sphere of legal and social constraints which delay or deny their full attainment of adulthood' (Barry 2005, 102). As such the young person is understood as occupying a liminal space. Crucially, Barry argues, that policies relating to youth and the transition to adulthood often deny responsibility for disabled young people (Barry 2005, 105).

Christine Griffin has observed how young people have been represented in academia in Industrialised Western Societies. She argues that policies and strategies surrounding young people have all been underpinned by the construction of youth as a 'difficult time' and of specific groups of young people being 'problems' as she argues that 'Young people are frequently presented as either actively 'deviant' or passively 'at risk', and sometimes both simultaneously' (Griffin 1997, 10). This has served to place structural constraints

on young people and their expression of youth. Young women are of particular concern due to their potential for pregnancy; they are understood as 'at risk' and ultimately sexually threatening. Similarly young black males are constructed as 'actively deviant' in their capacity to join gangs or engage in criminal behaviour (Griffin 1997, 18). It will be explicated further in the discussion that just as certain young people are represented as 'at risk' or 'actively deviant' so are disabled young people.

To a certain extent childhood, youth and adulthood and their meanings are cultural or societal constructions; they are not fixed or wholly biological as a child in one society can be understood as an adult in another. As Sheila Riddell observes, adult status is the product of the interplay between biology and culture (Riddell 1998, 193). This journey to adulthood bears both rights and obligations; the right to vote, marry, consensual sex, criminal responsibilities and in return the person is obligated to pay taxes, attend jury duty and so on. This becomes exclusory and problematic for disabled young people and their transition in to adulthood as disabled people are often constructed as being dependent on the state meaning that they are unable to fulfil their responsibilities as citizens; their position in society as full citizens is often questioned and 'tenuous' or precarious. This is particularly true in the legal sense, and with particular reference to those with learning difficulties who do not always have legal autonomy (Riddell 1998, 194). The adult status of rights bearer brings with it assumptions of autonomy, competence and responsibility (Priestly 2003, 117-119).

Many academics observe that there are markers or transitional pathways that serve to establish that a young person is successfully transitioning to adulthood. Monica Barry highlights how this has been traditionally split into three main categories the first being 'school to work transition', the second being the 'domestic transition' (moving from one's family home to your own family home) and thirdly 'housing transition' which is independent living (Barry 2005, 100). Riddell observes that being in paid employment is one of the most important markers of adult status; not only does it allow independence financially, but it provides a sense of identity, and crucially, a means to independent living. She importantly highlights that this is problematic for disabled young people, as are

any fixed markers that outline a linear progression to an end point that ascribes a person with adult status (Riddell 1998, 194).

However, this linear model of transition is problematic for many young people (not solely disabled young people). The uncertainty of labour markets has implications for how young people can earn money and achieve independent living. Riddell observes that the poor labour market in the 1970s had dire effects on young people and the length of time they remained with and were supported by their families (Riddell 1998, 191). This was problematic in achieving a 'successful' transition into adulthood; the current economic climate and scant labour market is problematic for today's young people. It can be seen that there is a severe shortage in employment, problems with delivering funding for students in higher education and prolonged periods of assistance by family is again challenging traditional models of youth transition, adulthood and independence (Hendey & Pascall 2001). Furlong and Cartmel (1997) similarly argue that the restructuring of the labour market and changes in social policy over the last twenty years have impacted on young people, their relationships with families, friends, education and employment.

2.4.2 Disabled young people

French & Swain (1997) and Priestly (2003) have written significantly on the importance of youth culture for disabled young people. Priestly has argued that youth culture operates through the consumption of music, fashion, leisure etc. Thus, youth culture is shaped through young people's consumer choices, he observes that disabled young people have limited consumer choices and power and therefore their access to youth culture and their shaping of youth culture is limited and restricted (Priestly 2003, see also French & Swain 1997). This exclusion from youth culture impacts on young people's process of forming identity and of expressing themselves, be it through leisure or fashion and so on (Priestly 2003, 91). Disabled young people can be faced with negative images of themselves in the media; moreover disabled young people are often absent from the media and from youth culture in media representations. As Morris argues, disabled people's ideas about themselves can be informed by able-bodied representations of disabled people in the media (Morris 1991, 37). Disabled role

models are absent for disabled young people and this can have a grave impact on how they construct their identities and sense of self.

Priestly argues that access to consumption and access to youth culture is limited for disabled young people. A key point is that disabled young people are less likely to take part in 'risky' behaviour and activities that are part and parcel with youth culture; for example smoking, drinking alcohol and smoking cannabis. This is in part because this kind of behaviour is reliant upon friendships and networks with peers that there are significant social and physical barriers to (Priestly 2003, 91). Furthermore, disabled youth are often monitored quite heavily by over protective parents and care workers and so are often not given access to the kind of social circumstances that would facilitate this behaviour (Watson *et al.*, 1999).

Absence from youth culture in general and youth networks impact on the construction of a collective disabled youth identity and culture. The disabled people's movement has been key in creating and developing disability culture that is underpinned by a collective political identity formed through resistance and challenges to societal norms (Priestly 2003, 92). This emergence of a disability culture has been empowering for many disabled people however, as Priestly argues, while this has been crucial in developing political identities for disabled people this is not generation specific and so is more influential in constructing disabled identities rather than youth identities for young disabled people.

This assumes that young disabled people identify with disability in the first place, are aware of disability culture and have friendships with other disabled young people. It can be the case that disabled people do not identify with the wider disabled community or disabled people's movements, as will be explored in this thesis.

For many disabled young people the key pathway to adulthood is living independently, and it is this that many disabled young people aim to achieve through transition planning (Morris 2002a, 2002b). However, as Morris highlights, there are significant barriers to being recognised as an adult for disabled young people; young people are often not included in the planning process. Care

agencies, school, teachers and social workers all liaise in order to support the young person through their transition process, unfortunately this all too often does not involve the person themselves and their voice becomes absent in decision-making.

There are significant practical barriers to moving in to adulthood such as a lack of accessible information in multiple formats, or information that is physically accessible (Morris 2002a, Shakespeare 1996). This becomes particularly significant in terms of disabled young people's access to sexual health education and information, and access to sexual health clinics and family planning centres, especially in terms of access to contraceptives and sexual health screenings (Shakespeare *et al.* 1996). Morris observes that for young disabled people with high levels of support needs youth can be a difficult time; many live in residential care or long-stay institutions and so have no peer networks systems or any contact with people their own age. As we have mentioned, this makes it difficult for disabled young people to access youth culture and make friendships (Morris 2002a, 2002b). Furthermore, transition and assessment plans for disabled young people focus more on the person's impairment effects than the barriers that prevent them from achieving goals; transition plans often reflect the wishes and interests of parents and care providers rather than the young person themselves, as such issues such as friendship, leisure and sexual relationships are not incorporated into transition plans (Morris 2002a, 2002b). These are important issues for young people, and disabled young people with high levels of support needs are often excluded from this aspect of youth that ultimately has repercussions for adulthood. This is particularly salient in terms of the barriers faced by young people with communication impairments and young people with learning difficulties. Exclusion from spaces that young people occupy (such as night clubs and so on) restricts disabled young people's identification with mainstream youth culture.

Disabled young people are often recipients of care from care-workers and of benefits for independent living and higher rate mobility; it is through this that disabled people are constructed as dependent and not functioning, autonomous and independent individuals in society. Priestly argues that adult status and recognition of such can in part be understood as how independent a person is. He argues that children and the elderly are placed out with this category due to

their dependence on adult care-givers and on financial resources from the state. Adults are constructed as ‘independent’ and capable of working and reproducing; as such disabled adults are constructed as ‘dependent’ similar to a child:

The perceived marginality of children, older people *and* disabled people in Western societies is premised upon a particular view of adulthood, based on ascriptions of adult independence, competence and autonomy

(Priestly 2003,118)

For disabled young people, the movement into the adult age category often does not mean that they will be socially included as adults. Moreover, many disabled young people will never attain ‘independence’, this leads one to question whether anyone is truly ‘independent’; the social organisation of the importance of ‘adult independence’ excludes disabled people and creates ‘dependent’ young adults. It constructs a picture for disabled young people that they will never become adults in the ‘true’ sense as long as they require care, personal assistance, financial benefit or aid. It is precisely here that fixed models of transition to adulthood serve to disable young people. Young people are constrained by a restrictive single ‘idealised’ road to adulthood (Hendey & Pascall 2001, 2).

This section of the chapter has explored the key arguments around youth and disabled young people. It has focused on the barriers that all young people face to independence and living independently. This section of the chapter has also considered how disabled young people are subject to low expectations and the following section will consider how these expectations have impacted on how disabled people are constructed in relation to sex and sexuality.

2.5 Disability, sex and relationships

While the last section explored the barriers that disabled young people experience in relation to transition and youth culture, this section of the chapter will look at disability, sex and relationships. This section will begin by mapping

out the representation of sex in Disability Studies, it will then go on to look at sexual citizenship and barriers that disabled people have faced in exercising sexual rights.

Sex, relationships and sexuality has not been the focus of disability as a category of analysis. While there has been some significant research and scholarship around sex and disability it remains deficient. Sex and relationships have been one of the key areas around which disabled people have experienced exclusion and oppression and the seemingly 'private' realm of sexuality has been left out of disability research for the most part. As mentioned earlier, sexuality is precisely one of the key areas of experience and 'private' life that have been disassociated from disabled people's citizenship, as Liz Crow neatly argues:

I've always assumed that the most urgent Disability civil rights campaigns are the ones we're currently fighting for - employment, education, housing, transport etc, etc, and that next to them a subject such as sexuality is almost dispensable. For the first time now I'm beginning to believe that sexuality, the one area above all others to have been ignored, is at the absolute core of what we're looking for...

(Crow 1991, 13)

Sex and disability had, for the most part, been looked at through a medical gaze with the focus lying on sexual function rather than the social experience of sex or equality of access to sex and sex spaces such as sexual health clinics (Shuttleworth 2010, 2). Siebers (2008) maintains that the sexuality of disabled people who resided in institutions was often monitored and restricted; who disabled people could and could not have sex with and whether or not they could have sexual experiences was controlled by medical authorities (Siebers 2008). There is a historical legacy of disabled people being on the margins of sexual discourse. As the WHO World report on disability (2011)² and Michel Desjardins (2012) have documented, disabled young people have been the subjects of involuntary sterilisation through the reproduction of the notion that

² For WHO World Report on Disability see
http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf?ua=1

disabled people are either sexual deviant, sexually vulnerable or indeed asexual (Mollow & McRuer 2012). Eva Feder Kittay's exploration of the 'Ashley X' example has demonstrated the ways in which authority figures, such as parents, have been complicit in the restriction of disabled young people's sexuality and experiences of their own corporeal and sexual developments (Kittay 2011). The Ashley X example is in keeping with multiple attitudes and perceptions of, certainly, sexuality and learning disabilities or intellectual impairments whereby the restriction of access to sex and sexuality has seen a greater restriction and level of control than people with physical impairments. Certainly disabled people, on the whole, have been characterised as out with certain 'sexual rights', as being subject to assumptions about sexual capability and potential (Richardson 2000 see also Siebers 2012)

Shakespeare, Gillespie-Sells and Davies' (1996) ground-breaking work on disabled people and sexual relationships was one of the first examples of scholarship that focused on disabled people's sexuality in the UK with reference to disabled people's experiences through frank narratives. This study was limited to disabled adults with physical impairments and it revealed that disabled people did not have access to the spaces and places where sexuality was 'done'; nightclubs and sexual health clinics were often inaccessible. Anderson & Kitchin (2000) have explored the impact that exclusion from 'sexual space' has had on disabled people's citizenship; they argue that sexuality is a key political issue and that the concrete realisation of sexual rights through inclusive sexual spaces is central to fulfilled citizenship (Anderson & Kitchen 2000, 1167).

Similarly, the exclusion of disabled people and the rejection of disabled bodies as sexual bodies have had ramifications for disabled people's sexual health. Tilley (1996) found that disabled women are less likely to have taken part in necessary sexual health screenings such as Pap smear tests and internal examinations as well as breast cancer screenings. Socio-structural exclusion such as this perpetuates the idea that disabled people are not sexual. Absence of young disabled people from this social arena is compounded by barriers to forming relationships. As has been acknowledged, disabled young people are by and large not expected to form sexual relationships and that these may go on to form marriages, partnerships and possibly families (Shakespeare *et al.* 1996, 17). Priestly argues that this is in part underpinned by the construction of dominant

cultural ideas about the body as youthful and the body beautiful. The consumerist obsession with an idealisation of the body sees its foundation in the construction of the body as fully functional, beautiful and its capacity for sex and sexuality, and for Priestly (2003) this construction of idealised attractive youthful bodies 'contributes directly to the construction of disability' (Priestly 2003, 95). The body of academic literature on disabled young people and sexuality is limited as work on sexuality and disability is largely focused on disabled adults and their experiences of sex and sexuality.

Numerous studies have found that disabled young people are also less likely to be included or involved in sexual health education in schools or who receive sexual health information that they feel is not relevant to them (Shakespeare *et al.* 1996, Tilley 1996). Chapter six of this thesis explores participants' experiences of exclusion from sexual health education and this has highlighted the links between public policy and sexuality as necessary in forming a comprehensive notion of citizenship that is inclusive of intimacy and the seemingly private world of sex (Richardson 2000, Mollow & McRuer 2012, Plummer 2003). The data presented in this thesis challenges the dichotomous relationship between private and public. The data in this thesis also challenges the idea that all disabled people struggle to participate in sexual relationships; most of the participants had had relationships despite the barriers that they experienced such as a lack of recognition, lack of access to social spaces and sexual health spaces.

Shakespeare *et al.*'s work *Untold Desires* argues that the construction of disabled people as asexual and at the same time sexually dangerous has its foundations in the absence of the normalisation of disabled people's experiences or relationships and sex. While the authors acknowledge their underrepresentation of disabled young people's experiences it is an issue that holds particular relevance to disabled young people, their experiences of youth and transition to adulthood (Shakespeare *et al.* 1996, 13). For many young people in school, sex education and sexual health information informs them of and reinforces their potential to have sexual relationships and to have children when they are older. For disabled young people (particularly in special education) sex education is given very low priority indeed; disabled young people are often infantilised in a bid to protect them from information deemed

inappropriate (Shakespeare *et al.* 1996, 8, Priestly 2003, 99). Moreover, there are barriers to information about sex and sexual health. Absence of disabled young people from sex education, media, and sexual health sends a resounding message, which is crystallised by low expectations and attitudes of parents, teachers and care workers:

If disabled children or adolescents receive negative messages about their sexuality from trusted authority figures it is likely that these will be accepted as truth. Disabled children, like their non-disabled peers, need to know the world has endless opportunities open to them and their destiny is shaped by a combination of personal choice, not by imposed restrictions...

(Shakespeare *et al* 1996,4).

The sexual lives of disabled young people are restricted and regulated by adults such as parents, teachers, carers and social workers and this is particularly true of disabled young people with learning difficulties (Priestly 2003, 99). Disabled young people with learning difficulties (particularly young women) face real barriers to transition to adulthood as sexuality and sexual expression is but one of the many areas in which they are infantilised and refused recognition as emerging adults.

Comparatively, young women in general are seen as problematic and difficult due to their potential to become pregnant at an early age. It seems both young able-bodied women and disabled young women are understood as sexually threatening and problematic for society albeit for contrasting reasons (Griffin 1997, 17, Priestly 2003, 98). This places disabled young women under increased pressure, as both sexually dangerous because of their gender and sexually deviant because of disability. The potential for disabled young women to become disabled young mothers is a challenge to normalised and attitudinal views of disabled people and of motherhood. The very social construction of sex as heterosexual and able-bodied activity can have implications for disabled young people and their sexual identities; it constructs disabled adults as sexless, relationship-less and childless. Shakespeare argues that sexuality, for disabled people, can be characterised by 'distress, and exclusion, and self-doubt'

(Shakespeare 2000, 160). Shakespeare argues that recognition is a key concept in changing dominant perceptions of disability and sex (2000, 165). Shakespeare utilises Honneth's notion of 'recognition'. In order to build a full sense of identity and have 'recognition', all individuals require access to relationships of love and friendship, legal rights and value and belonging to a community (Honneth 1995). It is argued that this would provide disabled people with the self-esteem and self-confidence to see themselves as sexual citizens.

International legislation has recognised the right for disabled people to have relationships and form families, it could be that this will have implications for future disabled young people and their experiences of transition to adulthood. The 'United Nations Standard Rules on the Equalisation of Opportunities for People with Disabilities' puts emphasis on the right for disabled people to experience sexual relationships, sexuality and parenthood and it urges member states to encourage and promote this with particular emphasis on disabled women and girls (UN Rules 1993, Rule 9). In the same vein, the UNCRPD has created international legislation that emphasises the rights of disabled people to have relationships, form marriages and become parents (2006 Article 23). It can be seen that sex and sexuality has, in many ways, remained the final frontier for disabled people. Disabled people face many barriers to exercising sexual rights and citizenship not least the dominant discourses that excluded disabled people from sexual spheres and the spaces and places where sexuality is played out and managed.

2.6 Conclusion

This chapter has explored the conceptual and cultural journey that disability has taken from personal tragedy to the political. The chapter focused on some of the key academic approaches in understanding disability: firstly, the chapter considered the individual approach to disability that was comprised of the location of 'the problem of disability' within the individual body. Disability was characterised by biological flaw and this was seen as an entirely social phenomenon. Further the individual approach was underpinned by the medicalisation of disabled people's lives and discourses of personal tragedy and patronage. By locating the disadvantage that disabled people faced as being the

result of impairment, the individual approach had a limited view of how disabled people might have been excluded from social life. These negative views of disability were reproduced in social relations and policies that further excluded disabled people.

The social and political oppression of disabled people and the legacy of patronage they were subject to acted as a catalyst for disabled activists to challenge these dominant social norms. The social model emerged as a product of the disabled people's movements' efforts and rejection of the lack of the control that disabled people had over their own lives. The social model sought to locate disability firmly within society; it focused on the material and economic barriers that disabled people faced and took a radical stance in overthrowing these through demanding equality in citizenship. However, while the social model was revolutionary and resulted in legislative achievement, it has subsequently been critiqued and further developed which has been explored in the third section of the chapter, thus section considers how the model has been challenged and critiqued since its inception. The foremost critique of the social model is its lack of engagement with impairment or experience; disability feminist scholars sought to bring the personal back in and politicise the 'private' sphere as a legitimate and relevant site of disabled people's everyday citizenship.

The chapter went on to explore youth and disability, an area of disability that has had limited attention. This section considered the barriers that young disabled people might face in living independently and the exclusion of disabled people from 'youth culture' and consumption. Finally, the chapter moved on to explore, arguably, the area of disabled people's lives that has received the least attention; sex and relationships are an integral part of many people's lives but disabled people have faced a legacy of exclusion from these aspects of social life through the construction of disabled people as incapable of sex to inaccessible sexual health services and a myriad of attitudinal barriers.

This thesis subscribes to the principles of the social model whilst also recognising that the body, experience and impairment are meaningful parts of disabled people's lives. This thesis incorporates an embodied perspective and the concepts of psycho-emotional disablism and impairment effects in approaching

disabled young people's experience of citizenship in everyday life. The following chapter looks at the body in more detail and seeks to bridge the gap between two seemingly unrelated paradigms: the body and citizenship.

Chapter 3. The body and citizenship: bridging the gap

The previous chapter focused on the development of Disability Studies as a paradigm and the development of the social model of disability as a tool with which to understand and grasp the social reality of disabled people. What was made apparent in the previous chapter is that Disability Studies and the disabled people's movement were, and to some extent, still are reluctant to engage with the body. Relatively recently, focus on the experience of impairment and the materiality of the body has become emergent particularly through the work of Hughes (2002, 2004), Hughes & Paterson (1997, 1999), Williams (1999) and Watson & Shakespeare (2002).

This chapter looks at specific sociological approaches to the body and citizenship and aims to reconcile the two through the concept of embodied citizenship. The chapter will be divided into six main sections. The first will begin with a brief discussion of the historical and theoretical separation of the body from the mind and how this dualism is continually reproduced through its intersection with other dualisms. This section will then go on to explore the relatively recent preoccupation with 'the body' through a focus on the social construction of the body.

The chapter will then go on to look at the notion of embodiment, which is central to this thesis, by exploring the notion of embodiment in everyday life. This section of the chapter will explore the notion that all experience is embodied; that people both are and have bodies (Mol & Law 2004, Nettleton 1998). This chapter will then explore traditional citizenship literature and the absence of the body from this scholarship; it will do so by critiquing traditional forms of 'Marshallian' (Marshall 1950) citizenship that posits citizenship in the public realm and through its focus on 'production' excludes disabled people from citizenship rights. The concept of 'lived citizenship' (Lister 2007) will be suggested as a more meaningful construction of citizenship that takes into account diverse groups in society, with diverse experiences and bodies. Finally this chapter will bring together literature on citizenship and the body to explore concept of 'embodied citizenship' as set forth by Bacci & Beasley (2000, 2002) as

a more useful lens through which to view citizenship in the everyday lives of disabled people. In so doing the chapter sets out to illuminate the gap in the literature whereby disability becomes a fertile terrain through which to better understand the body and citizenship and vice versa. The literature on embodiment and embodied citizenship will form the theoretical and analytical basis of this thesis.

3.1 The body and dualisms

This section of the chapter will explore the dualisms that pervade academic explorations of the body. While this has been well rehearsed elsewhere (for examples see Grosz 1994, Nettleton & Watson 1998 and Shilling 2012) it is critical to discuss here with a view to demonstrating how the mind/body dualism intersects with other dualisms that fuel the discrimination and oppression of groups in society

Turner (1996) explains the gravity of the impact that Cartesian dualism has had on Western thought. Firstly Descartes promulgated the idea that the mind and body were separate and exclusive, the mind held ownership over thought, reason, and the self while the body was conceptualised as a machine or a house for the mind, natural and causal (see also Valentine 2001, Grosz 1994, Scheper-Hughes & Lock 1987). This separation rendered the body unfavourable or subordinate to the mind as Elizabeth Grosz argues that ‘dichotomous thinking necessarily hierarchises and ranks the two polarised terms so that one becomes the privileged term and the other its suppressed, subordinated, negative counterpart’ (Grosz 1994, 3). Grosz sketches out how the body was not only denigrated by Descartes but has a much farther-reaching legacy of lesser importance. Grosz forms links between pre-enlightenment thought and the separation of mind/body. She maintains, for the ancient Greeks the body was a cage for the soul or the seat of reason and similarly for Christians the mind or soul was immortal with the body mortal and sinful (Grosz 1994, 5).

Crucially the reproduction of the mind/body dualism can be seen as a cornerstone of both disability activism and Disability Studies. In order to produce a politically viable and robust foundation for equality for disabled people, based

on the notion that society, and not bodies, disables people, a necessarily dichotomous relationship was produced namely disability/impairment. This separation, bound up in the social model of disability, fundamentally rejected the body as an active participant in the experience of disability. Impairment was seen as problematic, material, private and potentially damaging to the political goals of the disabled people's movement. Disability was cast as political, public, a matter of citizenship, and as disabled feminists such as Morris, Thomas and Crow would argue, decidedly male thus reinforcing and reproducing well trodden binaries (Morris 1991, Thomas 1999, Crow 1996 see also Bê 2012).

3.1.3 The 'privatisation' and rationalisation of the body

Crucially the body went through a long process of civilisation and privatisation resulting in the 'tidying up' of and management of messy bodily functions (Elias 2000). The historically located privatisation and control of the body and body products represented the continued distancing of the body from nature, characterised by Western enlightenment thought, and the modern move towards the socialising of the body (Valentine 2001).

Elias' work is particularly useful in understanding the privatisation of the body and bodily activities such as sex and going to the toilet. Not only does the privatisation of the body and body products allow us to see how the body was characterised as apart from the public but it allows us to establish the ways in which the body was also removed from citizenship and in fact status and being a good citizen was dependent upon restraining the body (Elias 2000). Hughes (2012) points to the work of Bakhtin (1968) as unfurling the gradual historical process of taming the volatile, unruliness of the body. Hughes describes the 'grotesque' Feudal body which laid bare the messiness of corporeal being such as the genitals, sex, death, eating, drinking and defecation (Hughes 2012, 74). Hughes argues then, that Elias' civilising process is a story of the modern body that rejects leakiness and messiness and crucially impairment (Hughes 2012, 74 see also Hughes 2012a). Indeed, Hughes relates the civilising process of the body to the exclusion of women and disabled people, women due to their leakiness and propensity for volatile excretion whilst disabled people refract the fear of the vulnerable and frail body, he writes:

Indicative of a failure of self control, the secreted saliva reminds non-disabled people of how they too might -in the course of time - fail to comport themselves in ways that conceal their vulnerability to decay, degeneration and infantilizing regression.

(Hughes 2012,74).

Elias asserts that the gradual routines of control over appropriate bodily activities like sex and defecation were moved towards management in 'private' and not 'public' (Elias 2000). Management of these processes, according to Elias, led to the prevalence of embarrassment which could be overcome through civility and self-restraint and managing bodies in private which Shilling describes as being 'hidden away in back-regions' (Shilling 2012, 136).

Women's bodies were characterised as sinful due to their 'leaky' character, the capacity to tempt and be dangerous; as Hughes writes 'leakiness is mired in the abject' (Hughes 2012, 75). The body therefore became associated with other unfavourable counterparts and feminist scholars argue that this can be through the gendering of the body or the association of the body with the natural, irrational and feminine by virtue of menstruation, pregnancy and childbirth (Kirby 1996, Price & Shildrick 1999), and the mind with the rational and masculine (Longhurst 1997). Similarly it can be seen that this dualism has been reproduced through other dichotomous relationships such as the body's association not only with the feminine and natural but also the private whilst the mind remained rational, male, political and public and crucially associated with the citizen (Bacci & Beasley 2002, Grosz 1994, Valentine 2001). Anna Greer discusses how the mind/body dualism has had a crucial impact on Western legal thought, which has served to perpetuate 'a series of violent binaries (male/female; mind/body, reason/emotion, nature/culture) fundamental to the privileging of law's ideological insider' (Greer 2006, 194). As Shilling notes, it was not only women's bodies that were seen as irrational and unstable but also the black body represented the 'dangerous other' (Shilling 2012, 49). The black body was constructed as naturalistic, bestial, wild and uncontrollably sexually threatening, and as Mercer & Race explain, black bodies were seen to challenge Western rationalism (Mercer & Race 1988).

3.1.3 Feminism and the body

Feminist scholarship has been critical in illuminating the oppressive impacts of the gendering of the body and furthermore the privatisation of the body. The association of women with the body, the natural and the irrational has had a long and lasting impact on women's' perceived capacity and participation as citizens. As Bacci & Beasley assert, the mind/body dichotomy is not solely an abstract philosophical tool and has had tangible consequences for citizenship for women and anyone whose body is categorised as different from white, able-bodied 'powerful' men (Bacci & Beasley 2000,327).

Bodily and biological difference has traditionally rendered women as 'other' to men (Shildrick 1997). Shilling highlights that women became concerned with 'reclaiming' their bodies in a bid to define their bodies as personal and individual, as an intrinsic part of their identities (Shilling 2012, 30). The 1960s onwards saw issues such as abortion rights and fertility rights on the political agenda, for example the landmark *Roe Vs. Wade* (1973) case saw the US Supreme Court protect the right of women over their bodies as a matter of private property under the Fourteenth Amendment of the United States Constitution. This was seen as an important development for second wave feminists who sought control over their own bodies in resistance to governmental control (Shilling 2012, 34).

Margaret Shildrick asserts that such dualisms as nature/culture, sex/gender and mind/body need to be rethought lest demolished in order to create a feminist ethics that bears in mind the female body (Shildrick 1997, 216). Shildrick uses postmodernist and postructuralist theory to explain that only through moving past dualistic relationships can there be a feminist ethic that does not 'other' female bodies to men's and that female embodiment is crucial to realising this ethic (Shildrick 1997). As Shilling argues, feminist concern with the body highlighted how the body could be the site of social oppression and inequality; crucially it also illuminated how dichotomous relationships such as sex/gender began to break down the perceived differences between women and men (Shilling 2012, 36).

Elizabeth Grosz (1994) has written extensively on the relationship between the body and gender and how ultimately it has served as an oppressive one. Grosz' discussion of Mary Douglas' *Purity and Danger* (1966) asserts that the leakiness of women's bodies, through menstruation for example, has been used to construct women as dangerous or 'dirty' while Irigay (1985) critically notes that men's' leaking is constructed as controlled, productive and solid rather than viscous and abject. This 'leakiness' or volatility attributed, mainly, to women's bodies has been a tool with which to limit women's participation in public or political life as Shilling neatly describes

There have been repeated attempts to limit women's civil, social and political rights by taking the male body, however defined, as 'complete' and the norm and by defining women as different and inferior as a result of their unstable bodies. Women were supposedly confined by their biological limitations to the private sphere, while only men were corporeally fit for participating in public life

(Shilling 2012, 59)

Similarly, feminist thought has been instrumental in igniting focus into the social and political relevance of the 'private' aspects of disabled people's lives. Disabled feminist scholars were clear that the disability/impairment dualism was actually counter to a holistic interpretation or representation of disabled women's everyday lived experiences of not only disability but impairment. The emphatic feminist dictum 'the personal is political' underlined what disabled feminist scholars sought to achieve and at the heart of this was recognition of the bodily aspects of their experiences of disablement. As has been explained in chapter two, feminist disability scholars have argued that personal or 'private' aspects of disabled people's lives were rendered apolitical and separate from the goals and principles of the social model and, as Bê argues, 'of no collective significance' (Bê 2012, 366). Similarly Garland-Thompson argues that women's bodies, and disabled bodies, have been cast as 'deviant and inferior' with both posited as 'other' to a norm of male, able-bodied strength as natural and given (Garland-Thompson 1997, 19). As discussed above, Hughes writes that, history has preferred the strong, rational, neat, male, able body to the female or

impaired body as the civilising process rejects the viscous, dangerous mess associated with the latter (Hughes 2012 see also Hughes 2012a).

3.2 The social body

Classical sociologists and social theorists such as Marx and Durkheim were concerned with bodies and populations of bodies, thus, for Durkheim the body was seen as an entirely biological entity and Marx was preoccupied with the oppression and subordination of bodies in labour production (Shilling 2012, 24, Turner 1991). Brian Turner argues that classical sociology failed to give way to a sociology of the body for many reasons. As mentioned, sociologists such as Marx and Durkheim were concerned with populations and their historical evolution rather than bodies themselves. Furthermore as previously mentioned the body was conceptualised as a shell for the mind, agency was conceived of as a product of the mind and this was underpinned by a general subscription to dualistic thought and dichotomous relationships such as mind/body and culture or society/nature plus the privatisation of bodily functions as sex, defecation and dying, for example, are hidden from view (Turner 1991, see also Shilling 2012, Csordas 1994, Elias 2000, Hughes 2012). The body was understood as a vessel or carrier for an active mind. Human agency was not understood as a corporeal activity.

Williams (1999) argues that there has been a relatively recent rekindled interest in the body, not only in academic thought, and that this, in part, can be linked to 'new technologies' of the body such as plastic surgery, organ transplants and reproductive technologies (Williams 1999). For Shilling (2012), this represents the 'body as project' that resists the fixed, biologically certain body.

Social constructionists aimed to understand and explain the body as a social phenomenon; social constructionists rejected the view that the body was wholly biological or naturalistic. This approach sought to understand the body as socially contingent and created, that the body could be shaped by society (Nettleton & Watson 1998). As was presented, in previous sections, through feminist contributions and activist movements such as the disabled people's movement, the body has become politicised. Turner has asserted that the body

has been at the centre of political and cultural activity and more and more states and governments negotiate the control and regulation of bodies that has led him to describe contemporary society as a 'somatic society' (Turner 1992, 12).

3.2.1 Symbolic interaction

Symbolic interaction refers to a subject's presence in the world as related to and constructed through interaction with others (Lemert 1979). In relation to bodies, it allows for an understanding of the body based around intersubjectivity and relationships between individuals and society. The body is an active mediator. Waskul and Vannini argue that the Interactionist tradition is founded on pragmatism but at its core is the emphasis on people as active and creative, shaped by doing, being and experience and thus invariably includes the body (Waskul & Vaninni 2006). Goffman (1969) has been crucial in exploring the interaction between persons, structures and institutions to which this discussion shall now turn.

This section will primarily focus on Goffman's contribution to sociologies of the body by building on discussions in Chapter Two and establishing the ways in which the body mediates interaction. Goffman's focus on 'presentation of the self' and of understanding interpersonal relationships between subjects has by proxy implicated the body (Goffman 1969). Goffman's work *Stigma* asserts that a person's confrontation with another is often mediated by their body; their self identity is informed by others' reactions to their body. Goffman asserts that a 'failed' or 'abnormal' person/ body is ascribed a 'stigma symbol' and with it comes 'a debasing identity discrepancy' (Goffman 1969, 59) which results in a reduction of value of that person; thus the body conveys a social message as to the status of a person. As Shilling maintains, it is the body that is at the centre of the relationship between a person's social and self identity for Goffman (Shilling 2012, 83).

Moreover, Goffman links the body to a person's self and to their identity on both a personal and social level, he also highlights once more that the treatment of a person and the status of that person is contingent upon the body. However, Shilling argues that the body presented by Goffman has no autonomy, status is

ascribed upon it by others, by 'normals', whilst this is true Goffman does see persons as embodied and recognises the body's importance in agency (Shilling 2012, 82). Again, Goffman's analysis of stigma and moreover his recognition of the body in identity and social agency is a powerful forerunner to contemporary understandings of disabled people and their experiences of their bodies and the relationship between body and identity.

However, whilst Goffman can be criticised for locating 'stigma' within the individual rather than societies' propensity to label the 'other' as deviant, he also links the body to the ways in which individuals are deemed competent or capable and for Goffman this 'competency' comes down to the control one has or does not have over one's body and its functioning.

Crossley (1995) maintains that, through 'Relations In Public', Goffman can be understood as a corporeal sociologist who through the process of body techniques establishes the ways in which agency and personhood are granted by being seen to have control over one's body (Crossley 1995). This can be seen in Goffman's 'Response Cries' (1978) where the example is given of someone who trips whilst walking down the street; in order to establish competency the person might examine the walkway for a flaw in the pavement or respond in such a way to indicate that the fault was not with them (Goffman 1978, 793). Goffman's example allows us to understand the ways in which a lack of control over the body might be seen as a lack of competency. Similarly Giddens' assessment that to be seen as a 'competent agent' in society persons must be seen as having control over their bodies and capable of demonstrating this control illuminates the ways in which the body is linked to social competency. As Giddens writes the 'Routinised control of the body is crucial to the sustaining of the individual's protective cocoon in situations of day-to-day interaction' (Giddens 1991, 56). This notion of a 'controlled body' marginalizes or excludes groups such as disabled people, women, children and the elderly because of its focus on what kind of bodies we should have and how they should function and these correspond to adult, able-bodied male bodies. Goffman's work on body techniques actively links the body to social interaction and exchange and to deviancy creation. It allows a lens through which to establish the ways in which inclusion and 'normalcy' is constructed around competent controlled bodies.

3.2.2 Inscribing the body

Michel Foucault's work has been important in developing one of multiple sociologies of the body. As Shilling asserts, post-structuralists argue that linguistic and discursive categories inform how we experience embodiment (Shilling 2012, 70). Foucault highlights in his work *Madness and Civilisation* (1967) how bodies were controlled through what he calls the 'great confinement'. Monarchical and Judicial authorities exercised their power through the confinement of the vagrants, the mad, the sick and the disabled and as such excluded them from social activity and life (Foucault 1967, 45 see also Hughes & Paterson 1997, 325). Power dictated the existence and experiences of bodies; confinement highlights how populations of bodies were removed from society. Foucault explicates that impaired bodies were imprisoned and excluded from society and this offers a theoretical model for how society disables impaired people through social exclusion, segregation and institutionalisation. It highlights how dominant carnal norms and discourse inform the lives of those out with those norms, and the socio-spatial exclusion of disabled people in contemporary society (Hughes & Paterson 1997, 325, see also Hughes 2002, 67).

For Foucault, power is inscribed upon the body and affects the body's activity as it 'reaches into the very grain of individuals, touches their bodies and inserts itself into their actions and attitudes, their discourses, learning processes and everyday lives' (Foucault 1980, 39). Foucault describes the change in the exertion of power and discourse through the punishment of bodies through time; in *Discipline and Punish* (1980) he explicates how the distribution of punishment and the inscription of power upon 'criminals' has developed as 'Subjects were no longer formed by discourses which directly constituted the body as flesh but, by discourses which indirectly controlled the body by constructing it as a 'mindful body' (Shilling 2012, 79). Foucault describes the treatment of the body in punishment in the Middle Ages; power was exerted upon the body by authorities in a public, brutal and violent manner to act both as a deterrent to others and as a display of authoritative power (Foucault 1977, 5 see also Shilling 2012, 79). The change from punishment as a disturbing and violent spectacle to confinement and control of criminals represented, Foucault argues, a shift in understanding of the body.

The body now serves as an instrument or intermediary: if one intervenes upon it to imprison it, or make it work, it is in order to deprive the individual of a liberty that is regarded as both right and as property...Physical pain, the pain of the body itself, is no longer the constituent element of the penalty. From being an art of unbearable sensations punishment has become an economy of suspended rights

(Foucault 1979, 11).

The treatment of the body was less focused on spectacles and public displays of ravaging the body; rather punishment was directed at the mind through confinement of the body, and through restricting liberties. For Foucault, this represented a change in social discourse, and thus discourse dictated corporeal existence and experience. Foucault gives an example of this through Jeremy Bentham's idea of the 'Panopticon'; a circular prison, at the centre a tower with the capacity to observe all cells around it in order to ensure that prisoner's would behave appropriately (Foucault 1979, 200 see also Shilling 2012, 79).

Foucault was primarily concerned with how bodies *en masse* were controlled by language and by social discourse, how power was exerted upon the body and how the body was excluded or oppressed through this exertion of power. There are, however, many who criticise Foucault and his treatment of the body. The argument against Foucault goes that he fails to see the body as having agency in itself, the body can have power exerted upon it, it can be oppressed through social discourse and language, it is not however the locus of power or agency itself. Foucault's body is a product of power and discourse. Physicality of biology is not considered by Foucault. For Shilling, 'the biological, physical or material body can never be grasped by the Foucauldian approach as its existence is permanently deferred behind the grids of meaning imposed by discourse' (Shilling 2012, 83).

Foucault's body is "inscribed upon" but does not seem to inscribe or experience, and is not an agent of social power in its own right; the body is not a subjective agent in creating its own world (Lyon & Barbalet 1994, 48 see also Turner 1994, 46; Csordas 1994, 12, Shilling 2012 and Hughes & Paterson 1999).

Poststructuralist and Foucauldian approaches to the body have been criticised by

some in terms of their usefulness in application to disabled people and impairment; the body's lack of agency or material foundation renders the disabled person powerless and incapable of 'collective embodied agency' (Hughes & Paterson 1999, 598).

It can be seen, therefore, that while social constructionist approaches to the body have been instrumental in demonstrating the relationship between the body and society it reflects what Shilling asserts it is guilty of; its 'absent presence' (Shilling 2012). Whilst embodiment is mentioned and there is recognition that the body mediates and shapes social interaction or is the site of oppression, control and power it fails to see the body as an agent of experience in its own right. The following section will explore the notion of embodiment and the lived body as a tool with which to explore the embodied nature of everyday life.

3.3 Exploring Embodiment

While social constructionists sought to move away from the naturalistic or essentialist body and explore and develop the ways in which the body was socially understood and socially produced, the experience of the material body was rejected as a category of analysis. Embodiment, asserts Nettleton & Watson (1998) is the integration of both the material reality of the body and the social reality of the body and this is achieved through experience. Csordas (1994) in particular has framed embodiment as the existential ground of culture and the self, arguing that through embodied experience we create and are created by the world. As Shilling (2007) argues 'embodiment' has been a critical conceptual tool with which to challenge dualistic thought within sociology. Embodiment, furthermore, seeks to establish the body as present and central to any sociological pursuit and to overcome what we have established in previous sections as the body's *absent presence* in sociology (Shilling 2012, Shilling 2007).

Everything we do is experienced through and done with our bodies. Therefore everything we do is 'embodied'. Nettleton & Watson (1998) neatly run through the 'every-day-ness' of embodiment describing going to the bathroom, eating, sleeping, running, walking, thinking, learning, getting dressed, playing chess and

so on, all as embodied aspects of our daily lives. They argue, then, “Everyday life is therefore fundamentally about the production and reproduction of bodies” (Nettleton & Watson 1998,3).

This section will look at phenomenology of the body by exploring the work of Maurice Merleau-Ponty and Drew Leder as establishing the body as the site of all perception and experience and the body’s centrality to the making of the world. This section will also discuss where phenomenology can be critiqued for its’ limited engagement with ‘structures’ and their interaction in everyday life. This section will go on to explore, in more detail, embodiment and experience as not only a useful way to theorise the body but also as an analytical tool and analytical framework for this thesis.

Phenomenology has, by some writers, been characterised by its capacity to offer a way of navigating through the naturalist/constructionist debates around the body (Csordas 1994, Leder 1990, Nettleton & Watson 1998). Phenomenological thought asserts that the body is the seat of experience, agency and subjectivity through its sensuous capacities; through perception (Crossley 1995).

Maurice Merleau-Ponty’s *Phenomenology of Perception* (1962) has been instrumental, if not the basis, for developing an understanding of embodiment. Merleau-Ponty rejects the Cartesian separation of the mind from the body and maintains that perception is ‘an embodied experience’ (Crossley 1995, 45). Merleau-Ponty (1962) argues that the body is both sensible (seen, touched, perceived) and subjective or sentient (it touches, can see and perceives) which he characterises as the ‘body-subject’ (1962). Drawing on Merleau-Ponty, Crossley (1995) argues that the body, through perception, is ‘our way of being in the world, of experiencing and belonging to the world’ (Crossley 1995, 48). This is an echo of Merleau-Ponty’s assertion ‘I am not in front of my body, I am in it, or rather I am it’ (Merleau-Ponty 1962, 173).

As Grosz (1994) details, the body for Merleau-Ponty is both subject and object; it has a material basis that is indistinguishable from the mind. Merleau-Ponty challenges the notion that body and mind are joined together or ungracefully stuck together (Nettleton & Watson 1998), rather, as Nettleton & Watson

maintain there is an ‘oscillation’ between the two (Nettleton & Watson 1998, 9). Grosz expands on Merleau-Ponty’s ‘oscillation’:

I am not able to stand back from the body and its experiences to reflect on them; this knowledge of my body is unable to grasp my body-as-it-is-lived-by-me. I have access to knowledge of my body only by living in it

(Grosz 1994, 86)

Here we can see that from this perspective the world is known, understood, experienced and created by and through the body, furthermore our experience of others or ‘intersubjectivity’ is mediated as and through bodies (Crossley 1995). Therefore every aspect of our experience is embodied.

We can take from this, then, that bodies are active agents in their own right not only symbols, surfaces or fleshy masses. However, the phenomenological approach has a tendency to leave out the relationship between the body, our perception of the world and the social institutions and structures that impact on everyday life. This is particularly salient for disabled people, I argue, as for many their experiences are intertwined with the social institutions that provide support, care and govern their access to benefits for example. I propose then, that ‘embodiment’ proves to be a more useful analytical tool with which to explore lived experience and everyday life.

3.3.1 Lived experience

Phenomenological insight has been crucial in challenging dominant discourses about the body and knowledge of the body through a focus on experience; this can be seen in Good’s (1994) research into chronic pain and illness. Byron J. Good offers a conceptual analysis of chronic pain in phenomenological terms and argues that chronic pain challenges ‘biomedicine’ and its very core that is that the objective knowledge that medicine has of the body in chronic pain can be understood as separate from the subjective experience of chronic pain (Good 1994 see also Leder 1990, 73). Thus Good argues that chronic pain is experienced through the body subjectively because consciousness is not apart

from the “conscious body”; the body, for Good, is an actor and creator of experience and “We act in the world through our bodies; our bodies are the subject of our actions, that through which we experience, comprehend and act upon the world” (Good 1994, 118).

Good asserts that upon experiencing chronic pain our selves; identity and life worlds experience a change as we attempt to manage our experience. He argues that through shared life worlds we can understand the experiences of others; the body is endowed with agency. He maintains that chronic pain resists the objectification imposed on it by medicine’s preoccupation with locating pain; pain is thus subjective (Good 1994, 132). Scarry (1988) maintains that embodied pain is objectified and understood, shared with others through its shaping of culture and belief; thus the human body is not separate to but intertwined with culture it is not inert or pre-cultural the human body is an agent in shaping culture and experience.

Phenomenology and its focus on embodiment offers a theoretical basis for understanding impairment and people’s experiences of impairment as not a wholly biological experience but as a social experience and as a social creation. Leder (1990) argues that the body often ‘dys-appears’ when in a state of pain or ‘dysfunction’; that is that for a disabled person there is a hyper-awareness of the body particularly in social situations, and it is in these social situations that the body appears in a state of ‘dys-appearance’ or negative focus (Leder 1990, 84, 92, 99).

Leder’s ‘dys’ thesis allows us to see the body as ‘taken for granted’ in everyday life therefore giving rise to significant challenges as to how one researches, talks about and gains insight from others about their bodies (Nettleton & Watson 1998, 10). Leder also forms a basis, through the notion of embodiment, to consider that the ‘lived body helps to constitute this world as experienced’ (Leder 1992, 25). Therefore it can aid in bringing abstract concepts, such as citizenship, out of abstraction and begin to understand it as something that is done and lived.

Csordas (1990, 1994) prefers the notion of ‘embodiment’ to ‘the body’ as embodiment makes way for an understanding of the material basis of the body,

lived experience, being-in-the world, and our situatedness. Similarly, Crossley (1995) critiques the 'sociology of the body' as he argues the body becomes external to the self as it concerns itself mostly with 'what is done to the body' rather than 'what the body does' (Crossley 1995, 43).

The next section aims to begin to explore our 'fleshy situatedness' and 'modes of living' by bringing together the body with citizenship to examine the ways that citizenship is not an abstract concept but is done, experienced and lived.

3.4 Towards an inclusive embodied citizenship

This section will explore and examine citizenship and view its relationship with the body in a bid to bring together two seemingly unrelated paradigms as a lens through which to understand disabled young people's experiences of citizenship in everyday life. This section will begin with discussing traditional concepts of Western citizenship by exploring T.H Marshall's approach to modern citizenship. The section will then go on to form a critique of this approach to citizenship by highlighting its exclusionary qualities; this will be done by looking at Plummer's notions of 'intimate citizenship'. I aim, initially, to focus on the distancing of the body from citizenship by exploring and challenging the private/public divide. This section will then end with 'inclusive' and 'lived citizenship' and the potential realisation of this by means of 'participatory parity' in order to establish a more inclusive approach to citizenship that takes into account the 'livedness' of citizenship.

Citizenship emerged as a key theme throughout the fieldwork process. The focus was initially aimed at 'rights' and how disabled young people experienced rights in their everyday lives. What became clear was that the participants discussed diverse and varied aspects of their everyday experiences that together constructed a picture of their experiences of everyday citizenship, not just rights. Through the interviews with participants as well as an exploration of the relevant literature, I was confronted with the absence of the body but also disability in the vast majority of citizenship literature. Lister points out that while Disability Studies has made citizenship central to its understanding of disability and inequality there is very little citizenship theory or literature that

includes disability in its debates (Lister 2007). Similarly, citizenship literature tended towards the more traditional models of citizenship relating to nationhood and economic participation. This section will discuss the development of inclusive citizenship and the ways in which the theorisation of citizenship has excluded groups such as disabled people, it will do this with a particular focus on belonging and participation as integral to inclusive and 'lived' citizenship (Lister 2007, 2003). It will seek to bring together citizenship and the body in order to form a meaningful discussion around how citizenship is an embodied activity.

3.4.1 Traditional approaches to citizenship

Citizenship is a historically located, far-reaching concept with little to no agreed upon defining character. Similarly, citizenship studies encompass a large breadth of paradigms and literature not all of which can be summarised or discussed here. Citizenship refers not only to the legal status of the individual but also to the ways in which citizenship is practiced and lived (Lister et al. 2007). As Lister et al. (2007) show, citizenship forms a bridge between the individual and the collective.

The notion of citizenship as the relationship between the individual or groups of individuals and the state was developed and practiced through ancient Greek and Roman societies whereby 'full citizenship' was attributed to particular subjects in society and as such these subjects enjoyed the rights and responsibilities that were attached to this status. Citizenship was not granted on the basis of where a person lived or their membership of a nation state and as such slaves, children, *aliens* and women were out with this status (Lister et al. 2007, 19). For Locke, for example, citizenship was founded primarily upon male claim to the 'rights of man' in so far as a man is able to mix his will and gain property as 'Man being born, as has been proved, with a Title to perfect Freedom, and an uncontrolled enjoyment of all the Rights and Privileges of the Law of Nature, equally with any other Man, of Number of men in the World, hath by Nature a Power' (Locke 1960, 323). While women were granted rights from her husband, according to Locke, they were firmly grounded in the familial or domiciliary sphere which was complimentary to but separate from the political

society. Not only does this posit citizenship with the masculine, but reinforces the notion that citizenship is a public activity.

T.H Marshall's contribution to the study and conceptualisation of citizenship has been hugely influential. Marshall developed a tripartite liberal system of citizenship based on political, social and civil rights characterised by legal justice, political representation and welfare (Marshall 1950). Marshall classically defined citizenship as:

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

(Marshall 1950, 28).

Marshall's citizenship model recognises a level of inclusion that was not present in former models of citizenship (Lister et al. 2007). However status and 'belonging' for Marshall are dependent upon fulfilment of the expectation set forth by society which can be characterised by productivity, work, voting and so on (Plummer 2003, 32). Feminist scholars in particular have been critical of Marshall's model of citizenship as they assert it has favoured working class men, and has been gender blind in terms of recognising women's continued exclusion from participation in 'public' and political life and representation (Lister et al. 2007, 2003).

Furthermore we can be critical of Marshall's model of citizenship as it favours ableist notions of productivity and necessarily constructs 'outliers' or 'others' as excluded from citizenship - citizen is constructed in opposition to those who are not citizen 'To be a citizen implies 'the other' who is not a citizen" (Plummer 2003, 52).

Key to traditional models of citizenship are that they are synonymous with 'public'. Habermas (1989) discussed the ways in which citizenship is founded on the Athenian Polis; citizenship was done and enacted in public spaces.

Citizenship is cast as both public and rational as we move through the period of

enlightenment, where it is invariably separate from the private sphere of women and the family and most crucially the body, as Bacci and Beasley comment:

The mainstream idea of citizenship is defined precisely in terms of an identity state based upon rights and activities enacted in the national public arena as against those merely private personal activities in the domestic sphere. Citizenship in mainstream terms is adamantly public

(Bacci & Beasley 2000, 340).

Similarly, as the volatile body becomes rejected from public spaces, activities or products of the body become similarly privatised, like going to the toilet as has been discussed above (Elias 2000). The 'public' sphere is the space of citizenship, public space is the place of controlled bodies hence out of control bodies such as female bodies (Grosz 1994), disabled bodies (Hughes 2012, 2012a) and the elderly (Featherstone & Hepworth 1991 see also Shilling 2012) are doubly excluded from citizenship.

3.4.2 Intimate citizenship; challenging the private/public divide

One of the key challenges to traditional citizenship models has been made by feminist scholars in their critique of the presumed synonymous relationship between public and citizenship (Bacci & Beasley 2000, 2002). In a bid to stretch 'citizenship' to include those which it had historically excluded such as women, children, ethnic minorities, LGBT communities and disabled people there has been an upsurge in formulating 'feminist citizenships', 'sexual citizenships' and 'minority citizenships' in order to recognise intimacy as a relevant aspect of citizenship. As Plummer argues the 'rights and duties' model of citizenship becomes problematic as inequalities come to the fore of citizenship debates (Plummer 2003). Therefore, Plummer asserts, a move towards intimate citizenship recognises those whose identities and experiences are embedded within intimacies such as single parents, surrogate mothers, children and transgendered people, for example (Plummer 2003).

Feminist scholars, in particular, have sought to challenge the public/private divide as it is seen to be active in limiting women's participation or recognition

as full citizens on the grounds that women are (still) traditionally associated with the domestic (and thus 'private') sphere. One of the key arguments is that women don't need to be 'freed' from the bonds of the 'private sphere' i.e. motherhood for example, but rather the private sphere should be recognised as a legitimate site of citizenship and the activities undertaken there are relevant (Lister 2007, Prokhovnik 1998). However, Prokhovnik (1998) argues that the justification for this divide is based in the state's reluctance to interfere in private individuals' lives. The problem here, however, is that so called 'private' issues are always already at the centre of governance and state surveillance; parenting, domestic violence, sexual health, reproductive rights, 'appropriate' clothing, 'appropriate' eating and marriage (for example) have and remain shaped, regulated and governed by state sanctioned policies, strategies and funding (Bacci & Beasley 2002, Plummer 2003). Therefore private issues have always been intertwined with the state but have not been recognised as legitimate and meaningful components of what it means to be a citizen or to participate in society resulting from the 'tendency to think in dualistic terms about public and private - the need to define oneself in opposition to, in rejection of, and in a hierarchy with something else, rather than in *connexion* to it' (Prokhovnik 1998, 87). Plummer rejects the idea that there ever was a public/private divide and maintains that in contemporary society the personal and the public are mutually constituted and created; they 'invade' one another (Plummer 2003, 68).

While women, parents, and LGBT groups are represented, albeit not always fully, in the arguments for exposing the connections and pathways between the public and private sphere and in arguing for a citizenship characterised by an appreciation of difference and equality, disability is rarely mentioned. As Jenny Morris asserts that 'even feminist challenges to the dominant concepts of citizenship, have, in inserting the private world of the family an women's caring role, still treated disabled people as absent' (Morris 2005, 5).

Kitchin & Law (2001) have focused on the ways in which disabled people have been excluded from public spaces that manage private or personal activities. Access to sexual and reproductive health clinics were discussed in the previous chapter on Approaches to disability and emphasised how poor access to sexual health clinics reproduced the exclusion of disabled people from sexual

citizenship (Kitchin 2000 see also Tilley 1996, Shakespeare et al. 1996).

However, toilets remain an issue that is, at times, intensely private for most but have to be publicly and precariously managed for most disabled people. Kitchin & Law (2001) assert that public toilets were designed for 'citizens' to defecate in but there is contest over who qualifies as these citizens, in any case Kitchin & Law posit toilets, firmly, as a matter to do with citizenship as a lack of access to public toilets prevent disabled people from participating fully in 'public' life by being able to move freely through 'public' space. This example, which is discussed in more detail later in this thesis, demonstrates the relationship, in quite explicit terms, complex interaction between the 'public' and 'private'. It also demonstrates that women are not alone in their relegation to the 'private' sphere or in their restriction from participation, a restriction that is characterised by the body; its physicality, morphology and needs. It can be seen that the body has been cast as private and citizenship as public therefore distancing the body from citizenship.

Furthermore, mainstream and dominant approaches to citizenship have paid limited attention to the ways in which participation and activities in the so called 'public sphere' are often dependent on or intertwined with activities in the 'private sphere' therefore failing to recognise their mutual constitution but also therein rejecting the private sphere and private lives as active in constructing citizenship (Bacci & Beasley 2000, 340). Feminist scholars have therefore argued that the rejection of the 'private' from citizenship is a rejection of women from being 'full citizens', it follows also that children, disabled people and older people are also, then, rejected from this category. Shakespeare writes that in order for disabled people to achieve inclusion in sexual citizenship and for disabled people to be recognised as capable of sex, for example, then 'reconciling the public and the private also means connecting the individual experiences of the body, to the collective experience of social structures' (Shakespeare 2000, 165).

We must be conscious of asserting that all feminist writers argued for the dissolution of the public/private dichotomy, with many feminist writers asserting the importance of the 'public' sphere (Jones 1990, 788). In fact feminist citizenship scholars such as Dietz (1985) have argued adamantly against the seemingly 'private' activities such as motherhood as being included citizenship.

Dietz argues that motherhood is a specialised, personalised activity and as such cannot be politicised (Dietz 1985). These arguments arguably mirror some attempts within DS and the disabled people's movement to reject the collapse of the disability/impairment divide lest it compromise the political foundations of the movement. However, it also perpetuates the notion that the private acts as a barrier to the public rather than conceiving of them as mutually produced and constituted, as such it perpetuates a barrier to full citizenship (Bacci & Beasley 2000, Lister 2007, Prokhovnik 1998).

Therefore it can be seen that while, of course, there are private and intimate aspects to everyday life - the public/private dichotomy is not useful in forming a concept of citizenship that is inclusive or meaningful. It can be seen that the private and public have always already had a complex interaction rather than exclusivity from one another. Exclusivity, in this context only serves to marginalise those who have been or whose activities are seen to be 'of the body' or 'of the private realm'. The following section will explore how the concept of citizenship has been challenged to become more inclusive as the 'lived' and everyday-ness' of citizenship is recognised as valid.

3.5 Inclusive citizenship, lived citizenship & Belonging

Citizenship has not only been challenged for its synonymous relationship with the public but also for its tendency to be perceived as an abstract concept bound up with rights and duties based on status - therefore rendering it exclusive both in academic focus, theory and practice, as has been alluded to already and as Lister notes, disability has been a 'lacuna' in citizenship studies (Lister 2007, 49). Scholars such as Lister (2007), Kabeer (2005), Morris (2005), Pakulski (1997) and Yuval-Davis (1997), for example, have been instrumental in developing a concept of 'inclusive citizenship' that recognises and embraces difference, culture, identity and belonging and perhaps most crucially a focus on 'the spaces and places in which lived citizenship is practiced' (Lister 2007). The assertion that citizenship is a 'lived' experience is a central analytical pillar of this thesis as it recognises and focuses on the voices of and experiences of those who 'live it'.

Lister (2007) cites Hoffman's (2004) claim that citizenship is a 'momentum' concept in that it must be continually reworked and reimagined in order to eliminate hierarchy of status and to realise the potential for equality (Hoffman 2004, 138 in Lister 2007). In order for citizenship to be inclusive, argues Kabeer (2005) it must be viewed from the perspective of those who are excluded; a 'bottom-up' understanding of citizenship. Kabeer (2005) focused on what people from the global south articulated as meaningful components of citizenship. Similarly, Jenny Morris has focused on inclusive citizenship as an appreciation of difference and valuing and recognising a 'common humanity' (Morris 2005, 40).

The idea of 'lived citizenship' further challenges the public/private divide as it focuses on people's lived experiences of citizenship in their everyday lives, which operates in conjunction with Plummer's notions of 'intimate citizenship' whereby the personal and political intersect (Plummer 2003). Lived citizenship forms a bridge between the individual and the social structures that inform and shape people's lives. Dorothy Smith (1990) argues that in order to understand the relationship between women's experiences and the policies that limit their inclusion and participation in social, political and economic life then it must begin at the site where women live and then build upwards from there. Lister argues that there is an increased focus in everyday life on 'how people negotiate and understand rights and responsibilities, belonging and participation' (Lister 2007, 55). Participation has become essential, Bacci & Beasley (2000) argue, to establishing who is excluded and included and how citizenship should be developed to include marginalised groups in moving beyond the more traditional formal rights model; for them 'social and political participation has become the litmus test and cornerstone of citizenship' (Bacci & Beasley 2000, 339).

Werbner & Yuval-Davis (1999) describe how belonging forms a meaningful category to an inclusive model of citizenship whereby identity, cultural and social meanings form a sense of belonging to a community that is crucial to citizenship. Belonging, as Lister et al. (2007 see also Lister 2007) argues, has both emotional and psychological components meaning then that people need to feel like they belong and this feeling of belonging is most often achieved through participation (Lister et al. 2007 see also Lister 2007). Therefore inclusive citizenship is comprised of an understanding of the 'lived experience' of

citizenship but also of belonging and identity and is inclusive through a focus on participation and equality of participation.

3.5.1 Realising inclusive citizenship through recognition and redistribution

In order for inclusive or 'lived' citizenship to be more than just a theoretical development it is pertinent to establish how it can be realised. Nancy Fraser (1995, 2000, 2004) has been particularly useful in thinking about the ways in which inclusive citizenship might be realised for disabled people who often require a material basis to their inclusion such as specialised equipment, adaptations, financial support, personal assistance, adapted buildings and so on. This ultimately requires financing. However, disabled people also require that their citizenship be 'recognised' as equal and valid. As Shakespeare (2000) highlights, disabled people often require that their rights to sexuality be recognised in order to be fulfilled and to result in feelings of inclusion, belonging and wellbeing.

Recognition and redistribution are well-versed terms which have come to be popularised and utilised in diverse circles and movements. Axel Honneth argues that recognition:

defines the conditions of a just society through the aim of recognising the individual dignity of all individuals...the idea of affording every member of society the measure of social recognition that makes him or her a full citizen

(Honneth 2004, 342).

Without recognition, according to Hegel, one's personhood is not valid. One must recognise and be recognised (Hegel 1991). For Honneth and Fraser, recognition affords personhood (Honneth 2004, Fraser 2000, Fraser & Honneth 2004).

Nancy Fraser has been critical of the recognition as a standalone model, instead arguing that social injustice can be combated through redistribution of wealth and resources; Fraser's analysis focuses on women's economic and social inequality (Fraser 2003, Fraser & Honneth 2004). Fraser (1995) asserts that

‘redistribution’ as a concept presupposes a level of recognition through concepts such as worth and value (Fraser 1995, 73). Furthermore Fraser asserts that misrecognition leads to ‘social subordination’ and therefore limiting individuals from ‘participating on a par with the rest’ (Fraser 2000, 113).

Fraser’s notions of ‘parity of participation’ are ultimately most useful in realising inclusive citizenship and this concept has been particularly salient when considering the varying and entrenched forms of exclusion that disabled people often face. Fraser, then, offers a three dimensional approach to social justice which she equates to participatory parity or ‘social arrangements that permit all to participate as peers in social life’ (Fraser 2008, 16). The concept of participatory parity involves both recognition and redistribution; maldistribution refers to those economic bodies and structures that deny people the capacity to interact with their peers; status inequality or misrecognition is the preferencing of some cultural values over others therefore denying people status; and thirdly misrepresentation whereby political institutions or decisions function to limit or deny people from participating with their peers either political or socially (Fraser 2008, 16-18, Davies et al. 2013).

Participatory parity as a concept is useful for understanding and realising disabled people’s citizenship as it takes into account status, political participation, social participation and private lived experiences although Fraser and others such as Lister (2010) have had limited recourse to disability in their exploration of participatory parity. This concept is particularly salient in reference to the current threats to disabled people’s benefits and social welfare (Roulstone & Prideaux 2011) and is utilised in subsequent chapters of this thesis. Utilising the notion of participatory parity in reference to disability extends the concept into new areas.

It can be seen that inclusive or ‘lived’ citizenship along with concepts such as participatory parity necessarily include the ‘private’ sphere, domestic or personal activities as being integral to forming an inclusive concept of citizenship that includes difference. What has not been addressed within this literature is how the body relates to it. The following section will explore the concept of ‘embodied citizenship’ and ‘citizen bodies’ as put forward by Bacci & Beasley (2000, 2002). The following section will maintain that a real

appreciation of difference, ‘livedness’, inclusion and the comingling of the public with the private must also include the body. As has already been established in previous sections, the body is the seat of self and experience (Budgeon 2003) and so citizenship must therefore be embodied.

3.6 Embodied Citizenship

This section will explore the work of Carol Lee Bacci & Chris Beasley as being two of a very limited number of scholars who have attempted to bridge the gap between the body and citizenship by way of ‘embodied citizenship’ or ‘citizen bodies’ (Bacci & Beasley 2000, 2002). Initially this thesis set out to look at the way in which rights were embodied through the process of doing and enacting, although it quickly became apparent that this offered a limited scope while citizenship encompassed the everyday experience of people’s lives.

Turner (2006) discusses human rights in relation to sociology of the body and surmises that human rights are connected to the body by virtue of the fact that all people have bodies and all bodies are vulnerable. However, while Turner’s approach recognises the relationship between rights and the body it subscribes to Shilling’s ‘absent presence’ thesis (2012). It is a disembodied account based mostly in a theoretical link characterised by vulnerability. Legal scholar Anna Greer (2006) also explores the relationship between rights and the body and argues that rights intersect with bodies in more than just a causal relationship but rather that rights are embodied. Greer argues that this can be seen through human rights abuses and that human rights abuses impact on bodies by imbuing them with meaning:

It does seem minimally clear that it is primarily as body-persons that we suffer from human rights abuses. Even the more ideological forms of abuse, those emanating from ideologies of difference such as racism sexism, heterosexism, and project their orders of meaning onto our embodied form encoding bodies with meaning based on colour, or sex (as male, female or intersexual) and so on

(Greer 2006, 197).

While Greer argues that rights are embodied by way of encoding ideologies onto certain 'different bodies' this also constructs the body as a surface which is encoded upon or projected upon; there is a lack of agency in Greer's account which takes a familiarly disembodied approach. There is little engagement with people's experiences of human rights abuses. However, it does go some way to bridging the theoretical gap and challenges the notion that rights are abstract normative concepts.

Lister (2003), through a feminist analysis, has explored the way that citizenship and the body interact. Lister explicitly identifies that women's ineligibility to practice citizenship has been due to women's association with 'the body'. While Lister has been critical in establishing the 'livedness' of citizenship and the importance of belonging and identity (Lister 2003, 2007 et al., 2007, 2010) there is still only a limited relationship with embodiment. Herein lies Bacci & Beasley's main critique of both citizenship and body scholarship; that bringing the body and citizenship together has been underdeveloped and there remains a lot of room to theorise and provide empirical basis for bridging the two, particularly within the realms of disability (Bacci & Beasley 2000, 337).

3.6.1 'Fleshing' out citizenship

As already pointed out, it is unusual to think of bodies and citizenship as fundamentally connected. However, we can see that institutions (both social and political), governance and policies are preoccupied with and bound up with how we go to the toilet, eat, sleep, drink, reproduce, appropriate sexual conduct, health, and housing (as a limited example) (Bacci & Beasley 2002, Anderson & Kitchen 2000, Pickering 2010). Therefore citizenship has always been 'to do' with bodies;

The body is not simply an outcome, it is not simply written upon, but materialises the operations of power in social life. It literally is what is social, since subjectivity is always embodied. Subjectivity, including political subjectivity, is *fleshy*

(Bacci & Beasley 2000, 344 emphasis added).

Bodies are, therefore, the 'social flesh' of citizenship, they give substance to citizenship; the manifestation of citizenship in operation and out of abstraction (Bacci & Beasley 2000, 2002). The aim, for Bacci & Beasley, is to relocate citizenship to bodies via 'breasts' and 'breast milk' (as an example) and also to 'spinal cord damage' (Bacci & Beasley 2000, 349). However, the 'fleshing out' of citizenship must also be extended to bathing, toileting, eating, dressing and sex in order to place the spotlight on those who are excluded, relegated to the 'private', reduced to their biology or seen as 'lacking' (Bacci & Beasley 2000). Furthermore it is necessary to explore the ways that the embodied self is linked to wider processes of power, citizenship and policy as Nancy Scheper-Hughes writes that the body is 'individually and collectively experienced, as socially represented in various symbolic and metaphorical idioms, and as subject to regulation, discipline, and control by larger political and economic processes' (Scheper-Hughes: 1993, 135, see also Scheper-Hughes & Lock 1987).

The lived experience of citizenship must also include the 'messiness' of everyday life in order to ensure that the body or 'the private' is not constructed as a barrier to full citizenship but rather a legitimate site of citizenship. There remains limited empirical research on bodies and further still there is a lack of empirical research on bodies and citizenship and in particular on disabled people whose bodies are usually conceived of in terms of disadvantage or 'lacking' rather than citizenship (Bacci & Beasley 2000).

In control and out of control bodies

As discussed in conjunction with symbolic interactionism, status as citizen can often be linked to the body and what kind of body a person is seen to have. Bacci & Beasley (2002), through cosmetic surgery, form distinctions between the 'control over' and 'controlled by' bodies which determines the kind of regulation and surveillance people experience. They argue that the 'control over body subject' is seen as a citizen while the 'controlled by body subject' is excluded from full citizenship (Bacci & Beasley 2002, 325, see also Shildrick & Price 1999). This constructs access to citizenship and recognition of citizenship through bodies that they argue are bound up with various dualisms such as mind/body, active/passive and 'sameness/difference' (Bacci & Beasley 2002, 326). While the aforementioned authors do not conceptualise this within the

framework of disability it can be seen to be incredibly useful as increased surveillance and regulation of disabled people can be seen to be linked to the level of need, support or lack of 'control' over body that person might have (Meekosha & Dowse 1997). They do argue, however, that control is associated with political autonomy and that 'activity' or being active has been associated, in mainstream citizenship literature (Turner 1993), as being associated with citizen which essentially excludes those who are seen as 'passive'.

As has already been discussed Goffman (1972) and Giddens (1991) have also alluded to the relationship between citizen and the 'controlled' body and for Featherstone & Hepworth (1991) in terms of ageing this controlled citizen or competent citizen is related to the control of bodily fluids:

Loss of bodily controls carries similar penalties of stigmatisation and ultimately physical exclusion...Degrees of loss impair the capacity to be counted as a competent adult. Indeed, the failure of bodily controls can point to a more general loss of self image; to be ascribed the status of a competent adult person depends upon the capacity to control urine and faeces

(Featherstone & Hepworth 1991,376).

Therefore it can also be seen that bodies and citizenship are connected through control and perceived status. Bodies can be the deciding factor in where on the citizenship scale a person might fall 'hence their activities can be regulated in ways deemed inappropriate for full citizens' (Bacci & Beasley 2002, 344). This, I argue throughout this thesis, is potent when applied to disabled people's experiences of citizenship in their everyday lives.

This section has aimed to explore the relatively ignored concept of 'embodied citizenship'. If we are embodied, if I am my body then everything I do is embodied including my experience of citizenship; what is essential is to move beyond theorising this and into exploring the voices that come from 'citizen bodies' in order to establish an inclusive embodied citizenship.

3.7 Conclusion

The purpose of this chapter was to ultimately bring together two vast, varied and diverse theoretical and empirical paradigms and demonstrate that they speak to one another and are fundamentally linked. The aim of this thesis is to explore disabled young people's everyday experiences of rights, and developed, through the process of interviews with participants, to explore the everyday experience of 'lived citizenship' with a particular focus on the body and how citizenship is embodied. Citizenship studies, and to some extent body and embodiment scholarship, have not focused on disability or impairment thus leaving an extensive gap in the literature. Similarly, body literature has had a limited focus on citizenship and vice versa (Bacci & Beasley 2000, 2002). In exploring participants' everyday experiences it became clear that citizenship and the body were inextricably linked.

This chapter aimed to demonstrate that there is fertile terrain for exploring embodied citizenship, particularly in relation to disability. The chapter sought to explore the impact of the mind/body dichotomy throughout sociological thought, writing and theory but also point to the impact it has had on everyday life. The series of dichotomies that are essentially and inextricably bound up with the mind/body dualism serve to reproduce and perpetuate one another through systems of marginalisation and exclusion and by the historical and social distancing of the body from citizenship. Similarly, citizenship has been far removed from the body in its development as a concept and yet it's very associated with the masculine and the public has been drawn across lines of differentiation associated with the body (i.e. citizen as male and rational and not female and irrational).

Feminist citizenship scholarship has looked at the relationship between citizenship and private lives and private spaces and in so doing placed some focus on the ways that citizenship impacts on the body with much focus on reproductive rights, breastfeeding and motherhood (Prokhovnik 1998, Lister 2003, 2007, Bacci & Beasley 2000, 2002). However, this scholarship rarely focused on disability as a fertile terrain for theorising the body, citizenship and indeed embodied citizenship. Furthermore, the popularity and vogueish nature of

academic interest into the body in the 1980s and 1990s has meant that the body has been theorised to such a great extent that there is an extensive ‘body’ of work relating to the body (all of which could be discussed here), while in contrast there remains a limited body of work that focuses on people’s thoughts, experiences, and feelings towards their own bodies i.e. the body in everyday life (Nettleton & Watson 1998). This thesis hopes to address this gap by presenting the embodied experiences that participants had of their everyday lives and how this relates to their participation, inclusion, and their citizenship.

Chapter 4. Methodology

This research aims to explore disabled young people's everyday lived experience of citizenship and embodiment. Initially the researched aimed to examine how disabled young people felt about their rights but very quickly grew to encompass broader notions of citizenship such as inclusion, participation and belonging. The research began from the position that life for disabled young people in contemporary society was underpinned by, at least on paper, a foundation of rights and legislation promoting, and to some extent securing, equality. However the research began at a time where these securities became contested through the medium of proposed cuts to disabled people's welfare and social care. The original aim, then, was to look at how life for these young people might tell a different story to older disabled people who did not grow up with equality legislation in place. Secondly, the research aimed to explore 'non-traditional' aspects of citizenship such as sex, sexuality, relationships and selfhood. It was hoped that looking at these facets of experience would cover ground that Disability Studies and citizenship studies has arguably paid limited attention to and allow for a focus on and appreciation of experiences of impairment and 'bringing the body back in'. It aimed to grasp an understanding of participants' feelings about themselves and their bodies by seeking to explore the areas where participants felt they were not included or able to participate and where they felt they were. Finally, the research aimed to explore the embodied nature of the participants' everyday lives and look at their process of 'doing' and 'being' in order to examine how disability, impairment, citizenship and the body are mutually dependent facets of experience. The purpose of this chapter is to outline the methods used and undertaken to explore and fulfil these aims, the emergence and growth of the research process, and then how these methods were employed throughout the fieldwork process.

The research utilised a qualitative methodology; this decision was taken because qualitative methods allow for a rich and deep insight into participants' social world and allows them the opportunity to voice their own personal and private views and experiences. This is particularly important for groups who have often been removed or excluded from the research process or whose voices are not represented through research. This chapter aims to document the research

process by looking at the research method that was undertaken, how this methodology was decided upon, how this methodology was employed during the fieldwork process and finally how the data were analysed.

This chapter will begin by exploring the emancipatory research paradigm. The chapter will then go on to look at qualitative research methods and the background to this research; this section will critically evaluate the notion of 'sensitive research' and 'vulnerable subjects' in terms of researching disability. The third section will specifically focus on the fieldwork process and the data collection by looking at, how participants were recruited, ethical issues, the role of the researcher and an insider identity before going on to look at how the data was collected and the use of interviews. Finally, the chapter will document and detail the way the data were analysed, how the data were practically managed, and how I dealt with researching and analysing narratives of 'the body'.

4.1 Emancipatory research

The emergence of 'critical social research', action research and participatory research and their focus on emancipation appealed greatly to disability researchers and Disability Studies in general. Early critical social theorists such as Paulo Freire in his work *The Pedagogy of the Oppressed* (1973) had an important influence on the development of participatory research and an emancipatory goal (see also Barnes & Mercer 1997, 4). The shift in mainstream social science research from a positivist approach to a more interpretive approach focused less on causal explanations and more on the experiences of social realities in certain situations; the focus was thus on the 'subject' rather than the objective world (Mercer 2002, 231 see also Ramazanoglu & Holland 2002, 47). Critical social research was founded on the basis that empowerment could be achieved through self-understanding or an awareness of the oppressive situation that a group found themselves in; it stressed the importance of the research in having an active role in this empowerment through having a political agenda in accordance with it (Mercer 2002, 231). The importance of this critical approach was the co-participation of both the researcher and researched, facilitating a more balanced relationship between the two.

4.1.1 Feminist emancipatory approaches

Feminist emancipatory research and the politicisation of research had a far-reaching ideological impact on the production of emancipatory research in Disability Studies. While the Disability Studies approach is difficult to operationalise as a methodology, feminist approaches take us further in providing a research methodology that supports a partisan approach to research through its focus on interpretivism, social constructionism and the use of reflexivity and qualitative interviewing. It is to this area that this discussion will now turn.

Feminist research methodologies emerged through the rejection of positivist 'objective' research and subsequently had a lasting impact on emancipatory disability research. The premise was that the positivist research paradigm was cast from a male standpoint "which insisted on a version of itself as 'objective' and 'neutral', as theorising in a 'scientific' fashion at the level of the collective and the general"(Thomas 1999, 69). Furthermore, the positivist epistemology is based on the dichotomy between object and subject and it is this that qualifies its study as 'objective' and as Kim England argues it is this epistemology that locates the researcher in a position of expertise and power in relation to their research 'subjects' (England 1994, 242 see also Lather 1988). Feminists argued that this faithfulness to binary thinking posited men as rational, powerful and cultural whereas women were constructed as subordinate to their emotions and bodies and were somehow inherently linked to nature:

Men's 'naturally' superior capacity for rational thought critically distinguishes masculinity from femininity. The rise of modern science entails ways of thinking in which these dualistic categories are both hierarchical and political

(Ramazanoglu & Holland 2002, 29).

Thus, feminist academics developed the interpretive paradigm particularly in the 1970s and challenged the positivist method of acquiring knowledge and 'truth'. Feminist research focused on emancipatory principles and political ends (Ramazanoglu & Holland 2002, 49). At its core it aims to research gender as a

social construction, similar to the researching of the social construction of disability by Disability Studies (Lather 1988, 571). As Lather argues feminist research is ultimately attempting to be a transforming force critical in ending the oppression of women (Lather 1988, 571).

The focus on 'praxis-orientated' research and action research encouraged the development of a feminist research methodology. As England maintains, feminist researchers came to favour a qualitative face-to-face interviewing approach and the relationship between the researcher and researched became of central importance through a focus on reflexivity and reciprocity, England writes that "those who are researched should be treated as people and not as mere mines of information to be exploited by the researcher and the neutral collector of 'facts'" (England 1994, 243). Like disability researchers, feminist researchers such as Oakley (1981) rejected the use of quantitative methods as exploitative and reinforcing power inequalities in research and maintained that the qualitative interview was a more empowering method (see also Ramazanoglu & Holland 2002, 155).

Where the emancipatory disability paradigm has fallen short or rather been reluctant to evolve in developing a disability research methodology, feminist research has been proactive in establishing a criteria for feminist research methodologies based on reflexivity, 'self-criticism', scrutiny and power hierarchies in society (Lather 1988, 576 see also England 1994, Lather 1986, Ramazanoglu & Holland 2002). Crucial to the feminist emancipatory model has been the development in who and what feminist researchers' research and the knowledge that is produced. While the emancipatory disability paradigm has been reluctant to move its scope beyond the social model and the focus on social structures as disabling, the feminist research paradigm has recognised that it is crucial that all areas of women's lives and of gender should be explored (Stanley & Wise 1979, 373).

Feminist emancipatory research does not only focus on oppressive social structures but on personal experiences; disabled feminists have argued within Disability Studies that disabled people's experiences of their impairments and of their bodies are not represented adequately and as such disability research only represents the experiences of an elite groups of middle class men with physical

impairments (Crow 1996, Morris 1996). Stanley and Wise argue that this has also been a feature of feminist literature whereby 'woman' is used as a universal category while actually only representing a certain groups of women "...the category 'woman' used in academic feminist writing then (and, to an extent now) actually reflected the experiences and analyses of white, middle-class, heterosexual, First World women only, yet treated these as universals" (Stanley & Wise 1990, 22). Since then, feminists have been continued to be self-critical and have sought to move beyond these limitations.

4.1.2 Emancipatory disability research

Even before the existence of UPIAS and the Social Model, research emerged that sought to look at the 'disabling society' and the ways in which it excluded disabled people from participation in society (Mercer 2002, 228). The focus of academic research into disability was geared around documenting the experiences of people living in institutions, residential homes and disabled peoples experiences of the rehabilitative process; despite a greater focus on the social provision of disability it was very much applied with a medical gaze (Barnes & Mercer 1997).

The research carried out by Miller and Gwynne in the 'Le Court' Cheshire Home provided the framework for how academic research reinforcing the individual model of disability had come to be understood as 'parasitic' (Miller & Gwynne 1972, Priestly & Stone 1996, Mercer 2002). The Miller and Gwynne study focused on institutional living for those in the home; residents at the home such as disability activist Paul Hunt expressed that the researchers dismissed the accounts of the residents (Mercer 2002). Eventually the study emerged and the result was that in an attempt to be 'objective' and 'scientific' the researchers had furthered a 'tragic' and individual understanding and construction of disability referring to life in the home as 'a living death' (Barnes & Mercer 1997, 2). This kind of individualist research led activists within the disability movement to question academic social research into disability and the agendas of researchers themselves and the social relations of research production.

Similarly research into gender and race has also questioned the social relations of research production and questioned the very methods of knowledge

production and retrieving data. Enlightenment philosophy and the focus on 'reason' and 'objectivity' resulted in the striving of social scientists to adopt scientific methods when carrying out social research; the view that the social world can be researched in similar ways to the natural world. This positivist approach to research has met resistance from both the feminist movement and the disability movement; with the view that the subjective world cannot be studied as if it were the objective world, as Ramazanoglu and Holland (2002, 45) write that:

Positivist approaches to methodology bring a particular conception of scientific method to bear on the study of social life, with the claim that reality is directly accessible given the correct methods.

Disabled activists and in particular Mike Oliver have championed emancipatory disability research as a standard by which research into disability should rise. The goal is to transform the political and social reality of disabled people through research, and furthermore to change the social relations of research production (Oliver 1992 see also Oliver 1997). Within emancipatory disability research there have been significant debates that have arisen, at the forefront are debates around research methods, who should conduct disability research and who are researchers accountable to? Oliver himself has questioned the emancipatory paradigm as an 'impossible dream' (Oliver 1997).

Participatory research

The critical social research approach was particularly salient with disabled people who had come to reject the mainstream research that constructed disabled people as passive victims. The emancipatory disability research agenda sought to reclaim research into disability in order to impact upon and transform the lives of disabled people through research. Oliver expanded the emancipatory model from feminist and anti-racist critiques of positivist social research, and further argued that emancipatory disability research should seek to end the oppression of disabled people (Oliver 1992, 102).

Oliver argues that that researchers have become alienated from the people that they are researching, that disability research has reinforced medical models of

disability and that research into disability should be actively partisan. As he argues ‘...you cannot be independent in researching oppression; you are either on the side of the oppressors or the oppressed’ (Oliver 1997, 17). Oliver argues that disability research must be grounded in the political goals of disabled people and the disability movement and that the research cannot be separated from the political aspirations and identity of the particular research participants (Oliver 1992, 106). Furthermore he posits the research relationship as a hierarchical one that reflects the disparity of disabled people in relation to their non-disabled peers; he argues that a facet of this alienation is realised in the fact that researchers are presupposed as experts and disabled research participants as passive thus allowing researchers to construct the political agenda (Oliver 1992, 102). For Oliver, disability research must align itself with the political goals of disabled people, and it is through this that research can (in part) be understood as emancipatory.

Emancipatory disability research is founded upon three key themes namely, reciprocity, gain and empowerment; it follows that the paradigm will succeed in the emancipation of disabled people through empowerment which will be realised through the reciprocal relationship formed through the research process ‘The issue then for the emancipatory research paradigm is not how to empower people, but once people have decided to empower themselves, precisely what research can then do to facilitate this process’ (Oliver 1992, 111). The inequality in power in the researcher-researched relationship is the motivation for the changing of the social relations of research production; through establishing a more equal process and affording power to the research participant the researcher is directly challenging the power hierarchies and deficits apparent in the social reality of disabled people (Oliver 1992, 1996). The growth of the emancipatory disability paradigm has crucially become intertwined with the social model of disability, in that, in order for disability research to be emancipatory it must commit itself to the ideology and principles of the social model and seek to establish the political oppression and social barriers faced by disabled people in the UK (Barnes 2001, 10).

A key facet of the emancipatory paradigm is the insistence that disabled people and their organisations be responsible for directing, driving and accepting research projects and furthermore be in control of how the information is

disseminated in order to change the social relations of research production (Barnes 2001, Priestly & Stone 1996). In addition to this it has been stressed that disabled people and their organisations should be responsible for the funding of research into disabled people's lives; the Joseph Rowntree Foundation³ (JRF) has been active in supporting this and has prescribed that disability research should not only be participatory but must be in line with the social model (Barnes 2001).

Insider Identity

Within the discussion around disability research and emancipatory research, there has been a particular debate that has emerged questioning the role of non-disabled researchers in disability research. The emergence of Disability Studies out of the disabled people's movement and the view that non-disabled people are the oppressors and disabled people the oppressed has resulted in a particular camp that question non-disabled researchers' capacity to produce a research relationship that is not oppressive. Furthermore, without an insider identity and first-hand experience of oppression can non-disabled researchers represent the experiences of disabled people:

‘Non-disabled’ people, their values, their policies, their culture, are the objects of the analysis of our subordination. We are the subjects - its driving force, its shapers and its initiators. ‘Non-disabled’ people are not where we are and can never be. This is the political impossibility of their relation to the disability movement

(Branfield 1998, 143).

The danger of the social model is that it serves to homogenise disabled people and their experiences and similarly the assertion that only disabled researchers can fully understand the experiences of disabled people further homogenises disabled people assuming that regardless of gender, impairment type, class etc., all disabled people have similar experiences of oppression and disablement (Barnes & Mercer 1997, Shakespeare 2006). This arguably stems from Disability

³ <http://www.jrf.org.uk/>

Studies' entrenchment in the disabled people's movement and its limited independence from it.

4.1.3 Critiquing emancipatory research

Despite the emancipatory goals principled in contemporary disability research, it has become apparent that not only is it incredibly difficult to call a research project emancipatory as per the criteria, but the paradigm has arguably rejected one orthodoxy in replace of another; the social model of disability. Similarly it is apparent that the dogmatic reliance on the social model as a guideline for research presupposes that all disabled people's experiences of disability are reducible to material barriers; the emancipatory research model carries with it all the flaws that the social model does. As a result it fails to stress the importance of researching people's experiences of their impairments and of 'the personal' and it assumes that all disabled people are equipped to manage, direct and vet a research scenario/project (which is not always the case particularly for those with a profound learning difficulty). Mercer writes that 'Not that all disabled people have the time or inclination, even if politically aware, to take control of research production' (Mercer 2002, 240, see also Shakespeare & Watson 2002, Watson 2012). Some disability activists and scholars have maintained that a person's understanding of their impairment as disabling is a form of 'false-consciousness' arguing that disabled people are not disabled by their impairments; this creates a hierarchy and excludes impairment from the research agenda, it also contradicts the assertion that disabled people are 'expert-knowers' (Shakespeare & Watson 2002, 20). It can be seen therefore that disabled people's views and feelings are only represented in emancipatory research so far as they are commensurate with the social model of disability.

Barnes himself maintains that despite the goal of making research accountable to the disabled community, the disabled community is diverse and disparate and regardless of this it would be entirely impossible to be held account to every disabled person (Barnes 2001). As much of the Disability Studies literature has since pointed out, experience not only of impairment but of disabling structures is varied across impairment type but also gender, ethnicity, class and so forth (Crow 1996, Morris 1996, Barnes 2001). Social barriers are experienced by many groups of individuals in society and it could be that the experience of oppression

on any level in society is a gateway to understanding the discrimination and oppression experienced by disabled people (Shakespeare 2006, 195). Furthermore it is misleading to assume that disabled people are able to automatically understand the experiences of other disabled people “Because impairments are so diverse, someone with one impairment may have no more insight into the experience of another impairment than a person without any impairment” (Shakespeare 2006, 195). It assumes that disabled people have homogeneity of experience. Whereas the feminist literature has also been guilty of this, feminist research has come to emphasise the variety of experience of being women simply because all women share experiences of oppression. Thus it can be seen that although the feminist research paradigm has similar origins and development as the emancipatory disability paradigm, in many ways the feminist paradigm has evolved to develop a functioning methodology.

Tom Shakespeare is a key figure in criticising the emancipatory disability paradigm with particular reference to it's expectations of academic researchers and academic institutions. Shakespeare's presents a reflective piece on his collaborative work *Untold Desires: the sexual politics of disability* (1996), the process of conducting the research and whether it could be called 'emancipatory'. Shakespeare argues that it is unimportant to him whether the work was emancipatory or not, he argues that the disabled people's movement and Disability Studies are not one and the same when he writes:

I do not believe that academics should be spokespeople for the disability movement: the voices of disabled people are the representative organisations of the disability movement, not individuals regardless of expertise or experience

(Shakespeare 1997,188)

There has been no significant development of an emancipatory or disability research methodology rather it is informed by a set of key principles around the social relations of research production. As a result emancipatory disability research is limited in its scope due to its reliance on the social model (Watson 2012).

It can therefore be seen that the emancipatory disability research paradigm has attempted to offer an alternative process of researching disability in accordance with the social model of disability. The emancipatory paradigm seeks to challenge, directly, the exclusion of disabled people from society by altering the social relations of research production. However, as has been explicated there are vast limitations to the emancipatory paradigm and few examples of disability research that can be qualified as emancipatory as per the foundational criteria set out by Oliver (1992, see also 1997), Barnes & Mercer (1997) and Priestly & Stone (1996) for example. The emancipatory disability research paradigm has not moved beyond the social model of disability and so remains exclusive to a certain category of disabled people and as such fails to include impairment effects as an important facet of disability (Watson 2012). Emancipatory disability research remains faithful to researching the structural and social barriers that disabled people encounter. Although at its core emancipatory disability research promotes the empowerment of disabled people through research which is crucial in bringing academic and social awareness to the discrimination disabled people face.

4.2 Exploring qualitative research methods

As has been detailed and discussed above the fundamental reason for establishing this study as a qualitative one was forming a research design that rejected research methods that exclude marginalised voices from research. The rationale behind using qualitative methods was that I felt that these would best achieve rich data, would make space for participants to provide narratives around their own experiences (thereby guiding the research to an extent) and finally to collect data with deep meaning. It is essential that, practically, these methods suit the research area undertaken and the participants that took part in the research. It is the 'job' of the researcher to strive towards a methodology that best fits the research aim and principles of the study. This section, therefore, provides an exploration of the qualitative methods employed, why they were employed, and particularly why semi-structured interviewing was best suited to this study.

4.2.1 Employing qualitative methods

Qualitative methodologies encompass a wide variety and diverse group of research methods which are constantly evolving (Creswell 2013, 34). Denzin & Lincoln (2011, 3) describe qualitative research as a 'situated activity' that positions the researcher in the world. Through the use of interpretive tools the research makes the world visible. These tools include the interviews, field notes, diaries, conversations and recordings that allow the researcher to study social 'phenomena' and seek to make sense of it (Denzin & Lincoln 2011, 3). Creswell (2013) maintains that Denzin & Lincoln's (2011) definition of qualitative research emphasises its capacity to shape and change the world. Ramazanoglu & Holland (2002) maintain that qualitative research looks at ideas, experience and material and social realities. They are preoccupied with the meanings that people make, the everyday experiences of life, and particularly from their feminist standpoint, relationships, power and institutions (Ramazanoglu & Holland 2002, 9).

For Silverman (2000), qualitative research can be utilised to provide 'deeper' meaning and understanding of social life and phenomena that would otherwise be hidden or inaccessible through quantitative data alone (Silverman 2000, 8). Therefore qualitative research, as has also been discussed above, can support the emergence of otherwise unheard voices, or allow excluded or marginalised groups' experiences to be made heard and visible.

Ramazanoglu & Holland (2002, 15) argue that feminist methodology, for example, has not been shaped by a singular research method rather that feminists have developed styles of researching and methods that are best suited to allowing women's' voices and experiences to be heard. This, they maintain, can be achieved through qualitative methods, a focus on relationships and sensitive topics. They do, however, argue that feminist methods and methodologies are underpinned by feminist theory that is essentially emancipatory in character.

Qualitative research, then, permits the researcher to seek and gain insight into the everyday lives and personal experiences of participants. It provides the space for participants to express their views, ideas and opinions about their social worlds and realities. Qualitative research can allow participants to be

recognised as 'expert knowers' in their own right (England 1994) and this is bolstered through the process of interviewing and face-to-face interactions between the researcher and participant. Therefore qualitative methods and research are often well suited to research that looks at marginalised or excluded groups (Bergold & Thomas 2012, 42).

Qualitative methods: Interviews

All of the data were collected through multiple in-depth interviews with 18 disabled young people between the ages of 18 and 30. Interviews were undertaken with the view that the participants were experts in their own lives (England 1994) and as such in depth interviews were the best fitting tool for collecting data as 'The most fundamental characteristic of qualitative research is its express commitment to viewing events, actions, norms, values etc, from the perspective of those being studied' (Bryman 1988, 61). Semi-structured interviews were employed as the most suitable way to carry out the interviews. Semi-structured interviews allowed the participants to express their views and opinions while still allowing the interview to be loosely guided.

Fylan describes semi-structured interviews as loosely focused conversations and he maintains that there are usually a set of questions and an idea of topics covered but these are likely to change between participants and thus the conversation can vary freely (Fylan 2005, 65). Semi-structured interviewing therefore allows space for each participant to express their own personal narratives, views and thoughts about their own lives and experiences. Ultimately semi-structured interviews should allow the participant to bring up topics and express views that they feel relevant and important whilst also allowing the interviewer to guide the interview as well as explore other ideas if they arise. Furthermore semi-structured interviewing seeks to eliminate, as much as possible, the unequal power hierarchies that can emerge in the interview process to ensure as far as possible that the focus of the interview is on the participant and their perspective (Oakely 1981). This interview style is favoured by feminist researchers and disability researchers because it affords the research participant both power and agency in the research process and stresses the importance of experience as knowledge (Ramazanoglu & Holland 2002). It is therefore essential that the experiences of disabled young people be the basis

for the knowledge generated throughout this research as ‘the dialogical nature of research increases the probability that the research may be transformed by the input of the researched’ (England 1994, 248). Semi-structured interviewing, while it affords the participant power within the research scenario, allows the researcher to keep the interviews on topic.

Multiple Interviews

I decided that multiple interviews would be useful for the purposes of this study. I decided that each participant would be interviewed twice with at least 6 months in between each interview so as to allow participants to reflect on the process. As Charmaz highlights, the benefits to conducting multiple interviews are that they allow the researcher to gain a deeper understanding of the social processes that may be occurring; it facilitates a relationship between researcher and participant gaining trust and the researcher can have a deeper grasp of phenomenon and is able to reflect on what was said in previous interviews, as Charmaz notes that ‘Interviewers then have the opportunity to follow up on earlier leads, to strengthen the emerging processual analysis, and to move closer to the process itself’ (Charmaz 2003, 319). Multiple interviews are beneficial for looking at how participants’ views might change over time; it allows the participants to be reflexive and allows the interviewer to build rapport with participants. Multiple interviews also allow the researcher to build up a narrative account of the participants’ lives and experiences (Charmaz 2003).

4.2.2 ‘Sensitive’ topics and ‘vulnerable’ people

‘Sensitive’ research is increasingly becoming part of the agenda of social research (Liamputtong 2007). The definition of ‘sensitive’ is varied and Lee & Renzetti (1993, ix) describe sensitive research as interested in behaviours that are “intimate, discreditable, or incriminating” (Lee & Renzetti 1993, ix) while others describe sensitive research as a preoccupation with the intimacies, private spaces and personal activities of others (De Laine 2000). Certainly ‘sensitive’ research, it is argued, includes sensitive areas such as sex, for example (Lee 1993). Lee also argues that sensitive research is that which has the capacity to harm or pose threat to the researched or researcher (Lee 1993).

Research can also be defined as 'sensitive' in terms of its impact on the researcher. There are a number of issues that researchers need to bear in mind such as managing emotions in difficult or sensitive research (Dickson-Swift et al. 2007, 328). Sensitive research is, furthermore, characterised as such if it includes 'vulnerable' people. Liamputtong (2007) discusses the difficulty in defining 'vulnerability' as it is a contested concept (Liamputtong 2007, 2). However, generally vulnerable people are, for example, those who experience inequality, diminished mental or physical capacity, can be easily coerced, are stigmatised, face political or social risk or are involved in risky behaviour (Liamputtong 2007). Certainly in many of the varying definitions discussed by Liamputtong (2007), disability and disabled people feature frequently. I found problematic the presentation of disabled people as inherently vulnerable, both in the literature and throughout the ethics process. As will be discussed in the section on ethics, I actively rejected the construction of disabled people as inherently thus.

Disability proves to be a challenging 'category' for this notion of vulnerability. To be sure, Disability Studies scholars have sought to reject the notion that disabled people are powerless and tragic (Shakespeare 2006) and the categorisation of all disabled people as 'vulnerable' subjects in social research may only serve to homogenise disabled people further and render them powerless and tragic. This is not to suggest that 'vulnerability' is not a useful term or that participants should not be safeguarded against potential risks in participating in research but rather that all people are vulnerable at varying points in their lives. Furthermore disability intersects with all other categories such as gender, race, and class for example and as such a disabled person could be present in any research context including research not deemed 'sensitive' or focussing on 'vulnerable' populations. As such it is the role of the researcher to be aware of any participants' feelings throughout an interview. The researcher should thus be ready to direct participants to appropriate sources of support should they need it and to move on from any topics that are causing undue distress.

4.3 In the field

This section of the chapter will give an overview of the fieldwork process undertaken during this research study. The aim of this section is to give insight into how the data was collected, the role of the researcher in its collection and the ethical issues that arose throughout the process. The aim of this section is to scrutinise the research process, what worked and what did not, in order to allow the data to be seen as valid and thorough.

4.3.1 Overview of data collection

The fieldwork was carried out between September 2010 and January 2012. The months prior to interviewing were devoted to gaining ethical approval and formulating an information sheet to be sent out to potential participants. I was committed to formulating an information sheet that was accessible and easy to understand in order to ensure that consent was informed, as much as is possible, and that the research documents met the ethical criteria of the University of Glasgow Faculty of Law, Business and Social Sciences Ethics Committee. The following months were devoted to participant recruitment through organisations for disabled people, sports groups, dance and arts groups, and university and college disability services.

The data collection was constituted by three main phases. The first phase consisted of taking part in two group workshops for disabled young people in Glasgow (run by an organisation for disabled people) in order to sensitise myself to the key areas that disabled young people were interested in. The second phase was comprised of in-depth, semi-structured interviews with each individual participant in a place of mutual accessibility and the third phase consisted of the second in-depth, semi-structured interview around four to six months after the first interview.

The decision to have two separate interview phases allowed me the opportunity to transcribe the first set of data and do a very basic initial analysis which helped me to formulate the topic guides for the second set of interviews. It also allowed the participants time to reflect on the interviews and gave them the opportunity to withdraw anything they wanted to from the data and to follow up

on stories and examples they had given me. The two interview phases also proved to be invaluable in terms of building rapport with participants.

It was always my intention that interviews would be held individually with participants, and where possible, without support workers, assistants or family members. I wanted participants to be able to speak freely with me about their views, thoughts and experiences without feeling they might be under surveillance. However, I was also fully prepared to conduct interviews where participants required a support worker or assistant or felt more comfortable with someone else there. In some cases a small number of participants required personal assistants in order to get to the interview, or required support during the interview either with speech or adjusting themselves and so on. I wanted to ensure that a wide variety of participants took part in the research and did not want to exclude anyone with complex support needs or speech impairments from the research. In order to make the research more inclusive and participatory it was essential that I be flexible on the inclusion of support workers or assistants where it was required. There were times when I would arrive at an interview and a support worker was present, I felt unable to determine whether this was the participants' choice or not (in all cases, apart from where a participant had expressly asked for someone else to attend). However, I found that participants asked their assistants for privacy when they wanted it and they managed this relationship as they saw fit.

Part of the ontological and epistemological framework of this research is the idea that disabled people are not a homogenous group and as such participants were recruited from varied backgrounds and locations, had attended a variety of educational institutions, and had varying needs and ages. Some participants lived independently and some lived with parents or in supported accommodation. The following three tables provide a breakdown of the number of participants, their gender and background.

Table 1: Breakdown of participants by gender (in first interview phase)

Total	Female	Male
18	10	8

Table 2: Breakdown of participants by gender (in second interview phase)

Total	Female	Male
13	9	4

Table 3: Participant information

Pseudonym	Gender	Age ⁴	Recruitment	Education ⁵	Living	Relationship Status ⁶
Adam	Male	19	Sports group	Special education	Lived with family	In a Relationship
Anna	Female	23	University	Mainstream education	Lived with flatmates	Single
Cara	Female	20	University	Mainstream education	Lived with flatmates	In a Relationship
Daisy	Female	25	Snowballing	Special education	Lived in supported housing	Single
Ella	Female	26	Advocacy group	Mainstream education	Lived alone	Single
Gavin	Male	18	University	Mainstream education	Lived with family	Single
Greg	Male	28	Sports group	Mainstream education	Lived with family	Single
Jack	Male	22	Sports group	Mainstream education	Lived with family	Single
Jamie	Male	19	Community group	Special education	Lived with family	Single
Jane	Female	25	Sports group	Special education	Lived with family	Single
Kate	Female	28	Sports group	Mainstream education	Lived alone	Single
Meg	Female	29	Research advert	Mainstream education	Lived alone	Single
Molly	Female	18	Sports group	Mainstream education	Lived with family	Single
Pete	Male	26	Sports group	Mainstream education	Lived with partner	In a Relationship
Ruby	Female	25	Arts group	Mainstream education	Lived with family	Single
Sam	Male	29	Advocacy group	Special education	Lived in supported housing	Single
Tim	Male	19	University	Mainstream education	Lived with flatmates	Single
Vicky	Female	26	Snowballing	Mainstream education	Lived in halls	Single

⁴ 'Age' refers to the participants' age at the beginning of the interview process.

⁵ 'Special education' refers to a special education school not located in a mainstream school but rather a segregated school (set out in the 1996 Education Act and 2001 SEN and Disability Act)

⁶ 'Relationship status' refers to the participants' status at the beginning of the interview process.

This discussion will now turn to the fieldwork process, more specifically recruitment and sample criteria, the pilot groups that I participated in, my own role in the research, the interviews themselves and finally ethical considerations.

4.3.2 The recruitment process

Sample criteria

The decision to interview disabled young people with physical impairments only, and not older people or people with learning disabilities, was crucial for the research design which aimed to explore disabled young people's experiences of everyday life in contemporary society who have grown up with rights based legislation already in place.⁷ This research question was embedded in my own experiences as a disabled young person and having, on the whole, good access to and inclusion in mainstream life. There have been well documented accounts of the struggles for equality and inclusion for older disabled people but limited focus on younger people in contemporary society as discussed in chapter two. I wanted to see if young disabled people felt included and what kind of barriers they might feel they faced from their own perspectives and experiences. I also wanted to see how this related to their bodies, how they felt about themselves and therefore the decision was taken to limit the study to physical impairments only in order to see how 'physical' inclusion or exclusion might be felt. This is not to suggest that people with learning disabilities do not face exclusion, but rather that physical impairment might be a key lens through which to understand embodiment.

I initially aimed to interview around twenty to thirty disabled young people with physical impairments between the ages of 18 and 26, as this is largely understood as the 'youth' category prior to 'adulthood' (Barry 2005). I focused on interviewing disabled people in this 'youth' category, as it is the point in a person's life where they are thinking about further education, employment, forming relationships and forming their political, social and sexual identities; it is the crossroads of adulthood. More importantly it is a group of disabled people

⁷ 'Rights based legislation' refers to the Disability Discrimination Act 1995 and the 2001 Special Educational Need and Disability Act.

who have not been appropriately covered in Disability Studies (Shakespeare et al. 1996), particularly in a society where young people have grown up with disability equality policy and legislation in place and a more general expectation that disabled people are far more integrated into the mainstream.

As recruitment progressed and through literature review, feedback from disability organisations and disabled young people it became clear that the age range was far too restrictive. This became apparent for a number of reasons. Firstly it was important to recognise that disabled people often ‘transition’ to ‘adulthood’ at a much later point than their able bodied peers and so widening the age range to thirty meant that these young people could be included in the research (Pascall & Hendey 2001). Youth is a term that has been constructed to define a stage of the life course that is not fixed or by any means definitive, not only are disabled young people transitioning to ‘adulthood’ at later points but research shows that their able bodied peers are failing to meet the same proposed ‘markers’ at the ‘appropriate’ time (Ridell 1998). Furthermore, the EU Youth category⁸ encompasses ages 15 - 29 and so it seemed more appropriate to include people over the age of 26.

Recruitment

The initial aim for recruitment of participants was to contact organisations for disabled people and, with their help, to send research information out to members of their organisations. However, it became apparent quite quickly that young disabled people did not tend to be members of these organisations. Furthermore, with the introduction of disability equality legislation, independent living and the demise of the ‘day centre’ for disabled people with physical impairments it became clear that disabled young people were so embedded in the mainstream that they were very hard to access through these routes. I decided to target the places that young people are involved in and therefore I aimed to get in touch with disability sports organisations, dance and arts groups, University student disability services and community based organisations. I also found that organisations for disabled people acted as gatekeepers often determining who would be a ‘good’ or ‘bad’ participant for

⁸ ‘Youth - Investing and Empowering’ EU Youth Report Brussels, 27 April 2009 SEC(2009)

the research. The role of gatekeepers through these organisations did lead me to question whether or not participants might have felt pressured into participating in the research if they thought it was associated with an organisation they were in contact with. Furthermore, through contact with advocacy groups and organisations for disabled people it became clear that lots of the young people they were in contact with had learning disabilities and not physical impairments. Similarly a lot of the community based organisations such as arts and dance organisations mostly in contact with people with learning disabilities. In any case organisations for disabled people proved not to be a very useful mechanism for recruitment but did lead me to consider these issues around recruitment.

Some participants were recruited through ‘snowballing’ which proved very helpful although did raise the question of anonymity; in order to overcome any potential identification of participants I made sure that all contact about the research was between me and each individual participant.

Sports groups proved to be a very useful source of recruitment; while ‘sport’ or ‘disability sport’ was not the main focus of the study it did mean that the participants recruited from sports clubs had diverse experiences and backgrounds in terms of education, employment, impairment, age and gender. This was crucial in forming a diverse group of participants with a range of experiences (see Table 3). Further and higher education institutions were incredibly helpful in the same respect, while education was not a key focus of the research recruiting participants from a range of educational institutions allowed me to recruit participants with diverse educational backgrounds and It became clear that experiences of education was important to participants’ experiences of inclusion.

One participant was recruited ‘by chance’ when I met her on the disabled platform at a gig and she asked to be involved in the research, while this was a surprise event it did highlight that this group are so dispersed and entrenched in the mainstream that recruitment strategies need to be broad. The process of recruitment also brought to the fore the realisation that young disabled people with physical impairments only were largely not members of advocacy groups, organisations for disabled people (apart from sports groups) and particularly those participants who had attended mainstream education had rarely met

another disabled person in their peer group and for the most part never socialised with other disabled people.

4.3.3 Ethical Issues

A fundamental part of the research process is ethics. Ethical approval was granted by the Faculty of Law, Business and Social Sciences⁹ ethics committee at the University of Glasgow, prior to any recruitment or fieldwork. Ethical issues are relevant to all aspects of the research process from the research design through to fieldwork, writing and the dissemination of knowledge.

Firstly, the research was primarily interested in all aspects of disabled young people's everyday lives and, particularly areas that had limited focus in literature such as sex and relationships, inclusion and participation and 'cuts' to welfare reform. As has been discussed already in this chapter, these topics are likely to be deemed 'sensitive'. In order to deal with this it was imperative that participants were fully aware of the purpose of the research and that they were under no obligation to answer any questions they did not feel comfortable with and further were under no obligation to continue with the interview if they did not want to. It was also crucial that I be able to 'read' where a participant might be uncomfortable with a question and not pursue it any further. I was also aware that in discussing 'sensitive' topics with participants that I should have a basic list of sources of information should they require it. I was very careful to let participants know that I was not an 'expert' and so would direct them to public information if they required it. This situation only arose twice, one participant was unsure about their rights in relation to welfare and social care and one participant was distressed at having no information about disability and family planning. In response I directed both participants to relevant government and charity based information rather than attempt to answer their queries myself.

The University of Glasgow's Faculty of Law, Business and Social Sciences' ethics committee highlighted some issues for consideration in regard to my application for ethical approval. The issues were all centred on 'informed consent' and

⁹ Now the School of Social and Political Sciences

ensuring that the participants were aware of potential questions they may be asked. The ethics committee also suggested that the criteria of 'physical disabilities' be placed in the project title. I overcame this issue by making informed consent explicit in the participant information sheet and to any organisations that I was in contact with. I dealt with the issues of informed consent by making sure that the information sheet was clear and easy to understand, that it covered all aspects of the research and indicated the kinds of questions that would be asked (Information sheet included as appendix 1). The information sheet included my contact details, such as telephone number and email address, the email details of both my supervisors and the head of subject area at the time. I made it clear to participants that they were invited to contact any of these people if they had any questions or queries. Consent was not assumed to be ongoing between the first and second interview. Participants signed two consent forms (see appendix 2), one for the first interview and another for the second interview. The consent form included gaining participants' consent for having the interviews recorded but were also given the option to not have it recorded. All participants were happy to consent to this.

Participants were made aware of the fact that the information they gave me would be used in my thesis and potential publications but that I would ensure anonymity through use of a pseudonym and ensure that their identity was kept private. I made sure that participants knew that consent forms with their real names, any identifying information, and any hard copy transcripts would be kept in a locked drawer that only I had access to. The recordings of interviews and transcripts were kept securely. When transcribing or writing about the participants all names were changed to a pseudonym and identifying details or information were changed to protect their identity. This made sure that participants' identities were protected without obscuring the data.

One key ethical issue arose during the interview process when it became clear to me that two of the participants knew one another and referred to one another during their interviews, this meant that there was the potential for me to be given information about a participant without their knowledge. In order to maintain anonymity and protect their identity I was unable to inform either participant, as such I moved the line of questions on to another topic and then took the decision not to interview these participants for a second time as this

was the best method to protect their identity. I did use the data from the first interviews but removed any mention of the other person so that their opinions and experiences could still be part of the research.

4.3.4 Doing the interviews

All of the data for this study was gathered through in-depth multiple semi-structured interviews with disabled young people aged between 18 and 30. This method allows for an understanding of participants' experiences, insights, opinions and lives from their own perspectives (Bryman 1988, 61). Fundamental to the research design and data collection was a commitment to the belief that participants were experts in their own lives (England 1994, Ramazanoglu & Holland 2002).

Group workshops and 'sensitising'

In preparation for data collection and in order to get an idea of what kind of things disabled young people might want to talk about I decided to attend some workshops for disabled young people run by an advocacy group for disabled people. They were very helpful in allowing me to participate and help in their group activities and gave me an opportunity to speak for 10 minutes about my proposed research. This experience proved to be invaluable to understanding what kinds of issues disabled young people were facing, what interested them and what kinds of things they felt were important in their lives.

Interviews

The majority of participants took part in two in-depth semi-structured interviews with around 4 to 6 months in between the two. There were some participants who were only interviewed once; two such participants were discussed in previous sections. Three other participants were only interviewed once due to their availability and their personal circumstances. Meeting participants for interviews was sometimes quite tricky; participants were free to choose a venue that they felt most comfortable with but due to my own access needs I also had to make sure that the venue was accessible for me too. For the most part this was not a problem and only proved to be an issue where

participants wanted to meet at their home and it was not accessible for me; in these instances the participants and I worked out together a venue that would be best for us both.

I met participants in a variety of venues. Not all of these were optimum settings for an interview but allowed the participant to feel more comfortable and in control. Interview settings included coffee shops, a sports centre, participants' homes, and my office where appropriate. In some cases the interview venue was not ideal. Coffee shops in particular proved to be noisy and distracting but felt informal and non-hierarchical. However, background noise could sometimes impact on the quality of the voice recording, furthermore public places were just that and I was concerned about participants feeling they could discuss their personal experiences. However none complained or seemed uncomfortable with this set up and I was most concerned with participants' comfort.

As mentioned above there were three times where participants brought support workers or, on one occasion, a family member to the interview. In this circumstance it was my youngest participant, Molly, and she felt more comfortable with a parent there although I was aware of how this might impact on the interview she gave. Towards the end of the interview Molly's dad offered up personal information about Molly without asking her, which she might not have chosen to tell me. I made sure that this was not included in the transcription or data. For the second interview Molly felt comfortable enough not to have a parent present. While I did not include comments made by Molly's dad in the transcript, like the two other participants removed from the research, It was harder to remove what had been said from the 'data' as arguably these comments had already shaped my understanding of the participants. This led me to look beyond data as a tangible transcript and helped me become aware of the complexities of data collection.

Reflexivity and an 'insider identity'

From the outset of the research I was aware that my age, gender and the fact that I am a disabled person would impact on the entire research process. There is a discussion of 'insider identity' in previous sections of this chapter. I found that there were positive and negative aspects to my being a disabled person.

Firstly it allowed participants to feel more comfortable and in some ways made it easier to form relationships and build rapport. Many participants expressed that they had never met another disabled person their age and part of their taking part was that they felt I would 'understand' what their experiences were. This proved to be both help and hindrance.

Due to my 'insider identity' and my position as a feminist researcher I felt it fundamental to data collection to employ both a reflexive and reciprocal approach in order to make transparent and visible how my role as a researcher might impact on the research. As Carol Thomas writes 'it is crucial to be reflexive, and to 'write the self' both experientially and intellectually, to make explicit the 'positionings' that inform the generation of new knowledge' (Thomas 1999, 69, see also Finlay 2002, 211). Further, as discussed previously, I made a commitment to reciprocity and felt uncomfortable at the idea that participants, in my peer group, would tell me personal stories about their lives and not reciprocate where appropriate. However, as mentioned, this could pose challenges where participants assumed that I knew what they meant or could corroborate experiences without their details or explanation; one participant was describing how it felt for a place to be accessible and said:

E: Well it's just so nice isn't it? You'll have experienced that yourself...

(Ella, 26)

This kind of remark was not uncommon and it meant that I had to be conscious to encourage participants to explain what they meant for the purposes of the research. However, participants were often keen to know if I had had similar experiences as them as in most cases I was the first disabled person of their age that they had had a conversation with.

Some participants were also keen to give me advice about various issues. One participant asked if I had a car through the 'Motability' car hire scheme, this participant was very encouraging of this and offered to help me apply for one. Subsequently I did apply, albeit without this participant's help. However it demonstrates the sharing of experience that was fundamental to these interviews and unsettles the notion of researcher as 'expert'. What I found is

that the interview process had a significant impact on me; prior to these interview I, also, had limited experience of being around disabled people in my age group and there was mutual satisfaction gained from being able to talk about the peculiarities of being a disabled person. This helped me greatly, it allowed participants to feel comfortable and in control and furthermore served to break down some of the hierarchical relationships present in the researcher-participant relationship (England 1994, 243, see also Ramazanoglu 2002, Barnes & Mercer 1997).

Semi-structured interviewing

The topic guide was developed, in part, through my participation in the group workshops previously discussed. The topic guide for the first phase of interviewing was developed and then adapted after the first two interviews in order to include areas of discussion that participants showed particular interest in, these included questions around intimate relationships in particular (please see appendix five for topic guide for first interviews). The topic guide for the second phase of interviewing was developed after transcription and basic coding of the first set of interviews (please see appendix six for topic guide for second interviews). This worked well as it meant that I could explore key areas with participants and it also meant the new ideas and themes could emerge during the interviews and could then be explored further in subsequent interviews.

The topic guides consisted of broad thematic areas of enquiry such as what participants enjoy doing, are relationships important to them and how do they feel about rights to support, for example. Each of these broad thematic questions also included a number of prompts that could be utilised if needed. In keeping with Fylan's (2005, 65) description of semi-structured interviewing, the interviews took the form of loose conversations and topics did change from participant to participant which allowed them to express their own personal narratives. This meant that while the interviews were semi-structured, it allowed me to explore other themes, topics and ideas as they arose. Dunn (2005) maintains that interviewing exists on a continuum with structured and unstructured interviewing at one end and semi-structured interviewing somewhere in the middle. He argues that semi-structured interviews can be more or less structured; the interviewing technique I employed was at the

unstructured end of semi-structured interviewing but still involved the use of a topic guide to aid in guiding the interviews towards key areas of enquiry. Dunn argues that it is this use of a topic guide or interview schedule, however loosely employed, that qualifies an interview as semi-structured rather than unstructured (Dunn 2005, 61). Similarly, the interviews were entered into with particular areas of enquiry around citizenship and so this focus on citizenship and embodiment shaped the content of the interviews. However, Dunn (2005, 81) helpfully points out that each interview is an individual social interaction that requires individual preparation and there are 'no hard and fast rules' that can be followed (See also Valentine 2005).

The aim of the interviews was not to test a hypothesis but to find out about participants' experiences and so differing opinions and experiences across participants was important and encouraged. Interviews proved to be the most interesting and insightful part of the research. The participants were generous with their time and this resulted in rich data that resulted in key insights into citizenship and the body. The timing of the interviews meant that the data captured a point in time where significant social and economic change could impact on participants making it a unique representation of experiences. The topic guide was, for the most part, successful although I had to be aware of questions that participants were not interested in; this tended to be questions around access to buildings and legislation. However, this allowed me to really hone in on what was important to participants. It became clear early on, for example, that participants really wanted to talk about their feelings towards sex and relationships and people's attitudes towards them and so more prompts around this topic were added to the topic guide. While they did not want to discuss access to public spaces and legislation it became apparent throughout the interviews that these impacted their everyday experiences.

There were times where interviews did not go entirely well and where I felt uncomfortable. There was one point where I felt that my gender and age coupled with the kinds of questions I was asking initiated some responses I was not entirely comfortable with. The following quote was in response to a question about whether participants found that sexual health clinics were accessible:

...and I usually find that the ones that ask that are the ones that want tae know for thersels you know 'you're no askin' outta curiosity sweetheart you're asking cause ye want tae go back tae mine efter' (laughs)

(Adam, 19)

While this comment was not directed at me it did make me feel uncomfortable, similarly this participant offered some aggressive responses to questions and expressed some derogatory views towards women and ethnic minorities.

I had a small number of participants who had speech impairments; I had to think carefully about how to make the interviews inclusive and accessible for them. I made sure that I gave these interviews enough time to make sure participants were comfortable and used closed questions where appropriate. I also asked participants if they would mind if I repeated some of the things they said to make sure I had heard them properly. Closed questioning is often critiqued for its potential to lead participants' answers, however in these circumstances it was the best way to include these participants in the interview process. I was conscious of being sensitive to these participants' needs as talking was a tiring process for them and certainly as they became more tired their speech became less fluent and thus their answers became shorter as they became frustrated. In order to overcome this I gave these participants the opportunity to type and email their answers to me if they felt they wanted to include anything they could not in the face-to-face interview, although none decided to do this.

The interviewing process was immeasurably useful to the research process and was an enjoyable part of the research. I found that participants were keen to talk and interviews were long and rich. It seemed that for the most part participants enjoyed the interviews too. Interviews lasted between 45minutes and 3hours.

4.4 Data Analysis

The following section of the chapters turns to the management of data, the organisation of data and the transcription process. This section will then go on to explore the analytical approach taken when the data was examined. Finally,

this section will look at the ‘analysing’ the body and will reflect on how the body was approached throughout the research process.

4.4.1 Managing the data: some practicalities

The fieldwork undertaken resulted in a vast amount of data and this had to be practically organised and managed. All transcription of data was done by me using transcription software, which had considerable benefits. Transcribing took up a considerable amount of time. The recordings from the first set of interviews were transcribed, as much as possible, directly after the interview. Making sure that transcription was done straight after the interview meant that the conversations were still clear and fresh in my mind. It meant that I could remember emphasis, facial expression, and the participants’ body language in different phases of the interview. This was only possible because the transcriptions were done by me alone. Ensuring that the first set of interviews were transcribed before the second interviews were undertaken meant that I could see what ‘worked’ in interviews and what did not. It also gave me an opportunity to evaluate my interview technique and, more fundamentally, gain insight into what to follow up in subsequent interviews. .

The exercise of transcribing is fundamental to the initial stages of analysis which is an iterative process in itself. Furthermore it allowed me to question the ethical consequences of transcription itself. I had taken the decision to transcribe the narrative of participants as it was heard; I included pauses, swearing, slang, and dialect where possible. This is fundamental to giving as accurate a representation as possible of the participant’s stories. The way in which participants have chosen to present their experiences and narrative are intrinsic to the narratives and experiences themselves. Speech is itself an embodied practice and so an appreciation of how that speech is conveyed to me, as the researcher, is essential in an appreciation of the embodied experience of the interview itself.

Where a participant has a speech or communication impairment it was at times difficult to transcribe, the process was often slower and took more time in order to give an accurate transcription. It was essential that these participants be included in the research as often people with communication impairments are

constructed as inarticulate and it is fundamental that any research into disabled people challenges these constructions.

What became evident is that the very process of transcription has the capacity to immediately change the text or narrative from its original context and meaning. The process of punctuating continuous speech, the adding of emphasis and inflection all serve to alter the shape and meaning of the text. It is the primary stage of the process of interpretation and it is the point at which the interpretation of the researcher becomes evident:

At best you can be as aware as possible that interpretation is your exercise of power, that your decisions have consequences, and that you are accountable for your conclusions. Simple decisions over how to categorize, what to include and what to exclude also carry theoretical, political and ethical implications

(Ramazanoglu & Holland 2002,161).

All recordings of interviews were transcribed into word documents and then moved into Nvivo9, qualitative transcription software. Nvivo allowed me to store the data securely and to organise it into different themes, headings, codes/nodes so that the data could be viewed and compared easily. This was particularly useful given the large quantity of data collected.

4.4.2 Analytical approach and framework

Critical analysis of the collected data was the next phase of the research process. The transcription process allowed me to begin to think about the emergent themes; however these needed to be organised formally by means of 'coding'. The data were reviewed continuously prior to the second stage of interviewing meaning that I was able to refine questions and hone in on areas of particular interest to participants.

I used a broadly grounded theory approach in this study through use of the constant comparative method outlined by Glaser (Glaser 1965) in order for the data generated to inform the theoretical outcomes of the research (Glaser &

Strauss 1967). Although grounded theory has come under attack, it remains that grounded theory is the approach used by a vast amount of qualitative researchers as it supports the view that theories and themes should be allowed to emerge through data and the notion that experience generates knowledge (Silverman 1993). Grounded theory is often understood as a 'a set of principles and practices, not as prescriptions or packages' (Charmaz 2006,9), thereby grounded theory provides the researcher with a toolbox to be utilized throughout the research process.

Grounded theory was originally framed by Glaser & Strauss (1967). It rejected positivist approaches to research and moved towards a process of induction that privileged data (Glaser & Strauss 1967). This tied in with the emancipatory research principles outlined earlier in the chapter. Grounded theory challenged the tradition of 'hypothesis testing' and instead allowed data to be seen as significant in developing and generating theory (Strauss & Corbin 1998). The focus, in grounded theory, is on 'process' and 'interaction' meaning that all participants included in the research will have loosely experienced the same process (for example all participants have a physical impairment). However, there has been significant debate over what constitutes grounded theory (Creswell 2013) which has meant that this analytical approach has been termed 'broadly' grounded theory.

The data were continuously read and reread throughout the process of collection and analysis and so the emergence of broad categories meant that the data could be grouped meaningfully into themes (Charmaz 2006). Initially I came to the process of coding expecting broad themes such as 'inclusion' and 'exclusion' for example. I went on to form broad categories or themes and looked for commonality across transcripts. As Charmaz (2006) highlights, the researcher influences the research process. The study of literature and relevant texts was always bound to inform and influence the topics developed in the topic guide. It was important to be aware of this to ensure that themes could emerge from the data rather than literature and theory informing my analysis completely. In line with processes of coding in grounded theory (Charmaz 2006) a loose coding framework was established which involved a broad analysis of a sample of interviews in order to look for emergent themes, whilst also using emergent coding thereafter.

It could also be argued that ‘thematic analysis’ was used as a tool for data analysis. While traditionally thematic analysis has been seen to be a constitutive part of analytical methods such as grounded theory there are those qualitative researchers who argue for its recognition as an analytical method in its own right (Braun & Clarke 2006). Braun & Clarke (2006) argue that due to the ‘theoretical freedom’ of thematic analysis it should be seen as a flexible research tool that yields rich analysis of data. Thematic analysis is the identification of patterns in data and allows data to be interpreted in a rich way (Braun & Clarke 2006, 73). Again, this research claims a ‘broad’ grounded theory approach as it also employs a thematic analysis of the data without subscribing to a ‘fully worked-up grounded-theory analysis’ (Braun & Clarke 2006, 81) which is arguably unattainable due to the various directions grounded theory has taken since its emergence in the 1960s (Creswell 2013).

As analysis continued through coding it became clear that the links formed between my data and pre-existing research and literature which allowed me to challenge and evaluate my initial insights and analyses. Through a process of constant revisiting and immersion I eventually felt confident that I had reached a point where the data was saturated and no new themes or ideas were emerging. Analysis, however, did not stop here. The writing process allowed me to refine and expand on interpretations and analyses as I had to engage with and consider the relationships between themes.

4.4.3 Analytical tools: researching the body/embodiment

The body was always a key focus of the research and had to be treated throughout the data collection and data analysis process quite carefully. There is very limited empirical research on the body. As Watson notes, grounded theory proves to be a useful tool in analysing the body as it allows personal experience to be at the fore of data analysis (Watson 1998, 166). Grounded theory allowed the body to emerge without participants having to specifically refer to their bodies.

Not only have there been limited examples of empirical work that focuses on people discussing their bodies but as Zola (1991, 4) points out there are a number of challenges in asking disabled people to discuss their bodies. It can be

uncomfortable, distressing and disempowering as often disabled people are required, in their interactions with medical health professionals, social care and welfare providers, to discuss what's 'wrong' with their bodies. Therefore I took the decision to not explicitly ask participants about their bodies but rather to see how the body emerged as they were talking to me about their everyday activities and experiences. This proved to be most useful as I got a sense of embodied activity and participants' feelings about their selves without having to ask them to reflect on their bodies explicitly which could be uncomfortable and exposing as disabled people have been continuously subject to the medical gaze. I also felt that as young people, discussing the body is a particularly difficult activity. Cunningham-Burley & Backett-Milburn (1998,145) describe this challenge neatly when they suggest that:

Accessing the body empirically, through interviews, demands the labelling of something truly intimate - 'bringing the body back in', in the interview situation is almost like asking someone to get undressed in front of you.

Furthermore, it became apparent that people do not talk about their bodies from an embodied perspective meaning that people often refer to their bodies as something external to themselves e.g. 'my body' rather than 'me'. People objectify their bodies in everyday life and participants referred to their bodies in these ways too almost always as a tool to refer to their physical selves (Cunningham-Burley & Backett Milburn 1998). Similarly it is necessary as a heuristic tool to separate the body out from the self in academic writing and theorising the body. Because this research takes an embodied perspective it maintains that all activities are embodied activities everyone both is and has a body simultaneously (Csordas 1994, Merleau-Ponty 1962, Mol & Law 2004, Nettleton & Watson 1998).

4.5 Conclusion

This chapter has sought to provide an outline of the methods used throughout this project and to make transparent the research process. The research is grounded in the social model of disability and in the principles of emancipatory

research whilst also being committed to moving beyond it, this informed the way the data was collected and analysed. The disabled young people who agreed to participate have driven the research and this was bolstered through the use of qualitative methods, an appreciation and application of feminist emancipatory principles and methodologies such as reflexivity and reciprocity and the use of grounded theory.

The chapter has aimed to explore how my role as researcher and as a disabled person deeply shaped and impacted on the data that were collected and how the data were analysed. The chapter has also considered my commitment to represent the exclusion that disabled people face and the need to seek equality for disabled people. This political position shaped the choice of research method, the methodology and also sought to recognise key critiques of the limitations of the social model, namely its limited focus into the lived, embodied experiences of disabled people.

This chapter has also focused on some ethical issues in the field as well as ethical considerations around sensitive topics and vulnerable people. My approach to this was embedded in the idea that all people are vulnerable at times in their lives and constructing *all* disabled people as vulnerable can be potentially damaging, homogenising and marginalising. I aimed to address sensitive topics through good research practice and transparency. This chapter also discussed some of the analytical challenges met during the research process, such as analysing the body, and has sought to unpack some of these challenges in order to 'validate' the analytical process.

This chapter concludes this section of the thesis. The thesis now goes on to focus on the data itself and to present the findings of the research. The following chapters are presented thematically. The following chapter and first data chapter looks at 'sameness' and 'difference' as key themes that emerged when participants discussed their feelings about themselves in relation to others. This is explored in relation to psycho-emotional disablism.

Chapter 5. Feeling the same, managing difference

As I began the process of analysing the data, sameness and difference emerged as key themes. For many of the participants there was an everyday negotiation between feeling the same as their non-disabled peers whilst also being reminded of difference by others, themselves and as a result of ‘impairment effects’ (Thomas 1999). It was this negotiation that was at the foreground of a, sometimes, precarious feeling of belonging and inclusion. This chapter will focus on participants’ feelings about themselves and their identities, how these feelings are constructed and how they perceive themselves in relation to their everyday lives, their bodies and everyday citizenship.

It has been pointed out that attention needs to be paid to more dimensions of restrictions on disabled people than only material or structural (Thomas 1999, 46). Thomas, as discussed in chapter two, critically assesses the way in which ‘socially imposed restrictions’ have been constructed and argues that the focus on these restrictions should not be limited to the process of *doing* or what we are prevented from *doing* but also on what we are prevented from *being* and our feelings towards ourselves, arguing that the relationship between doing and being is ‘interactive and compounding’ (Thomas 1999, 47). Psycho-emotional disablism and ‘barriers to being’ emerged as key concepts in understanding how the participants positioned themselves in their wider life-worlds. This was also underpinned by the notion that participants’ feelings about themselves were constructed in relation to others. This notion of intersubjectivity was often bound up in relationships with friends, families, lovers, strangers, clothes, television programmes and so on (Toren 1999). Feeling the ‘same’ or feeling ‘equal’ was often dependent on the co-construction of identity along with others through a process of recognition. It follows, then, that a lack of ‘recognition’ had psycho-emotional impacts on participants and their construction of self and personhood (Thomas 1999, Reeve 2012).

5.1 Co-constructing 'sameness'

Sameness and fitting in, or belonging, emerged as key themes throughout all aspects of the data. Feeling the same did not just relate to participants' feelings about themselves in relation to others but also in relation to wider ideas about inclusion and participation and whether they felt valued. The extent to which participants felt the same was influenced by a number of factors including family members, relationships with friends, intimate relationships and the clothes they wore (and as will be explored in the next chapter, representations of disabled people in popular culture). This section explores where participants felt the same and subsequently felt included in everyday social life.

Participants came from diverse backgrounds with varied living arrangements and experiences, as can be seen in Table two (chapter four). Most of the participants had attended mainstream education (13), lived out with their parents' or family home (10) and were single (15) at the time of the first interview. Two of the participants lived in supported accommodation. Most of the participants had no disabled friends and did not attend any groups or clubs for disabled people. A small number of participants maintained any contact or participation with organisations for disabled people and this was due to having attended special education or living in supported accommodation. A small number of participants were in work at time of the interviews. Most were in some form of further or higher education and the majority of all of their lives were spent in mainstream society and usually with non-disabled peers. Participants went to pubs, student unions, nightclubs, and various other mainstream social activities. These high levels of integration and inclusion were precisely what made the lines between 'sameness' and 'difference' so blurred and complicated. Heuristically it was necessary to separate this out. However as will be seen in this chapter, and subsequent chapters, it was usually a careful management of both sameness and difference at the same time.

5.1.1 Family

Families, and in particular parents, were one of the key sources of engendering and formulating feelings of sameness for participants. Participants talked about

their parents in particular as establishing positive feelings about their selves and from a young age helped them reject the idea that they were any different to anyone else. Families were crucial for participants in creating the framework for self-esteem and positive feelings about their bodies. Creating this sense of 'sameness' also formulated a sense of equality, normalcy and entitlement to the same levels of participation as 'everyone else':

If I was upset about how I looked or my legs or whatever, my mum would say 'right you have 5 minutes to cry about it and that's it!' and that helped me to see that I was never going to be treated any different by them. And I wasn't.

(Kate, 28)

Kate's parents established a framework of equal treatment for her and were crucial in formulating good ideas about herself. The fact that she was never treated any differently by her parents meant that she expected to be treated the same elsewhere in her life and this was reaffirmed by her parents at other times:

And it was always when we were on holiday and stuff like that my mum and dad were like 'make friends' and so I made friends and I always had a good circle of friends and never had any problems that way.

(Kate, 28)

As Kate demonstrates above, parents could be instrumental in helping participants build relationships around them and have inclusive friendships. Decisions that parents make about how to treat their children can have far reaching effects on how participants saw themselves later in life. Meg's parents, like Kate's, established very early on that Meg was exactly the same as everyone else regardless of her physicality:

My mum and dad basically put me on the list [for a mainstream school in her area] from the beginning. Before that I went to nursery and that was a mainstream nursery... like I was born with this disability so I have never known

anything different and when I was little my mum and dad were like 'well you can just be the same as everyone else thanks'.

(Meg, 29)

Meg made it clear that because she was born with her impairment she never knew anything else, and subsequently she felt that she had always 'been the same as everyone else' because her parents decided that she was. Meg's and Kate's sense of personhood was inextricably bound to their relationships with their parents and learning from their parents, through participation, that they were the same as their non-disabled peers (Evans 2006). It is this inter-subjective process of building personhood and selfhood that informed how participants constructed their sense of self and their position in wider social situations. The psycho-emotional impact of these affirmations was one of self-esteem and the expectation of equality and inclusion. Ruby described how she felt included and how this was a result of her relationships with her friends and family:

I probably...a lot of it is to do with my friends and they're really good at helping me out and they get quite annoyed about things as well. I don't feel excluded because my friends and family...I just don't feel excluded.

(Ruby, 25)

When discussing friends and family, participants did not feel excluded and this had the capacity to extend beyond these relationships to build ideas of 'sameness' and inclusion in other areas of social life. Meg talked about her transition from primary into secondary and her secondary school not being accessible:

And when I was about to go in to secondary school there was a problem because there was a lot of the classes upstairs and I actually was maybe going to end up going to the High School A instead and I had an interview with the high school and did the tests and stuff and I got in and they [parents] were saying to High School B like if you don't sort out this lift problem then we're gonna take her to another school but they managed to get the lifts in so I stayed.

(Meg, 29)

Meg's parents insisted that the school be made accessible for her or she'd leave, this reinforced the idea that not only is Meg the same but that institutions have a duty to include her and become accessible to her to facilitate that 'sameness'. It meant that Meg got to move on to the same secondary school as her friends, she was able to be in the same spaces as the friends she had made at primary school and that she felt like she fitted in and belonged there. Meg's parents established that Meg had the right to insist that things be made accessible to her, that she had the right to participate and be included. Positive psycho-emotional effects had the capacity to encourage self-esteem and feelings of inclusion.

5.1.2 Friends and 'others'

Friends were one of the other key relationships where participants felt the same and included. Almost every participant talked about friends at some point and referred to their friends as being a source of inclusion and sameness. One of the key ways that friends promoted these feelings was through making sure participants were included even when met with barriers or access issues. When asked if she felt included in general, Ella answered:

Yes, 100% yes. Sometimes if I can't go to something my friends will change it which I'm sure you'll have found as well. So I absolutely do feel included. I do.

(Ella, 26)

This example shows that even in the face of exclusion friends had the capacity to make participants feel included by changing plans willingly. Friends also

helped build participants' feelings of inclusion by showing their disagreement with places that were inaccessible. Friends were also able to invalidate or remove feelings of difference or psycho-emotional disablism, at times:

I have to say I think from the point of view of my friends I have a really good wide social circle and I got on with everyone on my course and I never ever had any problems since I started uni. I remember one night being on a night out with one of my friends and some guy or another, this guy who I vaguely knew but he didn't know me. Anyway this guy he made a comment about my walking. Twice it happened, one was like a random stranger and my friend who is the nicest guy in the whole world punched him and the other guy another time had this guy up against the wall and said 'if you ever say anything like that again'...

(Kate, 28)

Friends had the capacity to invalidate discrimination or disablist comments by emphasising and reinforcing their invalidity and by actively taking a stance against them. In Kate's example it made her feel a valid part of her wider friendship group, it allowed her to 'brush off' the negative impact that discriminatory experiences might have on her. Kate went on to talk about her feelings about herself as a disabled person and did not feel she related to a 'disabled identity' and this was directly constructed in conjunction with her friends' perceptions of her:

P: Do you feel that you see yourself as a disabled person?

K: No probably not, actually after we talked [in the first interview] I spoke to my friends and asked them and they said 'no not at all'.

(Kate, 28)

Inter-subjective relationships were probably one of the most important ways that participants formulated perceptions of themselves and their positive feelings about themselves and could help participants overcome insecurities or fears related to their impairments. As will be discussed in the next section, intimate relationships proved to be one of the key areas where participants felt

that they were not included and one of the aspects of their lives they felt was underpinned by 'difference:

I talk to my friends about it a lot and they just said that you've got to live your life basically and yeah you might get hurt but not anymore than someone who doesn't have a disability might get hurt. I always thought that If I was seeing someone and they ended it with me because of something to do with my health I just thought that that's going to be really hurtful but my friends you know they could be going out with someone who ends it with them for some reason and they're still going to be hurt so you're not any different from anybody else.

(Ruby, 25)

As Ruby's example shows, however, friends are active in changing her feelings towards her insecurities and perceptions around being disabled and having a relationship. Ruby equates having a relationship with 'good health' and Ruby's friends emphasized that relationships are precarious with or without a disability and that she is no different from them. The recognition that Ruby is 'not any different from anybody else' promotes ideas that she has a right to have or is deserving of a relationship. Friends also have the capacity to shape and challenge the psycho-emotional impact of impairment effects (Thomas 1999) to produce a new narrative of who is deserving of a relationship which ultimately formed ideas of 'sameness' and inclusion. Friends and family act as the promoters of ideas of sameness, at times. However, unlike family, relationships with friends, intimate relationships and others could also serve to highlight difference and participants often had to manage the two simultaneously and it is this that the chapter will now examine.

5.2 Managing difference in everyday life

As discussed above, participants spoke significantly of how they felt the same as everybody else and how this feeling of sameness was co-constructed through relationships with, primarily, family and friends. Sameness tended to be affirmed through an invalidation of difference and this could be based around the invalidation or acceptance of physical difference, the abjection of discrimination and also inclusion and adaption by friends. However, while this

had a forceful positive effect on many participants there were times where 'feeling the same' was overwhelmed by being reminded of or confronted with difference. Managing difference was, in most cases, related to feelings about the body and this was often highlighted through intimate relationships. A majority of participants talked about relationships as being a fundamental area where they felt difference to non-disabled peers and often this could not be overcome by friends and families' attempts to create feelings of 'sameness'. In looking at participants' experiences of feeling different and managing difference, this section will consider the role of intimate partners, strangers and the socio-structural impacts of compounding feelings of difference before discussing how some participants dealt with difference through resisting, often imagined, pre-conceived labels and others constructed identities that they felt were assumed by others.

5.2.1 Difference, worth and intimate relationships

Many of the participants' identities and feelings about their selves and bodies were in a time of transition. There is a strong body of research to suggest that youth is certainly a complicated time; young people have to form their sense of selves, all the while managing their identity and expectations from their parents, teachers and peer groups. It is an important point in developing their social, political and sexual identities and it is argued that this can be a complicated time for any young person (Barry 2005, Griffin 1997). Disabled young people are, at the same time, going through this process. However, disabled young people have extra imposed restrictions, are managing impairments and dealing with either low or in some cases no expectations from parents, teachers, employers and society in general (Shakespeare 1996, Morris 2002a, 2002b). Disability and impairment comes to the fore through negative experiences with others be that friends, partners, employers or non-disabled others. Feeling secure in oneself is fragile and contingent even when more general feelings about the self are positive, negative feelings become bound to disability.

P: Do you feel discriminated against?

I think a lot of the time, because I have such a positive attitude about my disability... see that kind of stops that because people are less likely to discriminate if you just get on with it. I forget I'm disabled so if I forget then there's no way that they can't.

(Anna, 23)

As discussed in the previous section, Anna's general feelings about herself and being disabled were quite positive and she felt that this positivity acted in opposition to discrimination from others. Crucially, here, sameness is linked to 'forgetting' about disability and on an everyday basis and this is how most participants felt. However when confronted with relationships, difference and low self-esteem came to the fore:

Relationships with guys, that is the major thing with me being disabled. I don't feel like I'm worthy. I never have done, so if somebody does like me I think there's something wrong because why would he? I don't understand why anybody of the opposite sex would like me, I don't know why and my friends can tell me that they think I'm gorgeous and I've got a great personality they can tell me that all the time but I won't believe it. It doesn't matter to me because I don't see, because of my disability, how a guy could like me...I just always think that a guy wouldn't want to have me on his arm showing me off or taking me home to his mum cause I'm not the same. I'm different and I'm not worthy of it basically.

(Anna, 23)

Here it can be seen that support, encouragement and promotion of 'sameness' by friends were not enough to overcome Anna's negative feelings towards her body or the way that she looks. However, this is not an uncommon experience or feeling for any young woman to have. Young people often have insecurities over their bodies; women in particular are under specific pressures about image and physical appearance, particularly in relationships and as Manderson writes that 'women especially incorporate in their self-perception the gaze of others,

assessing and maintaining self-awareness of their physical appearance through such refraction' (Manderson 2011, 74 see also Manderson 2005). However, Anna was describing something over and above this. Anna did not feel worthy of a relationship because she is disabled. Participants often talked about the lack of representation of disabled people in popular media and their lack of interaction with other disabled people. Anna's feeling 'unworthy' was a form of indirect psycho-emotional disablism (Reeve 2012) as she was responding to a legacy of disabled people's exclusion from being seen as capable of relationships (Shakespeare et al. 1996, Sanders 2010) and also the construction of disabled people's bodies as inferior. Furthermore Anna wanted to be 'shown off' or for a guy to have her 'on his arm' exemplifying a particular gendered ideal of women as trophy or object to be shown off which, for her, was commensurate with ideas about what a beautiful or attractive body was or what it means to be a woman. As mentioned above, disability exacerbated the insecurities that young people often feel over their bodies:

But in past [relationships] I have maybe felt that the person is maybe too good for me and because of the disability. It's like when you're young you have insecurities anyway and you're own self esteem issues and that kind of thing but the disability is one thing you latch on to and you think well there's no way I'm as good as this person or there's no way that I'm equal to them and they're better than me because of this. I think it's something you do to yourself. I don't think anyone is really bad inherently, once you do that then you give that person all the power because they have this dynamic where they can think they can walk all over you.

(Cara, 19)

In times of insecurity or uncertainty impairment becomes the yard stick against which this is measured and insecurity becomes corporeal insecurity whereby the body becomes the site of blame and inadequacy. Cara explained that in interactions with others, in intimate relationships in particular, feeling insecure could shift the perceived balance of power to the other person in the relationship. Furthermore, for Cara, negative feelings about herself, her body and feeling unequal created unequal relationships. Here we can see the impact of psycho-emotional disablism that has become ingrained in Cara's narrative.

Further, it illustrates the fact that lots of young women do face insecurities about their bodies, partners, and relationships for example. Critically, it is disability that is seen as the key factor.

Intimate relationships can prove to be situations where feelings about the self become most uncertain. Thomas' psycho-emotional dimensions and 'barriers to being' are particularly salient in this context whereby a legacy of exclusion from sexual spheres have left disabled young people feeling unworthy and undeserving of sex and intimacy which erects barriers to being sexual persons and feeling attractive. While Cara shows how participants reproduced ideas about unworthy or unequal bodies this could also be constructed by others:

I think it does affect me where relationships are concerned and I mean intimate relationships. I have issues over... like does the guy really like me cause of me? I have actually had cases where a guy has spent the night with me 'cause he wanted to have sex with a girl in a wheelchair and he actually bluntly told me that the next day. I laughed 'cause I didn't believe him and I said 'well you know where the door is and that's really sick' and I said that to him.

(Ella, 26).

Participants often worried that potential lovers pursued them because they might be perceived as 'desperate' or 'easy' and in this case, for Ella, she was pursued as a novelty or fetish to be tried and tested in order to satisfy a curiosity. These actions posited Ella as different in the sense that she was constructed as apart from or out with a 'normal' sexual experience - Ella felt that she was constructed as a freak and this was understandably oppressive to her (Gowland 2002, Shakespeare et al.1996). This harmed Ella's sense of self in a number of ways, not only did this experience have a lasting negative impact on her feelings about relationships and her capacity to have them, but Ella did not consent to having sex with someone on the basis that she was a sexual other or outsider, as she was only informed of this the next morning as the person made a point of telling her why he had sex with her. Whilst Cara explained that disability was the one thing you latched onto, it was not Ella who latched onto disability but the person she had the interaction with. Negative experiences like this undermined and harmed a person's sense of self and amplified feelings of

‘difference’. This experience imposed both ‘barriers to being’ and ‘barriers to doing’ (Thomas 1999) as it directly impacted Ella’s sense of self but also her confidence in having relationships in the future. It must be noted that, while this experience did have a negative impact on Ella and made her feel different, being made to feel the same and equal by friends and family meant that Ella felt like sex was open to her in the first place and furthermore that she was able to say ‘well you know where the door is’. This exemplifies the complexity of experience; that sameness and difference are not distinct or mutually exclusive ideas and further that (although useful as a heuristic device) direct and indirect psycho-emotional disablism comingle.

The practicalities of having an impairment and the prevalence of the medical gaze on the disabled body often meant that participants became aware of ‘difference’ in intimate settings or when they had to fulfill particular intimate roles:

I think you become more aware of your body in intimate relationships because of all the different procedures you have had in your life. Depending on your disability you do become more aware of your body and you know that your body is less mobile and you know that your body...you know you have to get used to your body in a different format I think. I think you are more aware when you’re in a relationship and there are times where you can’t do everything and because you have limitations on you already. There becomes a trust factor as well because an able-bodied lass can just do all the positions if you like and you can’t and you do wonder if the guy will stray.

(Ella, 26)

Ella positioned herself in opposition to an imagined non-disabled female other who can ‘just do all the positions’ and here difference was founded on negative feelings about the body in intimate situations. Ella maintained that a history of medical procedures had made her much more aware of her body and what she can and cannot do. In this view as the body has a history of being pathologised, it is then difficult to construct the body and self as a sexual body and self and as such ‘the guy will stray’. Here it can be seen that both direct and indirect psycho-emotional disablism (Reeve 2012) and ‘impairment effects’ (Thomas

1999) are simultaneously at play as participants experienced real difficulty in performing some physical roles but furthermore an awareness of 'all the different procedures' is juxtaposed with intimate relationships which, for Ella, had a lasting effect in 'being' a sexual person and certainly in constructing herself as someone who was less desirable than non-disabled women. Feeling different was constructed in opposition to a more valuable, worthy and, crucially, imagined non-disabled other. This example can be understood alongside a discourse of sex as an able-bodied activity undertaken by a functional, idealized and attractive body that all serve to disable and set disabled people apart from sexual citizenship (Priestly 2003). This will be discussed further in chapter six in relation to sexuality, citizenship and the body.

Male experiences of 'difference' in intimate settings

It was clear, while gathering the data, that talking about the body and about relationships in particular was gendered. The women who were interviewed tended to be much more open and keen to talk about intimate situations and no doubt my own gender played a significant role in this. The men who were interviewed spoke less openly about these experiences, however where they did discuss this it was through a similar lens of 'managing difference'. Men, similarly, discussed feeling and being 'normal' in everyday situations but this sense of sameness and normality became precarious with the prospect of intimate sexual relationships. Greg exemplified the fragility in negotiating sameness and difference at the same time as he discussed being 'normal' apart from using a wheelchair, which, epistemologically, he asserted as making him different:

You're a normal person and the only difference is you're in a chair; there isn't anything else that's different apart from the chair.

(Greg, 28)

Like Ella, the experience of medical procedures and issues was instrumental in constructing, for Greg, his body in opposition to intimate relationships. Greg constructed himself as burdensome and did not want to be someone who was

‘taken care of’. He was keen to make sure that he had ‘sorted out’ his issues before considering a relationship:

I don’t know because I’ve avoided it or I’ve avoided meeting people like that cause I have had a lot of medical problems and having a relationship is just adding on to another problem and I don’t want to burden anyone with my problems.

(Greg, 28)

Like Greg, the men who were interviewed were particularly aware of being a burden or seen as weak. Furthermore Greg also felt that he was attractive to women who wanted to ‘mother’ him which further expressed his perceived relationship between impairment, weakness and being infantilised. Greg associated the male body with strength and masculinity rather than ‘burdensome’, similar to Anna’s construction of the female body as being ‘shown off’ and for both disability made Greg feel weak and Anna feel unworthy of being on a man’s arm or approved by someone’s mum. Both Greg and Anna highlight the highly gendered ways in which disability comes to the fore as a site of difference in relation to intimacy.

Greg’s feelings tie in with discourses of disabled people being infantilised in matters of sexuality and further relates to structural inequalities around disability and sexuality:

Well I’ve been out and there’s been older ladies trying to get your attention and so to some people don’t see a chair they just see an attractive young man but I think some of them think ‘oh he can be mothered by me’.

(Greg, 28)

The impact of mainstream ideas about disability and sex, and the fact that Greg felt that older women were attracted to him because they wanted to mother him shows that Greg pitted relationships and disability in opposition to one another. For participants this was, at times, linked to a lack of visibility of

disabled role models, disabled people in relationships or disability and sexuality in mainstream culture (as will be discussed further in the following chapter).

5.2.2 Resisting Identities

As previously discussed, for the most part, this group had spent little time, if any, with other disabled people and in many cases had never met another disabled person. They lacked a collective political identity in that sense. Epistemologically they understood that they had a disability while ontologically they did not relate to disability and did not construct themselves as such (Somers 1994). Disability was viewed as 'uncool' and, certainly, far removed from how participants saw themselves; for the majority of participants, disabled people were constructed as a badly dressed, excluded 'other' antithetical to their self-perception. Participants put a lot of effort into 'fitting in' and often this meant finding ways to resist labels and 'identities' they felt were externally placed on them and often in conflict with their aspirations for 'normality' and normalising (Goffman 1969, DeSwann 1990). As will be discussed, these attempts at normalising were also exemplified through 'passing' and using clothing in order to promote or maintain feelings of sameness.

As already mentioned, most of the young people who took part don't know other disabled people, have gone to mainstream schools and do not necessarily or 'ontologically' see themselves as a disabled person, while they are of course aware of that fact that they have an impairment. Some of the participants have actively resisted the 'disabled identity' that can be placed upon them. For some this is because they want their achievements not to be linked to a discourse of 'triumph over adversity' and for others it is because they have negative ideas of what it means to be a disabled person. For all of the participants their identities and selves are intertwined with their bodies and what kinds of citizens they want to be seen as.

'Fitting in' was very important for some people and this sometimes meant constructing stories explaining why they looked the way they did rather than identifying as a disabled person. Pete felt it was easier to lie about having Spina Bifida (SB) than explaining what it meant to other people at school:

I also kind of, when I went to my last school, I lied to a lot of people I met as to why I had a limp, why I had a problem with my leg, why I had a disability. To look back now I don't think it was the best thing to do but it was the way I coped at that age. I think I worked out quite quickly that in some respects people can understand and get their head round...like I said I hurt it playing rugby and that's why I don't play anymore, and people can get their head round that much better especially at that age where if you say it's because I have SB then you have an enormous explanation to give to people and it's much easier to not.

(Pete, 26)

While Pete maintained that he did not think it was a good idea to lie about his impairment he later went on to say that this is sometimes the only way he can avoid unwanted looks or questions. Pete is also an amputee and often assumed the identity of someone injured in the armed forces rather than someone born with an impairment as he feels that this affords him more status from non-disabled others:

I would have been happy with them thinking it was ex-military or something because they get these ideas that you've done something good so like it's kind of different. Good disabled versus bad disabled, it sounds horrific I know. I think that's it. I think people see it as different to someone being born with a disability and I don't think it's right but it's sometimes how I perceive society. I think society is like that and I think there are ways to fit into society a bit easier and for me I understand that that's different from person to person but in the last couple of years I don't like that I've done that and I don't like that I've allowed people to believe that and believe what they want because I kind of felt and do feel that I shouldn't deny who I am and the disability that I have.

(Pete, 26)

As can be seen in the above example 'fitting in' was very important. Pete associated being born with an impairment as 'bad' disabled in opposition to someone who acquired an impairment, in the military, for example. As such Pete tried to resist the 'bad disabled' category because he perceives this as at odds

with society. Pete's example evidences the blurring of the lines between direct and indirect psycho-emotional disablism. Pete feels 'othered' or different as a result of how 'society' looks at disability, and he reinforced this by either lying or allowing others to make their own assumptions about his impairment. However, Pete also talked about how he recognises he should not deny that he was born with an impairment as he has grown older. This demonstrates the impact that legacies of negative attitudes towards disabled people have had on some of the participants and how far some participants want to distance themselves from disability as a label or a negative identity.

The negative stereotypes formed through a legacy of exclusion impacts on the ways disabled people see themselves; it makes it difficult for at least some young people to feel included and accept themselves at a point in the life course where body insecurity is commonplace. Similarly, disabled people themselves can in their individual quest for acceptance promulgate negative stereotypes by trying to distance or disassociate themselves from stereotypes and images of disability.

Jane describes her feelings towards appearance and dress (discussed further in the following section):

I think some people see disability as unattractive, I'm attractive because of my height and I'm thin and my personality and there are some disabled people who just don't look attractive.

P: Could you explain that a little more?

J: Some people with disabilities, it's pretty obvious in their disfigurement, the way they dress, the way they conduct themselves you know that they're just not attractive compared to people with disabilities who dress very well and present themselves very well and who are very driven or very proactive in sports you know? So they're all very well dressed and they look after their makeup and everything.

(Jane, 25)

Participants were often keen to distance themselves from disabled people who they felt did not represent how they felt about themselves or wanted themselves to be seen. In so doing participants were active in reproducing discourses of homogeneity, exclusion, and disablism that they were trying to resist in the first place. Jane's example replicated the psycho-emotional disablism that is both felt and perpetuated by disabled people. It also represents the, at times complex, process of managing sameness and difference often simultaneously. Furthermore it was an active resistance of the homogenising identities placed on disabled people. Moreover it also highlights participants' general lack of 'disabled' political identity or identification as very few participants, like Jane, questioned why some disabled people might not be 'very driven' or be 'well dressed'.

Resisting 'triumph-over-adversity', resisting difference

Negotiating 'sameness' and 'difference' was a daily event for participants; some had particular experiences of being used as examples by others to show how 'brave' they were or how much adversity they had overcome in their lives. Kate talked about being awarded a prize for completing her medical degree 'despite' having an impairment:

I was given this award when I was graduating and it was basically because I have a disability. I refused the award because I didn't want to be seen as the disabled doctor, my disability didn't even come into it. I didn't take the award. It was embarrassing.

(Kate, 28)

The highlighting of difference, in these ways, by non-disabled others meant that the body was characterised as 'out of place' or extraordinary in being able to achieve goals with an impairment. Similarly Ruby talked about resisting 'triumph over adversity' and also about resisting a disabled identity that she did not feel she related to:

All through my career I've never wanted to be identified as a disabled artist and I've always been very wary of being known as a girl with CF [Cystic Fibrosis] and not for the work I've done because I've worked with an organisation for artists with disabilities and I've always been quite hesitant about trying to contact them about doing work or working in their studios because I thought if I do work I'll be labelled as a disabled artist you know?

(Ruby, 25)

Ruby was insistent that she did not want to be labelled as a disabled artist as she felt that this would categorise her work as 'disability art' which was something she felt she did not relate to. Although having an impairment influenced and impacted on her art and when she was able to produce work, Ruby felt that in order to build an identity as an artist on her own terms she had to disassociate from the disability label. Ruby also discussed 'triumph over adversity' when she agreed to be involved in an article about her art work:

I did an interview with a paper. I was invited to the Scottish Parliament and it was actually about the work that I had done for a charity, I was doing art workshops for them and so I wanted to be about the work that I'd done, the art workshops I'd done, how it had affected the participants for the better but the article was about 'girl having CF' and that was a bigger story and it said...it asked me if I was on the transplant list and you know in the article it said 'life expectancy for someone with CF is currently at 31 years' and I read that and it made me feel really upset because It made me think that every person that reads that knows that I have a reduced life expectancy and I didn't want people to think of me that way...I want to be identified as a successful person...

(Ruby, 25)

Sameness and 'fitting in' could be compromised by others' attempts to construct achievements and activities as extraordinary because of disability, in Ruby's case this was very distressing as an article about her identity as an artist was usurped by CF. The article further cast Ruby as different as it made a point of her lower life expectancy. Lots of young people strive to 'fit in' and being singled out, even to award, can exacerbate insecurities and for Ruby and Kate

this only served to mark their bodies as different even when the intention was not malicious. Further it serves to remove participants even further from a 'disabled' identity:

I suppose for me, I have this view of being identified as a disabled person and a person with CF as a negative thing.

(Ruby, 25)

This often led participants to construct their 'selves' as separate from their bodies in order to forge their own sense of self on their own terms in order to avoid 'social attitudes of pity and curiosity' (Manderson 2011, 112). In this sense difference was highlighted by a narrative of 'triumph over adversity' being placed on Kate whereas she became a doctor with her impairment which challenges the notion that being a doctor is an able-bodied profession and that Kate 'beat the odds'. In the book *Urban Girls: resisting stereotypes, creating identities* (1996), Ross and Way highlight the experience of inner city teenage girls and their process of identity formation amidst popular conceptions of them. Ross and Way argue that young women operate within stereotypes of despair and the public images of them are ones of poverty, drug addiction and teen motherhood. When young women fall out with this stereotypical perception they are constructed as 'beating the odds' (Ross & Way 1996,5) rather than resisting stereotypes, or externally ascribed identities. Similarly the young people who participated in this study were constructed as 'beating the odds' by being doctors or artists while they expressed that they actively resisted this construction as it was in conflict with who they saw themselves to be, how they felt about themselves and how they wanted to be seen. Fundamentally participants resisted being attributed to, what they saw as, a homogeneous 'disability' label by non-disabled others as disabled people are not afforded full citizenship and they want their personhood recognised and seek to achieve this by downplaying that which they feel removes personhood in favour of that which they feel affords them status. However, this resistance was not present where supportive structures might be compromised (such as disability benefits, for example) as it is these very supportive measures that have contributed to the level of inclusion they have come to expect. Social welfare and provision for disabled people supported the achievement of participation in citizenship, for

participants, while awards for triumphing over adversity were seen to threaten it.

Not all participants resisted disability as an identifier or valued part of their sense of self. Where participants had attended special education, residential living or had friends who were disabled they formed more of a political identity and did not separate disability from themselves so vehemently.

Daisy lived in residential care with other disabled young people and she actively identified as and valued her identity as a disabled person saying:

I'm a strong believer in that without my disability I would be a totally different person.

(Daisy, 25)

Daisy's personhood and sense of self was explicitly bound with her corporeality. While this was the case she actively resisted homogeneity of identity in particular contexts.

Well it's like labelling you so to speak or here's a tiny example of everyday...see like the unit where I stay we have a buzzer that we can wear to buzz for support but I don't have it on today but the majority of people wear it round their neck whereas I won't wear it round my neck. I'll clip it to my seatbelt or put it on the table because I feel that if you wear it round your neck then it's labelling you and I don't like that. I know some service users wear it because it's easier for them to reach or whatever which is fine but a lot of people just wear it round their neck cause it's habit whereas I think that labels you and I discreetly wear it on my belt and If I need it then I press it.

(Daisy, 25)

While Ruby, Kate & Pete perceived disability as a pejorative label and did not always relate to 'being' a disabled person, Daisy both ontologically and epistemologically saw herself as a disabled person. However, Daisy also still felt that she had to actively resist labelling and homogenisation and took control of

her own 'identity' in creative ways by asserting individuality. In this context, while Pete, Kate and Ruby wanted to be seen as the same and 'fit in', Daisy wanted to be seen as different in a structure that could serve to homogenise disabled people. Similarly Jane wanted to differentiate and distance herself from a negative stereotype of disabled people that she herself was perpetuating. What can be seen is that resistance was important in managing sameness and difference. Participants, mostly, had highly individualised worldviews and resistance sometimes involved rejecting being highlighted as someone who had overcome adversity or a rejection of negative stereotypes of disability not by challenging them but by perpetuating them and at times resistance could be seen as challenging homogenising structures. What was apparent was that participants wanted to forge their identities and sense of self as individuals and resisted externally ascribed labels in order to feel the 'same' and be who they felt they wanted to be. Being singled out by others for being disabled was distressing to some participants and threatened their, at times very fragile, sense of sameness and 'being' (Thomas 1999, Reeve 2012). Managing 'sameness' and 'difference' was also understood in terms of how participants presented themselves and it is to this that the chapter will now turn.

5.3 Presenting the self through clothing

Like all young people, the participants in this study were in the process of constructing their selves and identity and clothing was one of the key ways that this was experienced and embodied. Clothing can link bodies to the social world; appearance, our gender, our clothing and how we perceive we look and are received are intrinsically linked to how we feel about ourselves (Twigg 2007 see also Butler 1990, 1993, Brydon & Niessen 1998). This was something that participants discussed throughout interviews. Clothing has garnered limited attention in the social sciences, as Wilson neatly argues:

Clothes are so much a part of our living, moving selves that, frozen on display in the mausoleums of culture (as they are in the historical, sensational and semiotic analyses), they hint at something only half understood...

(Wilson 1985, 1)

Clothing has been largely neglected by Disability Studies; much of the focus on clothing is from a medical perspective usually constructed around the usability and functionality of clothing for people with severe impairments and from the perspective of their carers and assistants (see for example Lamb 2001, Twigg 2007). Sociologically, clothing has generally been understood in terms of consumption and youth and has been constructed as separate from disability and older people (Hughes et al. 2005, Twigg 2007). Disabled young people are often excluded from youthful activities such as leisure, play and consumption because youth and disability are perceived as inherently antithetical (Hughes et al. 2005). Clothing and apparel can demonstrate social difference and act as embodied symbols for various social roles and activities such as work, play, age, gender and class for example. Clothing is a way to present the self to others.

Participants found that clothing was often inaccessible to them either through a lack of physical access to spaces where clothing was sold and displayed or because of 'impairment effects' (Thomas 1999). Clothing also provided some participants with a means of 'passing' and alleviating insecurities about the body and image. Clothing also brought to the fore notions of choice and agency in expressing self and identity. This section will explore participants' experiences of clothing and how their feelings about their selves and bodies were mediated, at times, through what they wore.

5.3.1 Choice and agency

Choosing clothing is one of the key ways that young people, in particular, can express themselves, form identities and mediate their bodies to the social world. Clothing, shoes, make-up and hairstyles were important to participants. As disabled people are often excluded from consumer culture it brings to the fore how they redefine discourses about disability (Twigg 2007, 286).

Daisy talked about meeting with other students for a project at university that she had never met before and how she decided to identify herself to them:

I have certain assignments and I have group work to do and it's fine now 'cause I know who my groups are and we are working well and it's fine. When I went in to the class at the beginning of this semester I didn't know anybody in that class and there was just a list of groups put up on the internet site and I thought 'oh no! I don't know these people'. I had to email them and see and one of the guys gave me his mobile number and he was like 'tell me when you're in uni and we'll work it out'. So when I was in uni I emailed him and my support worker at the time was like 'but how are you going to tell him who you are' and I was like well ok, so I kind of made a joke of it I said I'm the one with the crazy purple and blonde hair and oh by the way I use a wheelchair...

(Daisy, 25)

Daisy's narrative illustrates that her sense of self and her identity is intertwined with her appearance and modes of dress. She does not deny her impairment or use of a wheelchair as part of how she sees herself but actively challenges and resists this as the easiest or primary way to identify her or for others to identify her. Daisy took control over how she was identified by others by expressing the multiplicity of identities she embodies, this is in contrast to Ruby & Kate's examples in the previous section whereby they feel they had to separate themselves from their bodies. However, the difference is that Daisy is able to choose and be active in indicating to others how she would like to be identified.

Not only are clothing choices restricted for some disabled young people but access to spaces and places where clothes are bought and consumed can make disabled young people feel as if they are not wanted in those places and not worthy of wearing what they see to be nice clothes. The physical landscapes and spaces in which the consumption of fashion are often realised are in many cases not accessible to disabled young people and as such presents psycho-emotional barriers to 'being' and 'doing' (Thomas 1999):

When we go to shopping centres they're fine but wee shops are tight and everything's all in one place. You feel kind of like why can't you just make it a

bit less, and be able to have people like wheelchair users be able to go in, as if they're no' wantin' us in or something, not letting us see nice clothes.

(Molly, 18)

Here it can be seen that Molly can be restricted by access to places where clothes are sold. Molly explains that it makes her feel as if she's not welcome and prevented from 'seeing nice clothes'. In this instance Molly is prevented from exercising agency in choosing the kinds of clothes she wants to wear because of a lack of physical access.

Access to clothes shops was a big problem for some participants, not because it meant they could not buy clothes (as participants also used internet shopping) but in terms of the negative impact on their self-esteem and wider feelings of inclusion in everyday life engendered by a lack of access to spaces where 'nice' clothes are sold. Further poor access meant that participants had to rely on others to do things for them, which in the instance of clothing removed choice and agency:

J: [inaccessible clothes shops] makes me annoyed and really quite angry in a way because there's no need for it. It is depriving me for going in to look for things and I shouldn't have to ask my brother, and I mean they do it, but I shouldn't have to ask my mum, my dad or my brother as I'm nearly 23 you know. I shouldn't need to ask other people to go and find something for me in a shop I should be able to do it myself. A lot of the clothes rails they're tightly packed together and there's not a lot of room to get about in and it's quite awkward. It means I can't get what I want.

P: How does that make you feel?

J: It's as if you're not really thought about and that's the best scenario, the other scenario is that they're not really wanting you to come in. At best it's a case of they've not thought about it which is still a bad thing to have because things like that now should be easy - there's a lot of legislation in place now and it's a case of somebody's not given it a thought.

(Jack, 22)

Jack's example shows that poor access to clothing shops made him feel unwanted and excluded. It meant that his clothing choices sometimes had to be dependent on family members helping him get clothes, it also meant made Jack feel that clothing retailers hadn't considered disabled people as consumers of fashion. Not only does Jack's example show the psycho-emotional impact of exclusion but it also shows the way in which a lack of inclusive citizenship impacts on the embodied experience of participants.

Clothing and Passing

Clothing mediates our bodies to the social world. Clothing is, at times and in certain contexts, used to hide impairments and often symbolically delineated the kinds of relationships participants have with people. It must be noted that 'passing' as non-disabled is often undertaken by participants whose impairments were not noticeable by way of a wheelchair or comportment; these participants have more pronounced negative feelings towards their bodies and feel that their bodies are most 'out of place'. Here managing sameness and difference is even more complex as stares or questions from others led to profound distress. For Cara, in particular, clothes represent a way of hiding her body from others and subsequently a way of avoiding unwanted questions and thus passing, in some contexts, as non-disabled.

Clothes are hugely important to me, which is so stupid but I think it maybe stems from ...there are so many things that I can't wear and so I have to always be looking for things that I can and I always am so if I see someone walking down the street I'm like 'oh I can wear that' but yeah for me that's about my disability.

P: So is that about covering up?

C: Yeah it definitely is...

(Cara, 20)

Clothes that could or could not be worn, for Cara, are determined by how clothes serve to aid her passing. While other participants, like Ruby, Pete & Kate, seek to be seen as the same regardless of impairment, Cara aims to hide her impairment from certain friends in certain contexts. Feelings about clothing and the body are also a result of psycho-emotional disablism and here staring has a detrimental effect on some participants:

I'll be walking around and people aren't looking at my face they're looking at my legs and it makes me ...well I'm quite confident and just stuff like that I mean I'm probably making it up in my mind but it makes me really self-conscious like a couple of times I have had to go home and change which is stupid and I'm like 'you shouldn't do that you should just accept it' but sometimes I can't just walk around uni and be ok I'll have to go home and get changed.

(Cara, 20)

Cara, particularly, felt that clothing mediated her relationships with different people that she knew. For example she talked about how she would never show her legs or wear a short skirt or shorts in front of her friends from university, however she felt entirely comfortable doing this in front of her friends from home. The difference being that Cara's friends from home were active in constructing positive feelings about her 'self' and body, as discussed in the first section of this chapter, friends took active roles in promoting sameness and it was through these intersubjective relationships that Cara 'learned' to not feel badly about her body in front of those friends. However Cara's friends from uni were not part of this construction of self and personhood and so she found it much harder to trust them to accept her body and so she felt she needed to 'pass':

You know though things are different with my friends at home though...like it's stupid but it's things like I feel that with my friends at home I could just walk around in shorts and a t-shirt but here I'm like no! You know it's just different like that I feel that it's just different.

(Cara, 20)

It can be seen that passing, in Cara's example, was not a way of denying impairment but rather avoiding situations and questions that might threaten her self esteem or posit her body as outwith what is perceived as 'normal'.

'Passing', for Cara, was a carefully enacted way of managing her self and identity and avoiding the psycho-emotional impact of staring and probing questions. Furthermore her 'passing' was only in certain contexts and around people she felt were transitory rather than people she felt were close to her. Here, then, 'passing' can be seen as a coping mechanism and a way to avoid feeling different. This links in with a historical construction of validity, worthiness and competency based on a 'normal' body (Bacci & Beasley 2002, see also Giddens 1991).

Inclusion and clothing

Presenting the body and the self had implications for choice in terms of 'barriers to being'. Some participants found that certain types of clothing had to be worn for certain activities and this sometimes meant that they did not do what they wanted to do or be the kinds of people they felt they were. Sports and the gym were key areas where these feelings appeared. Ella described how she loved to swim but she did not want to be seen in a swimming costume as this was too exposing and invited stares. Furthermore Ella did not want to feel forced to go to a swimming club for disabled people:

I would love to join groups and things like that but I do find it difficult you know. Take the swimming for example; I want to be able to go swimming whenever I want. I don't feel that I should have to join a disabled club if you know what I mean and I kind of get really disheartened at the fact that you have to do that. There's only certain times that disabled people can swim in this club and yeah you have access out with that but I would want somebody to go with me and you know just to build up the confidence cause it's a bit daunting going swimming. Going to the swimming pool by yourself and having to show your body off in a swimming costume and having to get life guards to lower you down in the hoist and I feel conscious of showing my body in the costume. Yeah sometimes you get people looking and what are they thinking and that kind of thing.

(Ella, 26)

Ella's example presents a catch- 22; Ella wants to be able to swim on her own terms and not with a disabled swim group but at the same time does not want to feel singled-out or on display in a swimming costume whilst being lowered on a hoist. The swimming costume, together with the hoist and the stares makes swimming an uncomfortable experience. Being stared at results in negative feelings towards the self as well as not being seen as included or the same or a social citizen in the full sense as they 'impact upon disabled people in diverse ways and can lodge themselves in their subjectivities, sometimes with profoundly exclusionary consequences by working on their sense of personhood and self-esteem' (Thomas 1999, 48). Subtle forms of exclusion and singling out have far reaching effects on how far a person feels included in everyday citizenship; for Ella the staring highlighted her difference and set her apart from everyday citizenship making it difficult for her to swim with non-disabled people - the only legitimate place she felt she could swim was with other disabled people, which challenged her quest for 'sameness'.

Clothes can create a fine line between 'sameness' and 'difference' and feeling included or excluded. Meg has no legs and she feels one of the ways she is included by her friends is through the negation or forgetting of difference. This is achieved through clothes or rather the lack of clothing that Meg wears.

You know a lot of people say things to me without even realising like 'what shoes are you wearing tonight?' and 'are these your socks?' and I'm like emmm no (laughs) and I quite like it when people forget because it makes me feel like oh well I'm not any different! So it's great.

(Meg, 29)

Being included in the same 'clothing culture' as her other friends made Meg feel included and feel the same as her friends even though she did not wear the clothes that they are referring to. Being asked about certain clothes and questions such as 'what shoes are you wearing tonight?' represents how Meg's friends see her body and this relationship with her friends makes her feel the same.

Clothing was important in how participants felt about their bodies and how they felt their bodies were perceived by others. Clothing, having access to clothes, what clothes participants chose to wear, and other people's responses to them through clothing all contributed to participants wider feelings of inclusion and exclusion, sameness and difference. It can be seen that feelings about clothing was gendered and was something that women, in particular, spoke about. As Manderson argues 'women especially incorporate in their self-perception the gaze of others, assessing and maintaining self-awareness of their physical appearance through that refraction' (Manderson 2011, 74). While clothing impacted on how participants related to themselves, others, friends and social situations it became apparent that shoes were a particular site of tension.

5.3.2 Shoes: On equal footing

While the last section looked at how clothing was woven in to participants' feelings about themselves, similarly shoes proved an interesting lens through which to understand how the seemingly private world of participants' feelings, bodies and apparel linked to wider social processes and structures. Again, like clothing, discussions about shoes were highly gendered and were talked about more by women. Participants talked about how shoes could make them feel badly about themselves, particularly where shoes did not fit properly or had to be got from specialist shoe makers; in these instances participants were confronted with difference:

I hate going shoe shopping and I see so many shoes that I want to buy and wish I could wear but I can't. My feet are small and a funny shape so I don't fit kids shoes or adult's shoes properly. It is one of the things that make me feel so different from my friends. It's not fair; I want to wear nice shoes. Shoes make me feel shit about myself.

(Ella, 26)

In this example shoes highlighted the impact of impairment effects. Participants did not only experience the psycho-emotional impact of disablism but also the psycho-emotional impact of having an impairment. However, this is arguably also a response to dominant discourses around 'normal' bodies and the

dominance of 'able' bodies as good and 'disabled' bodies as bad or undesirable. This example further highlighted the gendered nature of shoe consumption founded on the premise that women should care about shoes and that the shoes a woman chooses to wear can denote intelligence or self-worth (Brydon 1998,6).

Some participants required specialist or more expensive shoes because of impairment; shoes became an extra expense that participants had to meet. Shoes, then, became linked to equality and inclusion and were a lens through which to see how, through shoes, citizenship was experienced through the body or embodied. While 'the cuts' will be discussed in more detail in chapter eight, it is necessary to discuss here how through shoes feelings about the self and the body were intrinsically linked to the state.

Due to impairment and necessity participants often had to buy shoes frequently and this sometimes meant that DLA was used to buy them:

I can't walk. I have more clothes expenses just because and shoes...I go through shoes like no one believes

P: Can you tell me about your clothes expenses?

Because of my gait, my shoes wear down and if I'm wearing pumps they just go out of shape the first time I wear them because my feet are really oddly shaped. So fair enough someone can have a pair of shoes and spend a certain amount of money on them and keep them, but I have to buy them all the time so I do feel like in order to be on the same level as everyone else that I do get that benefit.

(Cara, 20)

Cara explicitly linked feeling the same to being able to manage the extra costs of having an impairment and for her this manifested through her need to buy shoes frequently. Being able to manage her impairment this way removed barriers to doing and being (Thomas 1999) as being able to enjoy shoes in the way that her friends did contributed to her feeling 'normal'.

This section has explored how clothing formed an important part in how participants presented and felt about themselves. Access to clothes, using clothes as a way to fit in or sometimes hide impairment as well as managing the practicalities of having an impairment all played a crucial role in negotiating everyday experiences of 'sameness' and 'difference'.

5.4 Conclusion

This chapter aimed to explore participants' feelings about themselves in relation to their bodies, their friends and families and other people they encountered. 'Sameness' and 'difference' emerged as key themes in the data and represented the fragility that characterised their everyday lives and feelings. The chapter began by looking at how participants constructed 'sameness'; it emerged that participants' felt 'the same' through interactions and relationships with family and friends. Family and friends were important in promoting positive feelings and feelings of equality. Families' positive expectations helped participants to see that they were the same 'as everybody else'; this was established by parents' expectations about education, forming friendships and relationships. Friends also played a key role in engendering feelings of belonging and 'sameness'; friends were active in 'sticking up' for participants where others stared or made negative comments.

The second section of the chapter explored how participants managed feeling 'different'; while most participants said they saw themselves as the same as everybody else they also described how one of the key ways they felt different was when it came to intimate relationships. Participants worried about intimate relationships as they felt that having an impairment made them unattractive or undesirable to others. Some participants had had negative experiences of intimate relationships that had lasting psycho-emotional impacts on their sense of self and self-esteem. This section of the chapter looked at how participants identified themselves and how they felt they were identified by others. For the most part participants distanced themselves from a 'disabled identity' and felt that this constructed them as 'different'; this reflected the fact that only five of the participants had had any interactions or friendships with other disabled people. The desire to feel and be seen as the 'same' was so compelling for some

participants they chose to lie about their impairments with people they did not know. However, this was often in response to unwanted questions or stares from non-disabled others. This section highlighted the tension between how participants both challenged and reinforced social norms simultaneously.

The final section of the chapter focused on clothing and how participants' relationships with clothing shaped their feelings about themselves. It emerged that on the whole participants felt excluded from the spaces and places where clothing and fashion were sold. They found clothing shops inaccessible and understood this to mean that they did not 'belong' in these spaces. Some participants used clothing as a way to 'pass' or hide their impairments, which led to a close and constant management of clothing. Clothing acted as a way to mediate between the body and the social world in some cases by hiding 'difference'. Participants also spoke about their relationships with shoes; in discussions about clothing shoes were one of the key items that highlighted 'difference' for participants. Although women mostly discussed shoes, participants felt that they could not wear the kinds of shoes they wanted. Furthermore participants discussed how often shoes had to be bought frequently due to their impairments and this was an additional cost for them. Shoes were linked to the state as benefits were used to meet these additional costs. While participants, on the whole, did not see themselves as disabled they did discuss how feeling the 'same' was, at times, reliant on the additional support that levelled the playing field. While this chapter focused on the 'landscapes of interior worlds' (Thomas 1999), the following section will explore participants' feelings about sex and sexuality and how they felt this was represented in everyday life. Further it will explore how exercising sexual rights were shaped by social structures.

Chapter 6. Sexual Citizenship: recognition and embodied experiences of sexuality

Building on the discussion in the previous chapter, this chapter looks in detail at the way participants talked about their experiences of and feelings around sex, sexual health and future concerns about parenthood. It became apparent, very quickly through interviews that the participants were very keen to talk about more 'private' or intimate aspects of their lives. It was through these discussions about seemingly 'private' issues that it emerged that 'private' aspects or activities of the body were often experienced or played out in public arenas. Participants were keen to talk about intimacies like sex, sexual health and their feelings about starting families later in their lives. The key theme that emerged throughout these discussions was 'recognition'; participants discussed their need to have their rights to sex and sexual equality recognised by others in order to feel that these rights were valid or realised. Being seen as someone capable of sex or pregnancy, for example, was important to participants. It was often the case that participants felt excluded from these spaces and as such refracted ideas about disability and sex as antithetical to heteronormative able-bodied constructions of sex. Moreover discussions about sex and sexuality provided a useful lens through which to bring into focus how bodily activities, embodied experiences and knowledge were shaped by public processes such as education, medicine and dominant discourses around sex. In this sense it presented the blurriness of the private and public realms.

The first section of this chapter begins by looking at participants' feelings about rights to relationships and rights to sex. Participants spoke about public discourses relating to disability, sex and relationships; in particular participants spoke about the representation of disabled people in mainstream television programmes and some participants spoke about what they felt non-disabled others' views on disability and sex were. The chapter then goes on to look at how public institutions shaped participants' experiences of sexual health and information about sex. This section of the chapter explores how participants felt that knowledge and education about sex was cast as 'other' to them. Finally the chapter looks at how participants felt about the future in relation to having

children; this arose as a key area of concern and insecurity to lots of participants who felt that they were excluded from these areas.

6.1 Recognition and rights to relationships

This section of the chapter will explore participants' feelings about their rights to relationships and sexuality, it will look at whether they have ever felt they have been denied these rights and whether having relationships was something expected of them by family, friends, and others. What all the participants had in common was the notion that when relationships and sexuality was concerned they felt they required 'recognition' from others. 'Recognition' refers, here, as a means to accept and appreciate difference as a matter of social justice (Fraser 2003). Without recognition one's personhood is not validated, as personhood is constructed intersubjectively through interaction with and recognition of others (Fraser 2003). The previous chapter looked at how personhood and feelings of 'sameness' were constructed in dialogue with others; families and friends were instrumental in this construction. Inclusion was based on an appreciation of difference and a rejection of 'normalcy' as natural, innate or dependent on able-bodiedness. However, disability and sexuality have been constructed in opposition to one another and this is a product of historical legacies of disablism, the dominance of an able bodied discourse and structures that have served to locate disabled people as sexless or incapable of having sexual relationships (Priestly 2003, Shakespeare et al. 1996, Sanders 2010).

Particular groups of people are marginalised based on their corporeality and often this is where citizenship and inclusion are restricted on that basis. Although shaped by 'public' forces, policies and institutions, sex and sexuality has been understood as 'private' and intimate. Participants sought recognition that they were seen as citizens in the full sense; citizens who had rights to relationships, sex, sexual health and families. Many participants felt that there was a tension between how they felt and how they were treated; conversely when participants felt they got recognition they felt included.

6.1.1 Recognition from others

Constructing relationships and sex as citizenship

One of the ways I wanted to understand participants' feelings about sex & relationships was to see whether they framed them as 'rights' or a part of their construction of equality and citizenship in their everyday lives. In contrast to their feelings about their selves, which lacked a wider political engagement with disability, participants did construct disability and rights to sex & relationships as a political issue for disabled people:

Of course it's a right cause if it's not a right for a disabled person then it shouldn't be a right for an able bodied person. I couldn't be in a relationship without having sex and that's not me saying I'm a sex addict but it's important and it's important to me and it's a right...I want to have a family in the future and things and I think that's a right, we have a right to a family.

(Ella, 26)

Ella's example actively challenged a historical legacy of constructing disabled people as incapable of sex. Not only did Ella discuss sex, relationships and family as a right but as part of her everyday life and crucial to a relationship. Participants went on to discuss relationships as a 'human right' emphasising that everyone had the same rights to relationships:

P: Do you think that being able to have a relationship is a right?

Well it's a fundamental human right, it's a human right...it's not a disability right. I don't think it's a right as such but of course disabled people should have relationships if they want to. People should have the right to make their own decisions, no one should enforce upon you to make decisions for you.

(Gavin, 18)

The notion of 'sameness' featured again as participants emphasised that disabled people both *want* to have sex and have a right to sex in the same way that non-disabled people do:

P: Is having a relationship something that's important to you?

Yeah cause being...so I'm not different I'm still anyone and so I shouldn't be left out and not allowed to and we all should be allowed to.

(Molly, 18)

While participants established quickly that they ideologically saw sex & relationships as a right this was often, in practice, dependent on recognition from others. Furthermore participants did not believe their capacity to have sex until this was enacted. They felt that having sex was a form of embodied knowledge they did not have as, when it came to sex, the body was often cast as deficient and alien to them.

Exercising rights and gaining recognition

As discussed, in the previous chapter, sex & relationships were the key areas where participants felt most insecure about their bodies. Partly this was congruent with being a young person where bodily insecurities, especially in relation to sex, are commonly experienced. However, insecurities about the body were also about not knowing how the body might work or act in intimate contexts as this was knowledge participants felt they did not always have:

When I was still a virgin I worried about whether I would physically be able to have sex but then because 'T' was my first boyfriend, and we'd been friends first, I was really comfortable and happy and then after I slept with him I knew I would be fine (laughs). But then it's about guys being open minded enough to think 'well I fancy her and I'm just going to give it a go' and I think that that makes you end up being with good guys actually.

(Meg, 29)

It is important to note that Meg had never received any medical information that suggested she could not have sex because of her impairment, however like a number of the participants, she assumed that because she was disabled it might not be possible for her. This was linked to participants feeling that disability and sex were not represented in mainstream media, and that often they felt that sexual health information was not 'for' them whilst other participants were removed from sexual health classes, as will be discussed in the following section of this chapter. What this highlights is that a historical construction of sex as 'other' to disability has impacted on how participants felt about their bodies in relation to sex. Moreover, Meg worried about her capacity to have sex until this right was realised and enacted. Rights and citizenship existed as abstractions until they were exercised and recognised by someone else as valid. Meg's right was recognised by another person and this made her feel that she was physically capable of sex. This was experienced by participants who felt that their right to sex was contingent upon this kind of recognition - being recognised as someone capable of sex and someone sexually desirable. However, it is important to note that even when 'penetrative' sex was not possible, participants felt that there, ideologically, was still a right to sex, whilst none talked about sex as being more diverse than a construction of sex as penetrative.

Mainstream discourses of sex founded on notions of able-bodiedness were reinforced for participants in various ways. Whilst families were supportive of and reinforced rights to sex and relationships, families also inadvertently promoted able-bodied constructions of sex:

P: Have you always expected that you would have a relationship?

Yeah yes I don't think you should be prohibited at all from having a sexual life and my parents have always been very liberal about a sex life.

(Tim, 19)

While Tim's parents were 'very liberal' about his sex life, sex was still emphasised as being a penetrative activity dependent on his spinal injury not having affected his capacity to have sex:

Obviously at first there were speculations that obviously there are lots of nerves there that can be affected by spinal cord injury and for the first several months they [parents] were sceptical whether I could [have sex] but no it's fine...

(Tim, 19)

Tim's example highlights how understandings and ideas about sex were, in some cases, constructed around notions of sex as an able-bodied penetrative activity. Sex was seen as a possibility as long as there was the potential for it to be enacted. In this sense, rights to sex were constructed through mainstream constructions of sex and bodies.

Participants also spoke about how other people made assumptions about their capacity to have sex. Much of Adam's narrative was centred around his capacity to have sex and his being recognised as a body capable of sex irrespective of using a wheelchair. He often discussed this in terms of describing himself as being very sexually desirable to women and also in terms of proving that he was capable of taking part in sexual activity:

See that we're speaking about equality the first question you always get asked aff a lassies is 'can you have sex?' and I usually find that the ones that ask that are the ones that want tae know for thersels you know 'you're no askin' outta curiosity sweetheart you're asking cause ye want tae go back tae mine efter' (laughs).

(Adam, 19)

Adam demanded and asserted his sexuality by demonstrating his sexual desirability and by establishing that while women often assumed he could not or asked if he was capable of sex that this is because they wanted to have sex with him. Adam demanded recognition, from others, of his sexual capacity in an aggressive way because, as his narrative shows, he was often met with doubt by other people. Adam maintained that many people often asked whether he could have sex and throughout the interview was keen to establish his capability by citing the number of times he had cheated on his girlfriend and the number of

women he has had sex with and so on. While it is important to note that Adam was a 19 year old young man keen to establish his sexual capacity he was also challenging the notion that disabled people are not sexual, capable of sex or have rights to sex. Adam's example is also a demonstration of psycho-emotional disablism, his insecurity around sex reflected the legacy of the social construction of disabled people as sexless, undeserving or incapable of sex as well as a reaction to the psycho-emotional impact of the exclusion of disabled people from sexual realms and the kinds of assumptions made about disabled people by non-disabled others (Thomas 1999).

Adam felt that his capacity to have sex was questioned by others and he linked this to current political policies that sought to remove disabled people's rights:

You know if David Cameron was to come oot tomorrow and say 'disabled people cannae have relationships' I think he'd end up with a bullet in his skull either that or I'd tell him 'here mate I've had your missus and she's nae good'.

(Adam, 19)

While asserting an, at times, aggressive position on sex he linked his rights to sex, as a disabled person, to the political sphere by challenging a government he saw as removing disabled people's rights. Participants often felt that being recognised as a sexual being or someone capable of sex was questioned, fragile and precarious. This was often because participants felt they were left out of sexual spheres and the spaces where sexuality was depicted, taught and managed. This chapter will now look at participants' feelings about the representation of disabled people and sexuality.

6.1.2 Recognition and representation

While not directly experiencing negative comments about disability and sexuality, some participants discussed how there was a lack of media that showed disabled people as sexual and in this sense they felt that disability and sex was not represented in television programmes about young people and relationships or sexual health, for example:

You don't really see a lot of programmes. I mean it's not something that I've come across you know disabled people talking about sex or relationships. I mean there's probably stuff out there, I would imagine. I mean I've met doctors and stuff like that who have spoken about it a few years ago but in terms of being in the wider media it's not mainstream-sex and relationships I wouldn't say there's a lot of examples of disability.

(Jack, 22)

Jack's quote highlights how, for many of the participants, sex became medicalised and often there was a lot of focus on whether, 'physically', participants were capable of sex. Similarly participants talked about role models and the representation of disabled people and sexuality and felt that this was lacking. As such participants, like Jack, felt that disability, sex and relationships were not 'mainstream' thereby constructing disability as 'other' to sex and relationships. Participants felt that this was also the case in the representation of disability and pregnancy in popular media. Public discourse and television still tell us that disability and sex is an uncomfortable topic. Channel 4's (2012 and ongoing) *'The Undateables'*, BBC Three's (2012) *'How Prejudiced Are We?'* and BBC's Beyond Disability documentary (2012) *'We won't drop the baby'* have all highlighted contemporary mainstream understandings of disability, sex and parenthood as problematic and even dangerous rather than depicting positive examples of disability, sex and relationships (Morris, 1991, Priestly 2003). Often it was constructed as 'shocking' that disabled people would engage in overtly sexual activity or parenting - furthermore it was considered most shocking where the disabled person had a learning disability. For some of the female participants this lack of recognition and representation was felt:

You know that program One born every minute; well you don't see any disabled women on it having babies do you? Do disabled people just not have kids...if that show is filmed over a year in a maternity hospital then where are the disabled people?

(Anna 23)

While arguably this lack of representation is slowly changing it highlights the exclusion of disabled people from sexual spaces and ‘mainstream’ representations of sex and relationships. Where programmes did deal with disability and sexuality it promoted feelings of sameness for participants as disability and sex was depicted as ‘normal’ or mainstream:

You only ever get these specialist TV programmes [about disability and sex] once in a blue moon and I guess with inclusion it's the same. TV programmes tend to have characters who use a wheelchair like that girl on Hollyoaks, she had sex and that was good actually that probably...that's a mainstream everyday programme but to have her on the programme being just the same as everyone else I think really did help but she is actually disabled in real life...

(Meg, 29)

Meg's example highlights how social institutions such as the media shaped participants' feelings about sex and their bodies. Inclusion is multifaceted and participants were up against mainstream constructions of sex that excluded disabled people and this was evidenced, for participants, through a lack of representation in mainstream arenas such as TV programmes. Where, for example, TV programmes were inclusive it allowed participants to see disability and sex depicted in a way other than ‘specialist’.

Sexual health was another key area where participants' experiences were shaped and restricted by the built environment, attitudes towards disability and policies on sexual education and it is on this that the chapter will now focus.

6.2 Sexual health and information

It has been documented (Sanders 2010, Shuttleworth 2010, Shakespeare et.al. 1996) that disabled people receive restricted sexual health information and poor access to the spaces and places where sexual health is managed (Tilly 1996). Some of the participants who attended special needs schools felt that they received poor sexual health education or no sexual health information at all (Shakespeare et al. 1996, Priestly 2003), while some of the participants who went to mainstream school had segregated sexual health information and almost

all of the participants who went to mainstream school had been included in sexual health information but felt that it was not always relevant to them or inclusive of them as disabled people. Disabled feminists have argued that discourses around sex have been perpetuated as able-bodied, penetrative, and heterosexual and as such many young disabled people receive an education that is not felt as relevant to their corporeality (Thomas 1999, Shakespeare et al. 1996). For the most part participants found that sexual health information or information on sex that was relevant to them had to be searched for. Sexual health information and information on sex for disabled people was usually cast as 'specialist' or different to 'normal' or able-bodied sexual health information that was readily available.

This section will consider and explore participants' experiences of sexual health and sexual health information given at school and by people in positions of authority such as doctors. This section aims to show the relationship between policies on sex and sexual health and how this impacts and is felt by participants. This section will also look at participants' experiences of access to sexual health clinics. It aims to show that sexuality plays an important role in the participants' citizenship and that policies and practices around sexual health impacted on how participants felt about their bodies.

6.2.1 Sexual health education and information: constructing disabled sex as 'other'

Throughout the interviews, participants reflected on the kind of information they got on sex and sexual health, if any, and how this impacted on their feelings towards sex and being disabled as they got older and began to form relationships.

For most young people in the UK, school tends to be the place where formalised sex education and sexual health information is given. Participants talked about varying degrees of sexual health education received through the time they were at school. Some participants felt they received positive sexual health education at school and were included and as such this was a reflection of their inclusion more generally:

I was always included in that [sexual health education] in school and had that not been the case I can assure you my parents would have kicked up a fuss.

(Gavin, 18)

Gavin's example shows that he felt included in sexual health education at school but also that his parents also felt that he should be included and would have demanded that had he not been. This reinforces the notion that overall parents expected that their children would need and should get sexual health information. However, like Gavin, other participants who went to mainstream schools also felt that they were included in the same sexual health information as everyone else but that this information was not relevant to them or did not represent the diversity of sex that people could have:

P: Did you ever get information about being disabled and having sex or sexual health?

No like I have had that sort of stuff at school but never anything specific ... it was only when I was at leaving school age that I started to worry about it and I knew that I wasn't any different or whatever but I did panic about it because it's a personal and private thing for everybody but I did worry that I would specifically have a problem because I just wondered if I could [have sex].

(Meg, 29)

For Meg, sexual health at school was general and not 'specific' to disability and although she did not feel any 'different', information on sex and disability was not included in mainstream sexual health. Sexual health information and sex education reflects, for the most part, an able bodied perspective or narrative on sex which left Meg questioning her capacity to have sex at all. Participants felt left out of knowledge about bodies that they did not feel was relevant to their corporeality, while disability is not a homogenous group, participants also felt there were no examples or representations of disabled people having sex at all and this had lasting impacts on their feelings about their bodies. Vicky also had a similar experience to Meg's, sexual health education was 'general' and not relevant to her:

P: Do felt that there is relevant information about relationships or sex, or sexual health?

V: It was taught at school and stuff like that. They didn't ... it was just general

P: When you look back on it, was the information inclusive do you feel?

V: Probably not, no.

(Vicky, 26)

For some participants, in mainstream schools, sex was constructed as 'other' to disability. Not only did participants feel that the education they received was not relevant to them but some participants were actively removed from receiving sex education as part of a class:

I would say no, I don't think there's enough [sexual health information for disabled people] because obviously it is a lot different for me and that type of things is different for someone like myself. I don't really feel that the school addressed that as well as they should've. I didn't think about it at the time but looking back they didn't. It was more general boy-girl type things that were dealt with in school, I was dealt with one to one by a teacher but I wasn't given that information.

(Jack, 22)

Despite going to a mainstream school, Jack was removed from sexual health education and 'dealt with' solitarily by a teacher. Firstly, this firmly confirmed Jack as different and that the kind of sexual health information he received was controlled and filtered by teachers. Jack was not recognised by teachers as being a person who required the same sexual health education as his able-bodied peers or an education that represented sexuality as diverse. Furthermore, not only did this reinforce notions of segregation and difference but perpetuated the norm, among students, that there's only one way to have sex - an able bodied, heterosexual way. Jack discussed his lack of confidence in forming intimate relationships and that he had never had an intimate relationship of any kind.

Jack's experience demonstrated the ways in which a lack of recognition by authority figures and the controlling of his education had erected 'barriers to being' and had a lasting psycho-emotional impact on his self esteem and confidence (Thomas 1999, Reeve 2002, Reeve 2012). Policies around sexual health information and how this is conveyed in schools actively impacted on, not only how Jack felt about his body but, the spaces he could occupy and the kinds of information and education he was deemed capable of experiencing.

Like Meg, Jack spoke about sex education as 'general' or 'usual' whereby sex education and disability was seen as 'special' or 'specific' further constructing sex education for disabled people as 'different' to sex education in 'general':

Yeah, obviously I got the general information but there are other things that I have to encounter in my life. I think the schools have a duty to make sure that everybody that goes to the school has the information that they require to go on and lead their life and I don't think I was given that information and if you didn't get that information then you don't learn.

(Jack, 22)

Sexual health information is a form of body- knowledge that is given to people in order that they understand and can facilitate, explore and control how they experience sex and intimate relationships throughout their life. Sexual education is crucial for young people to navigate through adulthood and sexuality, where policies that govern that information and the authority figures that disseminate exclude young disabled people it impacts on their every day embodied experiences and shapes how they see themselves. It constructs the kinds of citizens that they are and the kinds of bodies they have.

Experiences of sexual health education in special education

Participants in mainstream education talked about irrelevant sexual health education or being excluded from sex education altogether, however participants who attended special education also felt that sexual health education was controlled and restricted based around corporeality.

Jane discussed how, at her special needs school, sexual education was given by the severity of impairment and the expectation as to who might and who might not be deemed capable of sex. Jane talked about how often people with learning disabilities would be excluded from sexual health information and because she had moderate physical impairments she was included:

I think it's to do with attitude and culture and some teachers in that school would tell people they would never have sex or have a relationship and so it wasn't important to go in to much detail compared to someone like myself who is quite physically able to you know what I mean. I still think that I would be quite keen to see if the information is accessible to disabled people. And a lot of disabled people get married and have families.

(Jane, 25)

While Jane got sexual health education, it was because she was recognised as someone capable of sex. The legacy of discrimination and exclusion of disabled people from sexuality has meant that recognition is only afforded to those deemed 'appropriate' the control of the dissemination of information is based on recognition and which bodies are seen as sexually capable or appropriate bodies. Therefore knowledge and information around sexuality becomes embodied and this is often knowledge constructed around the able body. Furthermore, authority figures such as teachers perpetuated the construction of disabled people as non-sexual or incapable of sex by telling people they cannot or will not have sex based around their attitudes to disability and sex. Further, this is a reflection of broader societal assumptions about who is and who is not capable of penetrative, able-bodied sex. The closer a person is to achieving this more likely you are to receive sexual health education which reinforces penetro-hetero normative ideals about sex thereby further excluding disabled people.

Sexual education at school was a key arena in which participants felt that they were not represented or recognised as being sexual persons and for whom sexuality was an integral part of their citizenship. Sexuality was highly medicalised for some participants, whose impairments impacted on their sexual health. However they felt that similarly their capacity to have sex was not recognised due to the heteronormative able-bodied constructions of sex that

excludes disabled people. The following section will explore participants' experiences of accessing and managing sexual health in relation to medical health professionals.

6.2.2 Accessing sexual health

While participants spoke about the kind of information they got about sexual health when they were at school, they also spoke about accessing sexual health in practice. Accessing sexual health demonstrated how embodied experiences of sex and sexual health were shaped and impacted by poor access and a lack of information, and here it emerged that 'public' institutions shaped 'private' experiences. As discussed in the above section participants wanted sexual health education in school to be more inclusive by recognising and representing that sex is varied and diverse as are the people that take part in sex. However, while most participants did not require information that related to their impairment, some participants did; this ties in to themes of 'sameness' and 'difference' as participants wanted to be recognised as sexual but their impairment meant they required 'specialist' information. This can be viewed through the lens of Thomas' impairment effects (Thomas 1999). While the previous section highlighted that most participants felt uncomfortable with the medicalisation of sexual health and information, as often disability and sex was dealt with by doctors, some participants' impairments necessitated this kind of information.

Where participants' sexual health required management alongside their impairment some participants felt that this was not managed appropriately. Cara was not given the appropriate sexual health information that she needed to avoid becoming unwell:

The only thing for me, which I didn't know about and should have known about before ... you know? I would get urinary tract infections a lot because of Spina Bifida and Kidneys. I didn't know that sex would make it a lot worse and mean that you would get them a lot worse and more frequently. I didn't know that and I was sitting thinking 'why am I so ill, I'm not supposed to be this ill' and when I went to see my consultant he was like 'oh have you been in a sexual relationship' and I said yes and he said 'well that's why' and I was like 'I'm 20 years old why did nobody tell me this beforehand' why did no-one mention, did

they just think I wouldn't? Did they just think I wouldn't be a normal teenager and I wouldn't be having sex? It was annoying more than anything else. I really felt that someone should have told me cause in school you get talks on sex when you're like 16 so I was kind of thinking why did no-one tell me that 'you have to wear this kind of condom, you have to do this and that' why did no-one tell me? It really puts me off having sex now just because of the awful experience that I had...it definitely puts me off now I'm thinking having sex will now lead to me being so ill and being in hospital and I don't want that... you shouldn't have to learn as a disabled person you shouldn't have to learn through bad experience because it'll impact on your health it's just not ok.

(Cara, 20)

Cara felt that doctors had assumed that she 'would not be a normal teenager' having sex and as such did not give her the necessary sexual health information which had repercussions for her health and her feelings about her body and sex in the future. Cara talked about how young people have sex and that was 'normal' but because she was disabled she was seen as different to 'normal' sexually active able-bodied young people. Cara's example also highlights how sexual health education in school did not deliver the kind of information that she needed. Participants were often met with assumptions that they would not be sexually active and not get involved in intimate relationships and this subsequently impacted the kinds of information and education they were given. Often participants were not recognised as being sexual. This often emphasised feelings of difference and made it difficult for them to pursue intimate relationships.

Sexual Health Clinics

As well as information not being given appropriately or reliably, some participants found accessing sexual health clinics difficult; participants reported a lack of accessible sexual health clinics. A lack of access meant that participants' faced not having sexual health tested or they had to navigate inaccessible spaces:

The one [sexual health clinic] in Aberdeen didn't have any disabled access and my boyfriend at the time had to go in and ask them if they had any access and then they didn't so I had to get out my wheelchair and crawl up the stairs and he had to help me in but I just wondered if I hadn't had him with me...like that would have been crap.

(Meg, 29)

Participants spoke about lack of access to places consistently making them feel as if they did not belong in those spaces; like participants' experiences of exclusion and feeling out of place in 'nice' clothes shops, disabled people were not considered in creating accessible spaces where sexual health could be managed. This reproduces the lack of recognition that sex and sexual health is an important part of disabled young people's embodied citizenship and that sexual rights are rights exercised by non-disabled people (Anderson & Kitchen 2000, 1167). Ella also talked about a situation where she encountered an inaccessible sexual health clinic:

It [sexual health clinic] had no wheelchair access, the taxi driver had to go in and say 'your appointment can't actually physically get into the building' and then not just that I was getting something fitted, I think I was getting the coil fitted because I decided to go on that but it's a bit embarrassing that a male taxi driver had to go in for me but then the doctor came out and sat and had the consultation with me in the back of the taxi and I just jokingly said to the taxi driver 'please keep that confidential because that shouldn't have happened in the first place' he said 'I am so sorry I should've stepped out the taxi' and cause I felt so guilty I gave him a massive tip so he could go get a drink, I was in so much shock I could've thrown back a whole bottle of wine.

(Ella, 26)

Ella's experience presented a complex picture. This was clearly a distressing and embarrassing situation to have been in and could have been avoided had the sexual health clinic been accessible. Ella's example does show the comingling of the public and private whereby 'privacy' was blurred in a number of ways, it highlighted how going for a smear test was dependent on access to a sexual

health clinic but also how Ella's sexual health was managed in public, in a taxi. However, it was clear that Ella's doctor recognised that Ella should have received the consultation rather than not having seen her at all. This example offers a layered picture of how poor access to appropriate sexual health care erects barriers for full citizenship and exercising of rights. The material environment and architecture implicitly informs disabled people that they should not need sexual health as they ought not to need, want or be able to have sex. This builds on the previous chapter and the psycho-emotional impact that participants felt in relation to being excluded from clothes shops and shoes, for example.

6.3 Worrying about the future: pregnancy and parenthood

The last section focused on how participants felt excluded from the spaces where sexual health was managed and lack of recognition had negative implications for participants' experiences of sexual health. This section will look at participants' thoughts and feelings about the future. During interviews participants spoke about their hopes for the future and this often involved getting married and having children. None of the participants had any children. Both male and female participants talked about the potential for having children in the future, however, female participants in particular faced insecurities about this. Female participants worried about how they, physically, might carry a pregnancy, how they would be treated during their potential pregnancy, and whether they were recognised as capable of being parents at all. While men did talk about having children in the future, they did not see being disabled as affecting having children, for women pregnancy was bound up with their bodies and whether their bodies were capable.

Disability and reproduction has been characterised by a history of sterilisation, removal of children, segregation of the sexes, stigma and deviancy (Keywood 2001, Anderson & Kitchin 2000, Shakespeare 2006). This legacy had, consciously or not, impacted the views, hopes and fears of the participants. While the Convention on the Rights of People with Disabilities (1993) has actively and legally recognised the rights of disabled people, and in particular disabled women, to have children, adopt and be supported to have families, disability

and parenthood remains tenuous. Disabled women have often been painted as dangerous, their bodies' potential to become pregnant have been characterised by deviancy (Griffin 1997, Priestly 2003).

6.3.1 Corporeal uncertainty

Insecurity and uncertainty emerged as key theme when participants were talking about their worries about pregnancies and their bodies in the future. While women, and men, face lots of insecurities about their bodies, participants were uncertain about their capacity to become pregnant because they were disabled. Women, without any confirmation from doctors, worried or assumed that they might be infertile.

C: Doctors have never talked to me about fertility or having children or anything like that. I assume everything's ok I assume it is so hopefully I will and it is very important to me and yeah it is absolutely a right

P: Is it something you have always expected for yourself?

C: Yeah I've never questioned that

P: So do you worry whether it will be possible?

C: Yeah a lot and I think a lot of girls do but when you have a disability and especially one that affects like kidneys and all the bits down there it does worry me but I'll cross that bridge when I come to it.

(Cara, 20)

Cara linked her fears about infertility directly to having an impairment. These kinds of uncertainties were common among women who felt that mainstream information around pregnancy were not relevant to them and this left them feeling uncertain. Like Cara, many of the women assumed or were worried that they would not be fertile or that their reproductive systems may be compromised by virtue of having an impairment. They often came to these conclusions with no information given by a doctor, or other health care

professional. Similarly, they had never had a doctor or health care professional discuss any kind of reproductive information with them. Where this did occur, women felt that through this recognition their bodies were capable of pregnancy.

In the doctor's, you know if you're going in for whatever they've never made me feel ...you know they still ask me if there's any chance I could be pregnant in the same way they could ask anyone else. So I have always noticed that. I have noticed that they have never hesitated in asking me, that you would worry that they would presume that you wouldn't be. So I guess I have always noticed that, so when they ask I think ' Oh good so you do realise that I would be able to' so that's good and you know things like smear tests and all that sort of stuff they never avoided asking because they didn't think you needed it.

(Meg, 29)

Meg's security in feeling capable of becoming pregnant 'like anyone else' was based on the recognition of others, in this case a GP (General Practitioner) or health care professional. Meg's corporeal insecurity was the felt response of a legacy of disablism or psycho-emotional disablism characterised by the exclusion of disabled women, in particular, from discourses of reproduction, pregnancy and motherhood.

Many of the young women worried about how their bodies would cope with being pregnant, in some cases this required that participants sought professional advice but in most cases women felt that they were 'out of place' when it came to knowledge about bodies, pregnancy and birthing and often the possibility that there could be negative effects on the body would be distressing:

P: Would there be any other information on disability and sexual health that you feel that you would like that's not available?

Not sex but on pregnancy, I'd really like to know what that would do to my body and my condition because I have no idea. I worry about it because I don't know how that's gonna affect me. I have a feeling that it'll mean that I have to be in a wheelchair for a lot of the pregnancy because of the demands on my legs

already add the baby to that and the added risk of falling over and stuff but no-one's ever told me or said 'this is what will happen to your body and this is what we usually do in your situation we'd offer you this this and this' I don't know, I don't know whether I'd automatically be offered a caesarean or something because it would be difficult?

(Anna, 23)

Most women, like Anna, worried that there would be a risk to their bodies. Furthermore they often looked for answers that might not be possible to get as it would be hard to predict how anybody might react to pregnancy. However, what is clear is that the lack of visibility around pregnancy and disability has led to a lack of education and information being offered, or even highlighting within public discourse that disabled women successfully get pregnant and carry out pregnancies. As such, it can be seen that public health policy and information can leave disabled women, in particular, feeling excluded and adding to the corporeal uncertainty that female participants experienced.

Anna sought medical advice and her physiotherapist assessed her capability to carry a pregnancy and did a 'gait analysis' to see how it might affect her:

She thinks I'll be ok. I felt good about that, she also said that my medical team would automatically offer me caesarean for comfort rather than medical need because it would be uncomfortable for me to give birth naturally but if I wanted to I could do it. It made me feel really good actually.

(Anna, 23)

Recognition and validation from medical professionals was crucial to participants' feeling that they were capable of having children. As mentioned, participants felt there was a lack of examples of disabled people having children in mainstream British culture. However, almost every female participant talked about Alison Lapper and the sculpture depicting her pregnant on the plinth in Trafalgar Square:

I'm sure you've seen that lady on TV the one with no arms or legs [Alison Lapper] the one that was on the plinth in London and I think it was interesting and I've always wondered how she managed 'cause she clearly managed...

P: How did you feel when you first saw that image of her pregnant?

I thought it was amazing I thought that she is a person that helps other disabled people realise that it can be ok...you worry... but I guess like people like that woman make you realise it will be ok or that someone worse off than you has done it before.

(Meg, 29)

Where women spoke about pregnancy they looked at Alison Lapper as a role model; they felt they benefitted from seeing the images of her pregnant body on the plinth and it acted as validation. Role models managed to quell some of the uncertainties and insecurities that female participants felt because they had seen another body with an impairment, pregnant. Able-bodied women see other able bodied women pregnant frequently, and although pregnancy is not a homogenous experience able bodied or not, participants felt better having seen images of Alison Lapper.

It can be seen that recognition, support and inclusion from health care authorities are central for disabled young women to see their own bodies as capable of pregnancy. Certain kinds of knowledge are embodied. Mainstream discourse on pregnancy promulgates a 'one size fits all' policy towards pregnancy and birthing; there is 'normal' way a pregnancy progresses. Many of the participants felt that they were excluded from this knowledge; that it did not make sense or apply to their bodies - indicating that information on pregnancy and disability was lacking. Similarly, many women and men were worried about how they would manage children - how they would hold their baby, wash their child, chase after them and so on. The lack of mainstream information for disabled young people on support and assistance in parenting left participants, both men and women, feeling very insecure. The lack of recognition that disabled people can be and are successful parents in mainstream discourses such as sexual education, civic information, and the

media was reported by participants. This chapter will now look at participants' feelings about disability and parenting in the future.

6.3.2 'How will I manage?': constructing a 'good' parent

None of the participants, at the time of interview, had any children or were pregnant however almost all of the participants talked about parenting in the future. When participants spoke about what it might be like to have a child in the future, discussions focused on what made a 'good' parent and how they would 'manage' a child. Participants tended to construct ideas about parenting, as a disabled person, as negative and again uncertainty and fear were reported. Uncertainty was largely due to a lack of information and not knowing how to access information. Like relationships, sex and pregnancy; 'good' parenting was constructed around notions of able-bodiedness leaving participants feeling excluded.

'Good' parenting was understood as 'normal' parenting; participants worried about being able to look after a child and this was often expressed as worrying about being able to carry a child, push a pushchair, hold a baby and needing support. Participants worried because they had no information and did not know where to source information about disability and parenting. Not knowing how to 'manage' a baby was often linked to being a less than desirable parent and so some participants decided that they would not have children because of impairment:

I don't think I could...personally I think I have made my mind up that I don't want children and that's just because of my disability. I'm worried because carrying a child would put a lot of weight on my legs and a lot of weight on my pelvis and I don't really have good pelvis movement so that might be a problem and the ability to look after that baby, I don't have good arm strength and I couldn't handle it. That's my judgement, you just have to look at your body and make the judgement for yourself whether you could hold the baby; all my cousins have had their children and when they were all babies I couldn't even hold the baby because I didn't have the hand control.

(Jane, 25)

Jane linked suitability to have a baby based on ‘the ability to look after that baby’ and for Jane that ability was linked to carrying and holding a baby. Participants rarely considered or knew about methods to support parenting¹⁰ and did not know where to find information:

I do worry that it would be difficult but I just presume it would be ok...it's the when you have the baby that worries me like I've thought about things like how I would be able to get it [a baby] about...how I would be able to push a push chair and like how I would ...like I don't know what kind of help there is for that stuff and that's something you would want more information on... but you know I wonder how you manage with the push chair and what if you were a single mum?

(Meg, 29)

Not knowing how to practically manage having a child caused participants to worry and question their capacity to have a child. For some participants, the lack of information on disability and parenting as well as the construction of disability as problematic for parenting meant that there was a fear that children could be removed:

When you've actually got the child you're responsible for it and you have to look after it and make sure it doesn't hurt itself or that you don't hurt it by accident. I suppose all those things go through my head and then I'd worry that if a relationship were to end badly then I worry that my you know, say my future partner was to go for full custody that the courts would award him the children because of my disability. I worry that social work will have to be involved; I do actually genuinely worry about how it will impact. I'm scared that my future children will be taken away from me.

(Ella, 26)

¹⁰ Methods to support parenting refers to aids and technologies that can help disabled parents such as adapted cots, technology that supports carrying and feeding babies for example. This information can be found through organisations such as DPPI/ Disability Pregnancy and Parenthood International (www.dppei.org.uk).

Ella, like other participants, worried that her children could be taken away from her in the future. Ella talked about being a disabled parent as commensurate with being a bad parent requiring the removal of children. Ella's fears were directly linked to psycho-emotional disablism and were founded on the belief that others would find her to be a bad mother or incapable mother because she is disabled.

Where participants felt insecure and uncertain about parenting in the future, one participant, who already received personal assistance, questioned whether assistance would be extended to help her raise her own child:

I need support on a daily basis, would they provide the support I need to allow me to look after the baby? I wouldn't be asking a carer to come in and look after my baby, but I would need support to maybe make a bottle, change a nappy or blah blah blah but I would do as much as I could do and surely assistive technology you would hope would go as far as to be able to help women or parents, not necessarily women but men as well - to allow disabled people to parent.

(Daisy, 25)

Daisy's example highlights how parenting represented insecurity for almost all of the participants. Daisy knew she had a right to personal support and assistance but when it came to having a baby, did not know if her rights to support would extend to this area of her life. Like in the previous section, participants' ideologically understood the notion that disabled people had the rights to have children, but practically most participants felt unsure about how to exercise these rights or whether rights, in practice, would extend to parenting. Therefore ideologically participants' felt that sex, pregnancy and parenting were matters of citizenship but felt that, in practice, they were excluded from these areas through a lack of recognition.

For the participants who talked about this, good parenting was associated with an able body and bad parenting was associated with not being able to manage a child in an 'able-bodied' way. This had such an effect on some participants that they had already decided that it would not be 'fair' or possible for them to have

children. The established lack of recognition, in dominant social discourses, of disabled people as capable parents alongside the lack of information around disability, pregnancy and parenting left participants feeling that they were not recognised as capable.

6.4 Conclusion

This chapter explored participants' thoughts, feelings and experiences of rights in relation to sex, sexual health, pregnancy and parenting. The chapter aimed to give insight into the ways in which seemingly 'private' issues were shaped by 'public' forces. Recognition, lack of recognition and uncertainty emerged as key themes in the data, which resulted in participants feeling excluded or 'out of place' in relation to sexual rights and parenting in the future. Participants' feelings about their rights, their bodies and their futures were intrinsically bound with feeling that these rights were recognised by others such as partners, teachers, doctors, and wider social institutions such as the media.

The chapter began by exploring the ways in which, ideologically, participants felt about rights to sex and sexual health as disabled people. On the whole participants reported feeling like there was a lack of information for disabled people relating to sex, sexual health, pregnancy and parenting and this lack of information represented feeling 'out of place' or excluded from these areas. In some cases rights to sex were constructed around physical ability. Participants felt their rights were realised and valid if they were exercised and some made the decision not to exercise their rights to have children for fear of losing them. For most participants sex was constructed around dominant able-bodied constructions of sex as penetrative. This left some participants feeling insecure and uncertain about whether they were capable of having a sexual relationship based on popular and educational norms around penetrative heteronormative presentations of sex. A lack of representation of disabled people, relationships and sexuality only served to bolster these feelings.

The second section of the chapter explored attitudes towards sexual health and the physical and attitudinal barriers that participants sometimes faced in accessing sexual health. Some participants found that their experiences of

exclusion from sexual education in school impacted on how they felt about sex later on. Some participants felt that the education they received was not relevant to them or representative of diversity. These forms of exclusion had lasting psycho-emotional effects and represented 'barriers to being'. Whilst some participants felt that sexual education was not relevant to them, others were removed from sexual health education altogether. Some participants who had attended special education also reported the restriction of sexual health education based on who teachers felt would be capable of having sexual relationships. Participants also discussed being able to access sexual health clinics; participants reported inaccessible sexual health clinics which further reinforced feelings of being 'outwith' the spaces and places where sexuality was managed. This linked to discussions about access to clothing in the previous chapter, while it is likely that disabled people are not deliberately excluded from sexual health clinics, it is more likely that they are not considered due to a historical and social discourse that does not recognise disabled people as sexual citizens (Sanders 2010 see also Siebers 2012).

The last section of the chapter explored thoughts, feelings and worries about starting a family in the future. There was a resounding desire, by almost all participants, to have children in the future. While men did not report worries about having children it became apparent that female participants felt distressed and worried about having children in the future. The lack of information, visibility and representation of disabled women having children led to the internalisation of this invisibility resulting in many of the women feeling that they were not capable of having children or, in some cases, that they *should not* have children (Thomas 1999). Some participants spoke about assuming that, due to impairment, they might be infertile. Women felt that knowledge about pregnancy, embodied knowledge, did not apply to them and they had multitudes of questions about how pregnancy might impact on their bodies and their lives. What emerged was that participants had no knowledge or information about assistive technologies to support disabled people to parent. In some cases participants had already made the decision, although they wanted to have children, to not have children in the future because they were disabled. Participants constructed 'good parenting' around holding and carrying a baby, being able to push a pushchair and chasing after a child, therefore a 'good'

parent or a parent who managed was an able bodied parent. Even where participants received personal support and assistance, they questioned whether this would be extended to parenting. Some participants' fears were quelled by having seen other pregnant disabled women, which mainly took the form of the sculpture of Alison Lapper pregnant. Seeing this image allowed some women to feel like having children and being disabled was possible. While this chapter explored participants' experiences and feelings about sexual rights and reproductive rights and how these were shaped by social attitudes and institutions, the next chapter will look at participants' experiences of public and private spaces.

Chapter 7. Everyday Citizenship: the 'public'/'private' divide

The previous chapter considered participants' thoughts on and experiences of sexual and reproductive rights. It explored the way in which participants felt 'out of place', uncertain and excluded from these spheres, at times. The data showed that participants required recognition from others in order to feel like they were able to exercise these rights. Recognition from others was understood as having a recognised as capable of sex, or reproduction. This chapter looks at notions of everyday citizenship in participants' lives and the way that everyday citizenship was experienced 'privately' and 'publicly' simultaneously by exploring how the state shaped and, at times, controlled everyday activity. The chapter is divided into three sections. The first part of the chapter looks at how the private sphere affects citizenship and aims to do so by exploring toilets, participants' access to toilets in public and the notion of 'the bladder's leash' (Kitchen & Law 2001). This section of the chapter focuses on participants' experiences of exclusive and inclusive toilets and how public toilets had the capacity to make participant feel equal and included but also had the power to make participants feel like they did not belong in some spaces, like pubs for example. Finally this section of the chapter will look at how managing bladder and bowel was explicitly bound to participating at work.

The second section of this chapter considers how access within the home impacted on participants' everyday citizenship. This part of the chapter considers access within the home and how participants could use their homes were, at times, dependent on provision by local authorities. This section begins to consider how 'control' emerged as an important part of some participants' lives. Where participants required more assistance and support it became apparent that they experienced more control by the state.

The third section of the chapter focuses on personal assistance in everyday activity and the notion of 'control over body' (Bacci & Beasley 2002). Many disabled people across the UK require personal support and assistance in order to live independently. While only two participants required personal assistance, this section of the chapter will focus primarily on their experiences of personal

assistance and how everyday embodied experiences were shaped and, at times, controlled by their care packages. This section of the chapter will use Daisy's (26) story as a case study and lens through which to focus on state control over the body. The chapter will then go on to look at one participants' (Ruby, 25) experience of personal assistance through the use of breathing support and how policies on the distribution of health care have impacted on her in the most fundamental way: breathing. These case studies act as a lens through which to view the relationship between embodiment, the state and citizenship in everyday life.

7.1 Private acts, public spaces: disabled toilets

During interviews, participants were encouraged to talk about and reflect upon their everyday activities. I was interested in what they 'got up to' on a daily basis and how they felt about participation. 'Private' and 'Public' emerged as key themes in this data, it became apparent that when participants' talked about accessing their homes or using 'public' toilets that traditional notions of private and public were being blurred. It also became clear that a lack of access in the home, or access to good toilets had an impact on the everyday embodied experiences of how participants could use these spaces. Citizenship has been conceptualised and theorised in relation to public, political activity (Plummer 2003). However, feminist scholarship and in particular disabled feminist scholarship have argued that 'private' activities must be recognised as part of citizenship in order for citizenship to be more inclusive (Lister 2007) and, in this case, disabled people to participate on a par with their peers as Bacci & Beasley write:

The mainstream idea of citizenship is defined precisely in terms of an identity state based upon rights and activities enacted in the national public arena as against those merely private personal activities in the domestic sphere. Citizenship in mainstream terms is adamantly public

(Bacci & Beasley 2000,340).

As discussed in chapters two and three, disabled people, disability scholars and disabled activists have fought for personal experiences to be recognised as

political (Crow 1996, Morris 1991). As disabled people, often, require additional support or adaptations to be able to live independently and participate on a par with peers, disabled people are often dependent on local authorities to provide support and adaptations; this impacts on how participants experienced their homes. Often participants were left with poor access in their own homes or, in some cases, were tethered to live in certain places as part of the adaptation contract.

Participants talked frequently about toilets. Toilets were, at times, the litmus test of good inclusion, participation and feeling equal. The second part of this section considers 'going to the toilet' as a matter of citizenship and explores participants' experiences of toileting and how this intertwined with other aspects of their everyday lived experiences.

This section will firstly explore public disabled toilets and how they are often not made accessible to disabled people and furthermore can be built in such a way as to exclude impaired bodies from these spaces. The section will then go on to consider participants' experiences of their bodies in toileting and how this impacts on their everyday lived experiences.

7.1.1 Where toilets exclude: using public disabled toilets

Many participants talked about their experiences of using public disabled toilets. Public disabled toilets provide fertile ground for being able to consider the relationship between intimate bodily processes (going to the toilet) and how these relate to the traditionally 'public' realm of the citizen. Toilets connect our bodies to the state; going to the toilet is directly linked to our citizenship and discussing the experience of using public disabled toilets allows us to explore how 'public' engagement is predicated on equal access to 'private' facilities.

Disabled toilets proved to be problematic spaces for many participants who found that toilets were either not present in public places and if they were present they were often used as store rooms or were not big enough to fit their wheelchairs. Kitchen & Law (2001) explicate that over time going to the toilet has become established more and more as a private bodily activity and as such

the creation of public toilets in which to privately go to the toilet became prominent in citizenship discourse. As such citizenship discourse became intertwined with intimate bodily activities. As Kitchin & Law assert, disabled toilets are about disabled people being able to participate in public life. However they are also about recognising that the body is active in citizenship and the doing of rights. For citizenship and rights to not be mere abstractions the 'fleshy substance' of citizenship must be acknowledged (Bacci & Beasley 2000, see also Kitchin & Law 2001, 289). Kitchin & Law explicate the relationship between the body and the role of public toilets when they note that 'without accessible toilets, people are subject to 'the bladder's leash' (Cooper *et al.*, 1998), restricting how long they are able to stay in a place and thus constraining their participation' (Kitchen & Law 2001, 289).

Pete explains his experience of needing the toilet when out and the barriers that he sometimes faces:

P: I hate going to...I'm so sick in Edinburgh especially of going to places and them not having a disabled toilet. You're in a pub and if you're drinking pints you need to go to the toilet and they're like 'oh you'll probably fit into the gents toilet' so you try but you can't and your chair won't fit in the cubicle and when I don't have my leg on I have no option but to go. I've had to go other places, I've had to leave one pub and go to another one to use a toilet just to come back and when getting annoyed at the pub they're like 'there's nothing I can do about it' or when you do find a pub with disabled toilets they're full of crap like a store room.

(Pete, 26)

Participants' capacity to go to the toilet is dependent on the provision of adequate toileting spaces in public. Private acts become a public matter, a matter of inclusion and being excluded from taking part in social activities, going to the pub or 'drinking pints' is felt. Furthermore, the enjoyment of these social activities is contingent upon and negotiated by the worry that there may not be an appropriate toilet. The public/private divide is challenged as public spaces are embodied spaces where private activities are enacted. Furthermore, exclusion is felt by impacting on how participants feel about themselves. Here

psycho-emotional disablism becomes imperative - the lack of recognition of 'going to the toilet' as a matter of equality and citizenship impacted on Pete's sense of self:

P: So how does that make you feel?

It makes me feel embarrassed and I get annoyed at myself for being embarrassed because I don't feel I should because I haven't done anything wrong but I feel like such a burden, I feel like such an inconvenience and it also means that you become a point of attention to people, people notice you and it becomes an ordeal and it shouldn't be. You should be able to go up and go to a toilet without having the whole of a restaurant looking at you because you've got to say excuse me, excuse me a hundred times to get there. So yeah it makes me frustrated and I do get angry about it but I tend to not say anything. I get annoyed because I want to say something but I won't say something because people will look at me and go 'oh he's just one of those bitter disabled people who needs to shout about it all' you know so it all becomes a bit of a nightmare.

(Pete, 26)

Pete did not only feel excluded because the toilet was inaccessible. Exclusion was felt as being seen as a burden or by being exposed as a difficult body with 'special' requirements. The lack of accessible toilet not only excluded Pete from the space but exposed his difference and made him feel different. While poor disabled toilets exclude people from participation it also impacted on how Pete felt about himself. It made him feel different.

7.1.2 The 'bladder's leash'

Many of the participants spoke about the process of using public disabled toilets. A large number of disabled toilets in the UK remain locked and can only be accessed by a 'Radar' key (Kitchen & Law 2001) under the National Key Scheme (NKS)¹¹. This means that when a disabled person needs to use a public toilet they

¹¹ The national key scheme: NKS <http://radar-shop.org.uk/Detail.aspx?id=0> is a scheme whereby disabled people can buy keys online to unlock public disabled toilets.

often have to go to another shop or location where they can collect the key. Furthermore, in many cases you are asked to go and wait at the toilet while the shop assistant brings it over to you. This is often to ensure that Radar keys don't go missing. Disabled people can buy radar keys online in order to access disabled toilets across the UK, essentially paying for the privilege to go to the toilet. Here it can be seen that 'going to the toilet' is contingent on a number of factors: access to a disabled toilet; access to radar key; and waiting for someone to unlock a toilet for you. This compounds the notion of the 'bladder's leash' (Cooper et al.1998).

Meg discussed the process of using a public toilet when a radar key is required:

M: ...y'know disabled toilets get used as a store room a lot and it does my brain in and then you have to wait an extra five minutes while you're already desperate for the toilet for them to move everything ... but I have a key...do you have a key [meaning Radar Key]?

P: No I don't have one

M: I have one...but I got it through means I rather wouldn't mention (laughs).

(Meg, 29)

Here it can be seen that disabled toilets being used for storage, which many participants spoke about, requires the controlling of needing to go to the toilet. For Meg, a Radar key means that toilets can become more accessible to her - although she refused to pay for it.

Ruby also discussed the practicality of using a disabled toilet and needing a key:

R: ... if you're going to a bar...the bar may be on the ground floor but the toilets might be downstairs. Or sometimes if they do have a disabled toilet it will be full of all the cleaning supplies and stuff and I get so frustrated sometimes. Obviously you'll know yourself but I hate it when you have to go to the disabled toilet and it says that you have to go and get a key and you have to go somewhere miles away to get the key and then go back...

(Ruby, 26)

It can be seen that not only does the key require that a person must 'hold it in' but they also have to publicly announce that they need the toilet to whomever it is that has the key, they have to wait for that person to come and make the toilet accessible to them. Once again, needing the toilet could be controlled by others.

Similarly, Meg spoke about the composition of disabled toilets and she felt that sometimes the space served to construct ideas about the impaired body. The lack of mirrors in disabled toilets made some participants feel that their bodies were not to be appreciated or looked at in mirrors:

M: Another thing that pisses me off in my day to day life is that disabled toilets never have mirrors as if because you don't need to or you don't want to look at yourself because of your hideous disability (laughs) so yeah so that really annoys me.

(Meg, 29)

Again, disabled people feel excluded at an embodied level. The lack of mirrors in disabled toilets brings to question a person's necessity to look at their body in the mirror - inaccessible toilets, different toilets and toilets without mirrors demonstrate that public provision and public spaces are built around ideas of 'normal bodies' and can limit the participation of those bodies in public spaces. The lack of mirror represented for Meg, the notion that her body was not acceptable and that she would not want to take part in the usual activities that can go on in public toilets. Toilets are used for a number of activities other than excreting waste; public toilets are also used to check your appearance and Meg felt that this was not open to her. Furthermore, disabled toilets often do not provide space in which someone who cannot walk or get out of their wheelchair can toilet, often forcing people to be changed or toileted on the floor.

This section has discussed the use of public disabled toilets and how the management of private activities can erect barriers to public participation. The next section will show how going to the toilet and having access to toilets can

create inclusion and participation and therefore demonstrating the relationship between private bodily experiences and citizenship.

7.1.3 Inclusion and public toilets

Toilets and participation in education

Where public disabled toilets were made accessible for participants it represented their inclusion at more than just an ideological level. They were able to take part because they had adequate provisions for their bodily activities. Some participants described their experience of accessible toilets and how it made them feel included on the whole:

P: In what ways do you feel you're treated better? [At College rather than school]

M: Well just in school I was always bullied in some sort of way and they [at college] just treat you as if you were anybody else...just like anybody else. If there's something wrong they'll fix it for you to make it accessible, like there was a toilet that was downstairs and it was a disabled one but if I wanted another one somewhere else then they'd get me another one somewhere else.

(Molly, 18)

Accessible toilets, for Molly, were juxtaposed with her negative experiences of school - her feeling 'just like anybody else' was realised through accessible toilets and provision for her in a public space. Again, Molly's inclusion and participation was felt through her capacity to use the toilet without issue 'just like anybody else'. As was discussed in the previous chapter feeling the same was integral to having citizenship in the full sense and this is recognized at the corporeal level.

Public toilets and participating in sports

Jack, a wheelchair athlete, discussed the importance of accessible toilets at sporting events and how this facilitated the doing of sport. For Jack, the

mainstreaming and inclusion of 'disability sports' in mainstream sporting arenas is felt through the provision of accessible toilets and changing areas for disabled athletes. For Jack this evidenced a level of acceptance and equality:

I think a lot of them [sports centres] are geared up for playing wheelchair sports in the facilities so obviously a lot of thought goes into changing facilities, toilets...they've all got them - some places could be doing with more especially when there's like a wheelchair tennis tournament and everyone's in the toilet at the same time and there's only two toilets. I think they certainly have made the effort to make things accessible and I think a lot of that is to do with the fact that you know a lot of them do host wheelchair events...

(Jack, 22)

Greg explained how accessible toilets made life easier, how it meant that less time had to be dedicated to going to the toilet and furthermore how it made taking part in wheelchair sports easier when the toilets were accessible:

Well playing the rugby we were playing in a secondary school and getting in was a bit of a nightmare cause there was a big curb and you're taking the sports chair up the curb and you're taking you up the curb and there's a ramp up into the sports hall and it's a case of 'oh where's the toilet' and there's a toilet out and round the corridor and you won't get in in your sports chair but you might get in in your everyday chair. Even in your everyday chair you might not get in so where's the disabled toilet and then you have to go down the hall, through a door, down a ramp, through another door and then push a button to get through to the accessible toilet and you think well that's no good it's a complete waste of time and we went into 'T' gym and everything was all flat and you go into the hall and the disabled toilets are right there and you can get in in your sports chair.

(Greg, 28)

For able-bodied people going to the toilet can be a taken for granted activity (in most cases); for some of the participants it became evident that going to the toilet had to be carefully thought about, planned and mapped out prior to

engaging in any kind of social or public activity - be that sport or college. Going to the toilet is understood as a very private activity. It is intimate to the body. This private activity is controlled and regulated, to some degree, by the planning and building of accessible and inaccessible toilets for disabled people. The feminist dictum that 'the personal is political' is useful to problematise the notion of a public/private dichotomy - going to the toilet becomes socially produced and publicly negotiated through accessibility or inaccessibility. Going to the toilet becomes a matter of equality and of citizenship.

Toileting and getting to work

Considering the 'semi-public' toilets of the workplace, Greg explained that going to the toilet was critically linked to his capacity to obtain and sustain employment:

If I have an accident I have to leave work. When I was working full time before I had a problem it wasn't a case of just nipping home it was a case of driving 30 miles to get home and then get sorted and get back into the car, get back to work to finish my shift. One of my friends he's working full time and he gets up at 6am to get in work for 20 past 9 and it's ridiculous. I hate not working; I want to get back into employment. I could work at the moment but it would be a case of working and not knowing what could happen.

(Greg, 28)

While what Greg discussed is what Carol Thomas maintains is an 'impairment effect' (Thomas 1999) - Greg's toileting problems were a result of his impairment-, it once again problematises the bifurcation of public and private. Greg's narrative illustrates the ways in which the 'private body' the urinating and defecating body are also 'citizen bodies' (Bacci & Beasley 2002). Greg's toileting problems impacted on how he could interact in the public realm, his potential for employment was linked to managing toileting and the importance of employment as pivotal to citizenship (as discussed in chapter two). Furthermore, it meant that Greg's daily experiences were enacted always with toileting in the background as this dictates where and when Greg could go places:

It can be murder though, it can take me hours to get ready in the morning and then I go out and have an accident and have to get changed and then I'm miles away and I have to drive home. It annoys me but it's a case of... it's just life now...life as a disabled person.

(Greg, 28)

The public and private are operating on a continuum whereby 'employment' and 'toileting' are necessarily interconnected through the body. The body becomes the site of this citizenship whereby toileting becomes a crucial part of Greg's participation or non-participation. Greg characterized his life as a disabled person as one where his toileting was always at the fore of his experiences and daily life. Furthermore, as Greg acquired an impairment 11 years earlier, negotiating going to the toilet was crucial for him in navigating his life as a disabled person. Greg's narrative illuminated the relationship between citizenship and the private sphere or more importantly bodies as private issues become integral to his inclusion.

This section of the chapter has explored toilets as a matter of inclusion and exclusion; it has considered how the private activities affect citizenship and the way that this impacts on embodied experience. Participants reported that good toilets meant good inclusion, it promoted feelings of belonging and value. The construction of disabled toilets, and the fact that they were often filled with cleaning products led to participants feeling unwelcome, and unwanted. While this section of the chapter highlights how participants' everyday lives were affected and shaped by toilets, the following section will consider how the 'private' sphere related to citizenship in relation to the home. The following section will begin to explore notions of 'control' and how participants' experiences of their own homes affected their everyday citizenship but also how this was restricted and controlled by the state.

7.2 Citizenship and the home

While the previous section explored toilets as a site of citizenship and participation, for participants, this section will focus on participants' thoughts and feelings about the home. The 'home' has been characterised as being part of the domestic, 'private' sphere. Feminist authors, in particular, have written about the necessity for the domestic or 'private' sphere to be recognised and understood as part of the political sphere and not separate from it, in order to conceptualise and practice citizenship in an inclusive way (Lister 2007, Prohovnik 1998). For many disabled people, the home requires adaption and this in turn, often, requires intervention from the state in the form of adaptations, accessibility and inclusive design. In this sense the state had a level of control over how participants experienced their homes; both the decision to fund adaption and not adapt homes properly had a lasting impact on how participants could participate in not only the 'private' sphere of the home but the 'public' sphere. This section of the chapter will explore control and intervention before considering more pervasive control in the following section.

7.2.1 'Private spaces': Inaccessible homes

This section will begin by considering participants' experiences of their homes, adapting their homes so that they are accessible to them and instances where homes have remained inaccessible. The participants, for the most part, felt that they were included and had access to public spaces such as buildings, cinemas, shops and so on. By contrast, participants often discussed their own homes as being inaccessible and felt excluded within these spaces. While 'the home' has been constructed as a private space (Prohovnik 1998), this was often not the case and it became apparent that how participants experienced and accessed their homes was shaped by interaction with local authorities. For some participants, the process of adapting their homes posed many barriers and to some extent the way in which homes were adapted was out of their control.

The adaptation of Jack's home restricted both Jack's and his family's capacity to move home or move out of home if they wanted:

The fact that we got a new accessible section of our house built last year means that I won't be moving out any time soon. I think I have to stay here for at least 10 years because it was a council grant that supplied it, yeah so they fund it but I have to live here a certain amount of time to warrant it. I'm not sure if it means 'us' as a family but I really think it would be me cause it's for my needs. It definitely said 10 years on the letter they sent out so I have another 9 to go (laughs).

(Jack, 22)

The local authority controlled Jack's accessible housing, where he could live in the future and his independent living because they had granted him adaptations for his parent's home. Jack's example demonstrated the ways in which the state had an active role in shaping how participants experienced and accessed their homes. It can be seen that policy and political decision making impacted on Jack and his experience of his home through the control of private spaces. This is particularly problematic for disabled young people whose 'transition' to adult life or independence can be a longer process due to managing impairments, expectations, parents and so on. Jack's ability to live independently was out with his control. The privacy of the home was not only subject to the state but the use of that home by both Jack and his family was stipulated on a temporal basis. Jack's example explored the way in which participation in the home becomes contingent upon policies governing adaption - it impacted on Jack's citizenship as it restricted his option to live independently away from his parents, whether he could gain employment in another city or move in with a partner for example. The decisions that were taken to provide accessibility in Jack's home in the present would deny him independence and autonomy in his future.

Finally, the lack of adaptation or appropriate adaption in Jamie's home has meant that he found it very difficult to manoeuvre around his house in his wheelchair. It restricted how he could use the space and his experiences of intimate processes such as toileting:

The house isnae suitable, it's got a special toilet and rails and that in the toilet but the house is just too wee and it's got the ramp and that but I cannae get in

and out the kitchen or the toilet. It makes you feel bad cause my dad's had a stroke and that as well .I'm not getting any privacy really and if I go into the toilet I can't shut the toilet door cause the wheelchair is in the toilet and then the kitchen as well when I go into the kitchen it's like an 'L' shape and I have to drive in and reverse oot and you cannae move about cause it's dead narrow and if there was a fire or that it would be hard to get out cause the hall's dead wee as well and you can't turn around in the hall.

(Jamie, 19)

As can be seen in Jamie's example, he had some adaptations in his home, however the local authority would not move him and his dad to a more appropriate house and they could not afford to move anywhere else without local authority help. Where participants required the most financial support, they had the most restrictions on the choices they could make. Jamie was one of the participants from a low-income background and lived in a very deprived area in Scotland and this brings to the fore the classed dimension of access to the home. Wealth and higher income meant that access to and within the home was affordable without state intervention. Poor adaptation in the home shaped Jamie's everyday life extensively; eating, toileting and moving within his home was difficult for him. Jamie felt excluded in his own home and felt that he was not able to live independently as a result. This had a negative effect on his self-esteem and wellbeing:

It's really bad, it makes me feel bad about myself cause I cannae get into the kitchen to make food or that and that's one thing I would like to do.

(Jamie, 19)

Both Jamie & Jack's examples highlight how the 'private' sphere affected citizenship and participants' everyday lives. These examples also give insight into how citizenship is linked to state intervention and control in the 'private' sphere. Both a lack of adaptation and state funded adaptation in the home impacted on participants' citizenship through restricting where they could move to, their independence, their capacity to toilet accessibly and cook accessibly.

7.2.2 Reclaiming the home, resisting control

As the above section showed, participants who required adaptations to their home became subject to the control of the state. While some participants felt unable to challenge the restrictions placed on them, other participants had to find other means of making the home accessible, often at their own expense.

For Meg, the process of adapting her home was quite difficult. Like Jack and Jamie, where Meg could or could not go in her home was dependent on the decision-making of the local council authority:

The second time I came to view the flat I got a lady from the council to come with me to tell me if she thought I could get a ramp and tell me if she thought I could get the step fixed in the bathroom. So because you have to have a path of a particular length in order to have the ramp...A foot of ramp for every inch of step...is that not the most ridiculous thing ...a foot of ramp...legally speaking and she was like 'well I mean I'm not sure if your path is long enough' - so I decided fuck it! I'll just go ahead and get the flat and this was before they had confirmed that I could get a grant to fix the bathroom floor...when I first moved in my dad actually made a ramp for me which is not 6 foot long (laughs) it's actually at the back door now because they would only build one ramp...even though there's a step at the back door and the front door apparently they only have to provide you with enough access to get into your house they don't need to do one for the back.

P: How would you take your bins out?

M: Exactly... I said that to them and they told me if I wanted another ramp for the back door then I would have to pay for it...and I wasn't going to pay for it, it's accessing my house...and they said it wasn't [essential].

(Meg, 29)

Meg highlights that how people operate within the 'private' sphere of the home was dependent upon the decision makers that funded and supported adaptations, how those adaptations were to be carried out and what parts of the

home were *essential* for Meg to access. In this example, the local authority controlled how Meg would experience her own home, and what access she had to all parts of her home. However, Meg's decision to 'fuck it' and 'just go ahead' and make the adaptations without knowing where funding would come from demonstrated the assertion of her agency. While there were barriers to her accessing her personal spaces such as her bathroom, Meg took the decision to control those spaces by making the adaptations anyway albeit at her own expense.

The state and the body are connected; the state makes decisions about how these participants experienced everyday life and private spaces such as using their homes, how long they had to live there for, whether they could access their toilets, bathrooms or kitchens and these all had impacts on their wider participation. Here it can be seen that the public/private divide becomes an unhelpful dichotomy when considering participants' lived experience of citizenship and participation. Through the examination of the home as both a private space and a space where citizenship and participation is practiced then we are better able to explore citizenship as experienced on multiple terrains.

This section has explored participants' experiences of private spaces and in particular their homes and this has been done within the context of control. It has been concerned with how political decision-making impacts on the body in private spaces.

The previous section has explored how, for some participants who required additional support or adaptations, everyday experience was linked to state intervention and control. The following section will explore control and intervention more deeply. It emerged that participants' who had more severe impairments required more support were subject to greater control and intervention from the state and this had far reaching implications for their everyday citizenship.

7.3 Personal assistance: control, choice and independence

This section will explore further the relationship between the private and public spheres by examining the complex relationship between state intervention and private activity in particular participants' lives. This section will focus on the complex ways in which control plays a part in participants' lives; both private and public. It will focus on participants' experiences of personal care and assistance and examine how the management of their private activities is connected to their public participation and the role that the state plays in shaping how and when this occurs. This section will focus on the assertion that those who are seen to have the least control over their own bodies are subject to more control by the state and state intrusion; that control over one's body is, in many ways, the litmus test of social competence (Goffman 1972, Giddens 1991, Bacci & Beasley 2002). This is salient to disabled people as often state intrusion or the limitations of autonomy on disabled people is precisely because they have an impairment or are seen to be 'reduced to their bodies' and thus there is a historical legacy of marginalization based around bodily difference.

Disabled people who require an additional level of assistance in many ways experience more control by the state and this can be seen in the coalition government led cuts to disabled people's welfare, as Bacci and Beasley write:

The role of the state is described in terms of not intruding on a citizen's control over their body, a control that is equated with political autonomy. If a political subject is deemed not to exercise this control, forms of regulation and constraint - limitations on 'autonomy' - become justifiable. The 'control over body' subject is equated with 'citizen', whereas those reduced to their bodies are constituted as lesser citizens.

(Bacci & Beasley 2002, 325)

This section will be concerned with those participants whose 'autonomy' is limited based on their requirement of a high level of assistance; it will focus on

their experience of citizenship and participation as connected to their bodies. The previous sections have focused on instances where participants have experienced ‘limitations on their autonomy’ or rather choice because they require use of adaptations or have additional toileting needs - however this section will focus on ‘limitations of autonomy’ as more pervasive as particular participants are seen to have less control over their bodies.

7.3.1 Personal assistance and personal care

Most disabled people, and to be sure non-disabled people, require assistance in their daily lives. However (as examined in data chapter four) the participants required varying levels of assistance or support to go about their daily lives. As has already been discussed participants’ required assistance in the form of adaptations in their homes, cars and workplaces and also in the form of accessible toilets in public in order to participate on a par with their non-disabled peers. Some of the participants required an additional or higher level of assistance and support. While most of the participants required the kinds of support listed above, Vicky (26) for example required 24 hour support:

V: Almost all the time I need someone [a personal support worker]

P: So that’s the level of support that you need to participate?

V: Yeah yeah yeah

(Vicky, 26)

So while most of the participants did not require personal assistance, a particular few such as Vicky required personal assistance ‘almost all the time’ and this included bathing, toileting, dressing and eating. For Vicky, having access to personal support was liberating and allowed her to go to university away from home, to live in halls of residence and to participate on a par with others. Personal assistance provided independence for Vicky, and support in the management of personal activities such as toileting and bathing made it possible for her to enjoy her citizenship.

The daily experiences of 'personal' activities such as these have had little attention within disability literature (see Hendel & Pascall 2001, Morris 1991, Priestly 2001) as have their connection to wider social structures and so called 'public' participation. Within the concept of 'the personal is political' it became clear that these personal experiences were connected to the public but political decision-making, public policy and public participation for the participants. While for the most part personal assistance and support, whether in the form of assistance, adaption or accessibility, was liberating for most of the participants - there were some participants whose experience of personal assistance and support represented a tension between independence and control.

This section will focus on two participants' experiences of personal assistance and support in their daily lives as a lens through which to explore control in everyday life. Although the majority of participants did not require continuous personal support, many disabled people do and although minorities, these experiences necessitated representation.

The first will examine Daisy's (26) experience of personal assistance and care at home and then as she moved into transitional residential care and how this impacted on her personal and public participation, and the second will focus on Ruby's (25) experience of managing her oxygen and breathing and how this related to wider policies of health care and distribution in the UK and its subsequent impact on her personal life.

7.3.2 Managing personal care: Daisy

For some of the participants, private spaces became regulated and facilitated by carers or assistants thus problematising the notion that the 'private' sphere is separate from the public (Twigg 1999). Participants' became subject to the care packages and protocols that managed intimate activities such as washing, toileting and dressing. While Vicky's narrative described positive experiences of personal assistance and characterised it as promoting participation and independence, Daisy (26) had a more complicated experience of personal assistance which highlighted the tension between independence and control and the relationship between the private and public.

This section will focus on Daisy's experience of personal assistance as a case study aimed at examining the relationship between private and public and within that the relationship between independence and control.

Like Vicky, Daisy required 24 hour assistance:

On a daily basis I require like personal care support to get up in the morning and all that sort of stuff, get washed and dressed and then throughout the day to go to the toilet...

(Daisy, 25)

Daisy also required further assistance in cooking and eating, and throughout the night in being able to turn and to go to the toilet. Daisy, at the time of the interviews, lived in transitional residential care and was the only participant who lived in residential care. She described how her personal assistance was managed prior to moving to the transitional care home:

D: I got 4 visits a day for personal care but as I was saying to you earlier with the best will in the world I'm not a robot so...

P: So what would happen if you needed to go to the toilet more than 4 times a day?

D: I needed to ask my dad or his partner or my friends if they were around and don't get me wrong if they were round they had the hoist out before I'd even finish the sentence but the point is and one of my reasons for doing what I'm doing and looking to the future is my dad's not fit to do it now but because he's there they would expect him to do it.

(Daisy 25, lives in residential housing)

Whilst living at home with her dad, Daisy had a negative experience of personal assistants and often her personal care had to be facilitated by her dad. In the first instance Daisy's narrative indicates how personal activities are, for some disabled people, managed by public policy in the form of 'the care package' -

this placed control over how Daisy had to manage her toileting and was sometimes dependent on when carers showed up and if they did was limited to 4 visits a day. This was problematic for Daisy in a number of ways, firstly it meant that her toileting, as a 25 year old woman, was at times managed by her dad but it furthermore removed Daisy's independence. Daisy was 'looking to the future' and was conscious that her dad 'was not fit' to manage her personal care. In order to achieve more control over her care Daisy chose to move to a transitional residential care home that would provide her with independent living, and crucially for Daisy, to alleviate some of the care pressures from her dad.

Living in residential care meant that Daisy got to live much more independently:

It's not your traditional residential care. Everybody has their own flat and everybody gets up in the morning and does what they need to do whether that's with or without support...

P: It sounds to me like that's the perfect assisted living situation?

D: Yeah that's right

(Daisy, 25)

Daisy chose to move out of her family home in order to achieve more independence; she sacrificed a level of independence from the state in order to achieve more control over her personal assistance and activities. However, Daisy's decision to move into residential care and have an additional level of support led to restrictions and limitations placed on her participation in public activities such as attending university and in the management of her own money. Because Daisy lived in residential care she was unable to keep the stipend she had been awarded to do her PhD full time, she was forced to do her PhD part time and without any funding because whilst living in residential care she was only allowed to keep specific amounts of money:

D: No, when you're in residential care the only money that you're allowed to keep is your motability money [disability living allowance mobility component], that and about £20 a week. That's it.

P: So you're not allowed to keep any money that's your own?

D: No, a part from your motability money.

(Daisy, 25)

Daisy's experience represented a complex interplay between public and private and independence and control and this was all connected to the kinds of assistance she required in her daily life. Daisy's choice to go into residential care and have her living supported and facilitated by the state meant that she gained independence in her toileting and bathing and was able to control and manages how this was done. However, in doing so she experienced a loss of control in other areas of her life such as in doing her PhD and managing her money. Her management of her toileting had direct impacts on how she experienced her public participation. Due to the kind of support that Daisy required she was limited in the choices that she could make about her own life and further that she was forced to make choices about over which areas of her life to lose control in order to gain control in others:

The social work are always like 'you're very unique, it's unknown for somebody who's able and wants to go to uni and work to be in residential care' so that's where a lot of the arguments come from...

(Daisy, 25)

Requiring support in her personal activities and its public management directly impacted on not only how Daisy experienced her personal activities but directly affected where she could live, whether she could do a PhD and how much money she could have of her own. 'Social work' highlighted the tension that Goffman (1978), Giddens (1991) and Bacci & Beasley (2002) all pointed to: because Daisy required personal assistance and assisted living her decision making capacity about her own life was limited as more control was asserted by the state.

Furthermore, assumptions made by social work about the kind of person who lives in residential care or the kind of person who attends university erected barriers to being (Thomas 1999) for Daisy and was an example of psycho-emotional disablism.

7.3.3 The politics of breathing: Ruby

Ruby was one of the participants whose daily experiences were very different from the others; she, in many ways, was an outlier. Ruby (25) had been diagnosed with Cystic Fibrosis from birth and the resulting deterioration of her CF meant that she had significant impairments making it very difficult for her to breathe or walk and so she had a number of mobility aids to support her in her mobility and more significantly she used oxygen canisters, which she took everywhere with her, in order to breathe properly whether at home or out.

Ruby's ability to do daily tasks; go out, see friends, and go to work, were all reliant upon the oxygen that she had and how long it would last. Ruby's daily experiences were divided into sections of time based on either six or nine hour oxygen canisters:

So when they [oxygen canisters] run out I have to go home and fill them up again, so it's very limiting because I can't stay out overnight anywhere cause I just don't have enough oxygen.

(Ruby 25)

The means by which Ruby had to manage her breathing meant that she was unable to socialize with her friends in the way that she wanted, she was not able to sustain an entire day at work due to the temporal dimension of her breathing and she felt unable to have a sexual relationship because she had to wear an oxygen mask through the night. Ruby explained that in order to go on holiday or go away from home she had to book an oxygen compressor over six weeks in advance meaning that how she achieved many of the activities she wanted to were out of her control and subsequently dependent on being able to book an oxygen compressor. Ruby described the level of planning that controlled how she lived her life:

I've got to be very organised and think 'right where am I going today, I'm going to be out there and then think should I use the 6 hour first or the 9 hour first?' And then swap them over, and when should I swap them over? Is it going to last me until that time? You just have to plan things.

(Ruby, 25)

Ruby, due to the severity of her impairment, would be deemed 'not in control' of her own body or 'reduced to her body' and therefore in many ways was subject to the control of the state in terms of how she managed her breathing in her everyday life (Giddens 1991, Bacci & Beasley 2002). The limitation on participation based on how Ruby was forced to manage her breathing was entirely contingent upon policy and NHS (National Health Service) decision making for those with CF in Scotland.

Ruby, at the time of the interviews, was trying to find funding to buy an 'oxygen compressor'; a small device that would allow her to manage her breathing freely and no longer be dependent on oxygen canisters. The compressor would mean that Ruby would be able to work without restriction, socialise without restriction; she would be more mobile as the compressor is lightweight and could recharge the batteries simply by plugging it in. However, it became apparent that the compressor cost upwards of £5000 which was unaffordable for Ruby. The NHS supplied them to people with CF in England but not Scotland. Politics, policy and decision making on health care based on geography directly impacted not only Ruby's health but also her capacity to participate on a par with others:

I feel quite angry about it 'cause I feel like I should be provided with that, especially if young people in England get it for free.

(Ruby, 25)

For Ruby, the management of her breathing demonstrated the tension between accessibility, independence and control. While use of the oxygen canisters meant that Ruby had a certain level of independent living this was regimented and controlled by the size of the canisters she could have. Furthermore the politics of healthcare distribution in the UK directly impacted Ruby's everyday

life due to her not having access to an oxygen compressor. Ruby was limited in her capacity to buy an oxygen compressor for herself. This was not only unaffordable for her but she was not allowed to spend her DLA to fund the compressor. While Ruby's case study was not commensurate with the experiences that other participants had it allowed a lens through which to examine the ways in which state involvement or control (in this case over medical services) impacted on Ruby's everyday experience and thus highlighted the complex ways in which the 'public' and 'private' comeingle and intertwine.

7.4 Conclusion

This chapter has explored the participants' experiences of inclusion and exclusion in their everyday lives. The key themes that emerged were control and intervention. The first section of the chapter looked at 'private' functions of the body and how these impacted on everyday life; accessing 'the public', going to work and feeling included were all bound up with going to the toilet. Participants spoke about going to the toilet and toilets frequently. What emerged was that good accessible toilets led to wider feelings of inclusion and belonging whilst poor inaccessible toilets were barriers to participating on a par with others. Toilets were often used as store rooms or cleaning cupboards which led participants to feel like they were not welcome in certain spaces like pubs or clubs. The notion of the bladder's leash, limitations placed on the body by inaccessible toilets, was highlighted by participants' needing to find a key to use a public toilet or managing their fluid intake in order to avoid having to go to the toilet. What could be seen was that toilets were a key part of everyday citizenship and participation.

The second section began by exploring participants' feelings about their homes and the kinds of adaptations they needed in the home. Participants who needed adaptations experienced more control and intervention by the state and this shaped, not only, how they accessed their homes but also how they participated outside the home. Some participants' adaptations determined how long they would live in a single place. It began to emerge that where participants required more support they had less control over their own lives and at times were forced

to forfeit some forms of choice to access others. This section aimed to explore how 'public' authorities affected the 'private' sphere.

The final section looked at participants who had the most control and intervention exerted over them. These were the participants who were seen as having least control over their own bodies (Bacci & Beasley 2002). This section focused on two participants in particular in order to explore themes of private/public, the body and control. Daisy required the most support out of any of the participants; everyday Daisy required assistance to get dressed, go out, eat, sleep and go to the toilet. This resulted in her having very little control in some areas of her life, such as her bladder. Daisy's story explored how seemingly 'private' activities shaped how Daisy was able to participate. Similarly Ruby's case study explored breathing and how her breathing was linked to policies around the distribution of oxygen through canisters and compressors. Ruby's story showed how her everyday life was controlled and shaped by her access to oxygen. This final section aimed to explore how participants embodied citizenship and how 'private' aspects of their lives were interwoven with their participation and inclusion. The next chapter will explore participants' thoughts, feelings and fears about 'the cuts' and how the support that had made them feel equal and able to participate was under threat.

Chapter 8. Facing the ‘Cuts’: participatory parity and precariousness

Our experiences are always already contingent upon the things that facilitate, enable and direct them. For disabled people, experiences, rights and citizenship are always already contingent upon the myriad ways that support can facilitate inclusion and participation and subsequently remove them. This chapter seeks to explore the notion of contingency; that the kinds of experiences and lives that the participants have come to expect and enjoy are conditional. As explored in chapter one, the level of sameness that the participants felt was fragile and easily broken. Similarly, the level of participation and access to mainstream spaces were contingent or reliant upon the things that facilitated that inclusion, be that state funded support, support from family and friends, inclusive education and so on. Many of the participants discussed how their lives would be different if they had never had a certain level of family support, or if their access to financial support or mobility support was removed. These narratives exemplify the contingent nature of citizenship and of rights for the participants and for the wider disabled community in the particular political climate at the time of interview, in 2011/2012.

The most striking and pervasive aspect of these narratives were participants’ discussions of the provision that they received that enabled them to do things in their daily lives. This was mostly discussed within the context of the then impending welfare reforms that, as of 2010, had been proposed by the Coalition Government to completely re-imagine ‘benefits’ for disabled people in the UK (Department for Work and Pensions 2010)¹². Discourse that have used the deficit as a basis for making cuts has led to a large scale overhauling of the benefits system in the UK as well as health care provision and tax credits and so on (Roulstone & Prideaux 2011 see also Patrick 2012). While it is by no means only disabled people who face the ‘cuts’, arguably the fall out of reform to disabled people’s benefits will completely alter the way in which disabled people live their lives (Wood and Grant, 2012).

¹² The Public Consultation on Disability Living Allowance Reform (2010) can be accessed at <https://www.gov.uk/government/consultations/disability-living-allowance-reform>

Disability in Austerity

It is important to highlight the temporal and political context within which these data was gathered. As discussed in chapter four of this thesis, the data were gathered and participants interviewed from 2011 to 2012. At this stage in data collection many of the proposed disability welfare reforms had been in the process of consultation, for example the reform to DLA had been proposed but not yet come into force. Only two participants had actually been impacted by disability welfare reforms in any way. While the focus of this research and this chapter was not on the impact of austerity on disabled young people, it did emerge as a theme. Policy change was not a key focus and the aim was not to define the cuts. However, it became clear that participants were not aware of the extent of the cuts but rather their fear of the potential for cuts and how this impacted on their embodied selves formed a central theme in participants' narratives. While austerity was not the main focus of this research, it is necessary to present the links between disabled people's disproportionate receipt of the cuts to academic work on austerity. More detailed discussions on the relationship between disability and austerity can be found through the longitudinal work undertaken through the *Destination Unknown* project (Wood and Grant 2010, see also Wood and Grant 2012). This work has uncovered the lasting impact that welfare reform has had on access to public services, support services and most strikingly the sense of fear and precariousness that disabled families lived with, since its proposal in 2010. This sense of fear, unknowing and precariousness mirrors the findings presented in this chapter.

Certainly Mary O'Hara's (2014) recent work charts the ferocious impact of Governmental austerity measures on disabled people and chronically ill people in particular. Although none of the participants in this research had yet been impacted by the reform of DLA by 2011/2012, by 2013 it became clear that the move to Personal Independence Payments (PIP) would drastically impact on disabled people's access to mobility (O'Hara 2014). This is something that participants voiced deep concern over at the time of interview. Like the work of Wood and Grant (2010 see also 2012), O'Hara discusses the visceral feelings of fear and uncertainty engendered through austerity (O'Hara 2014, 209).

Chapter outline

This chapter seeks to explore the precarious position that participants occupied in relation to the cuts; the ways in which the participants' experiences, rights, inclusion and ultimately citizenship were dependent upon the support they received from the state. Citizenship is not fixed or static but dynamic and shifting. For the participants, there was an additional layer of need that meant removing, restricting or limiting the ways in which they could participate would drastically alter their capacity to get dressed in the morning, go to work, go to university and socialise for example. Furthermore it emerged throughout the interviews that the process of welfare reform, in particular, had deeply impacted on participants' feelings towards themselves, their status and their sense of inclusion and belonging to a wider social or citizenship community resulting in negative impacts on psycho-emotional wellbeing. Citizenship is lived and constructed through the many avenues that enable participation and this becomes increasingly salient when considering disabled young people who are currently residing on a precipice.

This chapter will be comprised of three sections. Section one will focus on what participants used support for. The first part of the section will consider the role that parents, in particular, took in providing support and inclusion. This section will then explore the avenues that the participants have taken to support their inclusion; this will be done by focusing on participants' use of state funded provision and support for disabled people through avenues such as the DLA, the ILF and, in particular, the 'Motability' car hire scheme which acted as a life-line for some participants. Furthermore it will focus on the ways in which participation was dependent upon enabling facilities such as adaptations, inclusive education and support by family and friends. This will make visible the ways in which citizenship and 'participatory parity' (Fraser 2008) was achieved by the participants.

The second section of the chapter will explore the impact that restricting or removing support might have on participants' capacities to live their citizenship. This section will consider participants' fears and worries regarding the potential cuts to disability welfare and how this might impact on their capacity to participate. This will be done within broader discussions of 'recognition' and

‘redistribution’ as necessary for both social justice and inclusive citizenship that recognises and appreciates difference. Participants’ thoughts and feelings about the impact of welfare reform and will be framed within Thomas’ (1999) and Reeve’s (2002, 2012) constructions of ‘barriers to doing and being’ and psycho-emotional disablism.

The third section of the chapter will seek to examine the impact that contingency had on participants’ feelings towards themselves. It will reconvene with notions of ‘maintaining sameness’ that were covered in chapter five and show that feeling the same and feeling equal was often bound up with and dependent upon the material support that enabled good inclusion and participation; that without this participant’s feelings about their selves and their self value were often affected. Section three will also look at the body sensations participants’ talked about when considering the effects of the cuts on their lives.

8.1 Levelling the playing field: facilitating participation

Participation, inclusion and access to the formal rights that constructed ‘inclusive citizenship’ were often dependent upon the myriad avenues of support that enabled participants to take part on an even playing field. As discussed in chapter five, participation was, at times, dependent upon the support and attitudes of families and friends, teachers and other authority figures and perhaps more instrumentally upon the formal financial support mechanisms that facilitated inclusion and participation.

8.1.1 Support from families

Families played an important role in facilitating participation for many of the participants. Many of the participants discussed their families as being instrumental in enabling them to attend mainstream schools, university and being able to take part in mainstream activities. In many ways this familial support provided the foundation for and enabled inclusive citizenship; for some of the participants this meant that their capacity to participate was dependent upon the support offered by parents and other family members. Families often acted as key gatekeepers for participation.

Anna explained how her mother fought for her to be able to attend a mainstream school where local authorities were adamant that she should have attended special education. It was through the support of her mother that Anna was able to attend mainstream education and participate with her able bodied peers:

P: Did you go to mainstream school?

A: Yeah I did, my mum had to fight a lot with the council to let them do that. They didn't want me...I'm 23 so it was the early 90s and they didn't want me in mainstream school because they had never had a disabled person before. My mum had to have meetings with the council and meetings with my doctors and physios and things to say that I was physically disabled and perfectly capable of going to school. Eventually she won and I went to a mainstream school and it was ok.

(Anna, 23)

While Anna's narrative shows the ways in which families support and promote feelings of sameness, which was discussed in chapter five; Anna's example explicated the added level of support required, whilst not always material, to be able to attend a mainstream school in order to be able to participate on a par with her able bodied peers and the battles her family had to have in order to get Anna into a mainstream school. This example separates the additional level of support required by disabled young people that makes their access to the terrain where citizenship is practiced often distinct from their able bodied peers. For example, not all able-bodied young people can attend the schools they want to attend; this is often dependent on income, geography and so on - their exclusion, however, would not be founded on physical difference. However they are able, without facing barriers, to attend mainstream education and receive the same education as their peers. Anna's example demonstrates the ways in which access to participatory parity was possible by having a supportive family that negotiated her rights for her in relation to the state.

Participants often discussed the ways in which parents had supported their rights to attend mainstream education where they had faced barriers to that inclusion. Similarly, participants had discussed instances where authority figures such as teachers acted as barriers to inclusion or participation; whereby their participation was enabled by the support given by parents. Jack's teachers had not wanted him to take part in physical education in the school, they maintained that they would not be able to assess or examine him on the same grading scheme (standard grades) as his able bodied peers. As a result their solution was to prevent him from taking part in swimming, or other sports at the school, instead Jack watched DVDs while his peers enjoyed physical education. Jack's parents had repeatedly tried to demonstrate to his school that he was a competent swimmer and even got his personal swimming coach to testify to this. The result was that the school and Scottish Qualifications Authority (SQA) decided that he could not be graded the same way as everyone else and could only ever receive a mid level grade regardless of his performance in exams. Jack discussed how this made him feel and how it impacted on his taking part in school at higher¹³:

They were just going to give me a general mark because they basically had no alternative way of grading me. To me it wasn't like maths where I should be able to do the same exam as everybody else, PE [Physical Education] has got a totally different structure for disabled sport and you would think they would be able to adapt it. It's not like any other subject in the school, whereas disabled sport is a whole sport in itself but because they did not have anyone disabled before they basically didn't know how to deal with me, and it put me off doing higher. I didn't do higher at school because I just wasn't willing to put myself through another two years like that and I should've been doing higher because I did lots of sports out with school and I enjoyed sport and I still enjoy sport....

(Jack, 22)

For Jack, participation was restricted to the ways in which the school and education authority were willing to facilitate his inclusion in sport. The 2012 Paralympic Games has brought to the fore the importance of inclusion in sport

¹³ A higher qualification refers to the Scottish national school-leaving certificate awarded by the Scottish Qualifications Authority (SQA). See <http://www.sqa.org.uk>.

for disabled people as being an active and relevant part of citizenship. Jack's capacity to play sports in school and receive formal qualifications in sport on a par with his peers was dependent upon the support provided by the school. Jack's narrative brings to light the tension that many of the participants experienced; while many of them had access to mainstream schools the level at which they could achieve 'participatory parity' required inclusion and best practice which for some of the participants, like Jack, meant that there were barriers to the kinds of qualifications he could receive. Jack was 'misrecognised' as a person capable of sport and this was mediated through his having an impairment, by being characterized as different.

This section has aimed to show the nuanced ways in which access to participation and the terrain upon which citizenship is practiced is often dependent upon the support and willingness of parents, teachers, and education authorities and so on. The next section will explore the ways in which participants accessed formal support through mechanisms such as the DLA and ILF and how these provisions facilitated inclusion for them.

8.1.2 Accessing formal support

The DLA is arguably one of the most crucial avenues of support for disabled people in the UK. The DLA emerged in 1992 replacing the Attendance Allowance and Mobility Allowance (Department for Social Development)¹⁴. It was proposed by the Thatcher Government as a way to provide extra financial support for disabled people to overcome environmental, social and economic barriers and ironically now faces dissolution by the Conservative - Liberal Democrat Coalition Government (Patrick 2012 see also Wood and Grant 2012). It is made up of a care or living component and a mobility component which was often used by participants to fund a car through the 'motability' car hire scheme. The DLA came under scrutiny in 2010 along with the broader proposals of welfare reform through Governmental welfare reform (Department for Work and Pensions 2010). The DLA has been wrongly publicised as an 'out of work benefit', however receipt of the DLA is not dependent on employment or unemployment and many disabled people including the participants used their DLA in order to get to and

¹⁴ Background Notes on Disability Living Allowance can be accessed at: <http://www.dsdni.gov.uk/dla>

from work every day. Participants also used the ILF in order to access personal assistance in order to live away from home and attend university, for example.

This section will explore participants' narratives around how they used their benefits to participate and maintain a level of equality.

Personal support and assistance

Daily personal support and assistance, it is one of the most fundamental ways that participants, and many disabled people throughout the UK, used their benefits to participate and be included in daily life. The intersectionality between the use of welfare provision and numerous other activities is so pervasive in disabled people's lives that it is quite a task to neatly compartmentalise. Two of the participants required 24 hour daily assistance in order to achieve participatory parity (Fraser 2003).

Daisy required state funded support through the mechanisms of assisted living, and DLA to be able to realise the basic needs that allowed her to go about her day:

On a daily basis I require like personal care support to get up in the morning and all that sort of stuff, get washed and dressed and then throughout the day to go to the toilet and I need...I can do stuff in the kitchen and some of the meal preparation but I need somebody there to just be there... I also need support through the night to move 'cause I can't turn right over.

(Daisy, 25)

Support, allowed Daisy the necessary means to participate in her daily life and social world in all the ways she wanted. In order to go to university every day, go out and meet friends and so on - Daisy used her benefits to get up in the morning, brush her teeth, go to the toilet, eat and sleep safely. Having access to this kind of support made it possible for her to choose and shape her living independently and meant that she could take part on a level playing field with her non-disabled peers. As discussed in previous chapters, without this level of personal assistance Daisy would be reliant on her family and tightly timetabled

carers to be able to 'do' her everyday life. Daisy used her assistance to access many of the formal rights that contribute to citizenship and have a sense of belonging (Lister 2007). Citizenship, then, was for Daisy dependent on the continued receipt of these avenues of support. The level of participation that she enjoyed was only realized through these mechanisms of support. It can be seen that enabling citizenship for many disabled people across the UK, was expensive and unlike other minority or marginalized groups there is an additional level of redistribution required for participatory parity (Fraser 2003, 2008).

Similarly, Vicky required assistance in order to attend university and to live independently from her family in another city from her parents. Like Daisy, Vicky required 24 hour personal assistance and this facilitated her living independently. Vicky used her ILF to fund her support away from home. Vicky's narrative focused on her sense of belonging at university, her feeling a part of the student body and her inclusion in university life. Vicky could live in halls of residence because she had a personal assistant who stayed with her. Good support and provision at university enabled Vicky to feel included in university life this was achieved not only through the support of a personal assistant but through supportive staff:

P: Did you feel things changed from being in school to coming to uni?

V: Oh yeah. There's more acceptance for everybody and I'm more accepted by everybody.

P: Do you feel that staff are inclusive at uni?

V: Yeah yeah. We have a whole programme and we get support for exams and assessments and things

(Vicky, 26)

The concept of inclusive citizenship, which is promoted by feminist citizenship scholars places emphasis on belonging as crucial to good inclusion and participation (Lister 2003, Lister et al. 2007, 2007, 2010; Werbner & Yuval-Davis 1999). Good support meant that Vicky could not only attend university but also

felt that she was accepted and belonged there. Through state funded support such as the ILF, Vicky was able to experience University life. This represented not only overcoming ‘barriers to doing’ but also ‘barriers to being’ - not only could Vicky ‘do’ university but she could also ‘be’ someone who lived independently and experience the student community in an inclusive way. Vicky and Daisy’s experiences were demonstrative of ‘distributive justice’ their social inclusion was facilitated by the distribution of services and support but also that they were recognized as capable of participating on a par with others (Fraser 2003, 2008).

By exploring these narratives it becomes clear that welfare provision facilitates participation and inclusion, welfare provision and personal support services affected practically every aspect of Daisy and Vicky’s lives; making their inclusion possible. It makes visible the ways in which bodies are connected to wider social structures through the accessing and using of support and welfare provision.

8.1.3 ‘I couldn’t live without my car’: Getting around

Getting around and having adequate transportation and mobility was crucial to participants’ being able to take part in social activities, personal activities, education and work. Many of the participants used their DLA to fund a car through the motability car hire scheme.

One of the ways in which participants used their DLA, was to go to work. Anna (23) used her DLA to fund a car; her car was incredibly important to her and was crucial in enabling her to take part in her teacher training and then to be able to be a teacher and live independently. Anna talked about the ‘transformative’ nature of good support and provision:

My physio said the minute I got my car my life transformed; I was able to live independently...

(Anna, 23)

Anna's impairment meant that she could not walk around for long periods of time; she became very tired and sore and was not able to access public transport to get to work. Her car became crucial in enabling her to get to work. However, Anna described the benefits that she received and highlighted how the enjoyment of these benefits and of participation as a result, required the continued receipt of them

I have the DLA and I have the higher rate mobility and the middle rate care and that's something I never set up myself, that was set up by my mum, my doctor and my physio and when I was about to turn 16 they wrote a letter to the DWP to say that it would never change and that it's always going to be the way it is. So I have it indefinitely and I never have to reapply for it unless the Conservatives take it away.

(Anna, 23)

Anna felt she established the legitimate nature of her claim to benefits through emphasising that this was supported and 'set up' by authoritative figures such as doctors and physiotherapists. She established that she needed welfare provision and that she would always need it due to the nature of her impairment. However, through the political and economic climate, in 2011 at the time of interview, it was made clear to Anna that this 'indefinite' support in participating and equality was shaped by and linked to the state and state intervention.

Like Anna, Jane used her car to get to work and more generally to be and feel independent. Jane described how having the car made her feel:

I love my independence and being able to do things and having the car and giving me that freedom...

(Jane, 25)

Jane's car became emblematic of her independence, her being able to do things for herself and having freedom. The car enabled her independence in more ways than she realised. Jane mentioned her car on numerous occasions and how this

allowed her to travel to work, meet with friends by spending time with both her disabled and non-disabled peers. Jane described how having her car was the only way that she accessed welfare provision:

I don't get much support apart from Disability Living Allowance and that goes on the car and that's it, so in a way I am very fortunate that my disability isn't so severe that I need a lot of support from the state apart from the car.

(Jane, 25)

For Jane, her car was the key to her independent living. It was the key provision that she required for participatory parity. While Jane mentioned that her disability is not so severe and so does not require a lot of support from the state - her narrative explored all the ways in which the support that she does receive facilitated her full and active lifestyle. Many of the participants when discussing the use of their benefits were unaware of how this provision allowed them to enjoy their daily citizenship in the way that they were used to. It was only in reference to the possibility that this might be removed that the contingent nature of their participation was brought to the fore. This demonstrates the ways in which disabled young people have come to expect a high level of inclusion and participation and that the removal of this would represent an overwhelming upheaval of the experiences that they currently have. This will be discussed more thoroughly in the second section.

The mobility car funded through the DLA proved to be the single most enabling feature of provision for participants. Pete (26) discussed his use of his car for getting to work in another city from the one he lived in. Use of the car facilitated Pete being able to work in disability sports, where jobs were often hard to come by.

Having access to the DLA enabled Jack to get to work and to get around more generally:

I've got DLA, the mobility and care component. Certainly for myself for getting around it would be difficult. I do struggle with getting to different places. I've

got a driving license but I need a full time job before I get a car and I think the motability is really good because I would struggle with the price of insurance.

(Jack, 22)

Similarly, the DLA provided inclusion and participation in other ways than getting to work or getting to university. Participants talked about the effects of their impairments often meaning that they could not always access the places and spaces that they needed to and similarly environmental barriers created problems when being able to socialise - these barriers were often overcome by the use of the mobility car which facilitated participatory parity with non-disabled peers.

Cara was keen to discuss how her mobility car facilitated her being able to do every day activities such as shopping and socialising:

I have to drive an automatic car which is so much more expensive. It's like even where I live I will have to drive there a lot of people could walk it - it's only a mile and a half but for me I have to drive every single time even if we're going out to the pub. The car is my life line. I mean people would have to come and get me and I would feel like a burden on them and I wouldn't go out and I wouldn't do things as much because I was imposing on people and even getting to appointments and things and even going shopping when I can't take the train because it's too far away from where I need to go. I just wouldn't be able to do it I would just not be as in the community as I am, I would be in the house.

(Cara, 20)

Having access to a car meant that Cara could live independently; she felt that without it she would become a burden on the people she knew. Therefore the cuts to mobility had the potential to change and colour the relationships that participants have with other people. For Cara she felt that without her car she would be forced into dependent relationships with her friends rendering her a burden. Not only did the car provide her with practical independence by being able to do the things she wanted to do but it also provided her with a sense of feeling independent of not having to feel like a burden on others. This was

crucial to her sense of self, her self-value and sense of belonging and involvement in 'the community' was hinged upon her having access to mobility and transportation facilitated by the DLA. The DLA provided Cara with a sense of control over her own daily activities as well as the kind of person that she wanted to be (Thomas 1999). The mobility car represented a complex relationship between bodies and broader social structures; it allowed participants to be in the world and participate in the many complex ways that they wanted to. Selfhood, agency, independence and inclusion were all intrinsically bound up and experienced through access to support and mobility.

Furthermore, for Cara, the car was otherwise unaffordable without the DLA. Like many disabled people, Cara required an automatic and adapted car which is considerably more expensive. Without the DLA she would not have been able to afford a car and this would severely restrict her level of inclusion. As mentioned, environmental barriers often meant that the mobility car was the only option for Cara. Not only did she not feel she could rely on public transport but living in a rural area meant that often there was no public transport for her to use and walking was difficult for her. When home in Northern Ireland, the car meant that she was able to participate in rural community life:

I need my car and at home I live in a rural area and it's very rural and even here I still think for me there's some places that are hard to get to. A lot of people will think a 10 or 15 minute walk isn't too much but that for me is a lot and it would be the equivalent of an hour walk for someone else and that's the only way I can describe it. I'm walking on half par and it's not so easy.

(Cara, 20)

In the same vein, participants used their cars to take part in a variety of activities. Sam, who is a former Paralympian, used his car to be able to participate in disability sports. Sam's narrative represented a number of different dimensions relating to welfare provision and participation. Firstly, Sam's Cerebral Palsy (CP) resulted in him having severe speech impairment; as a result Sam faced exclusion and discrimination in a number of areas in his life. Sam discussed how he found it difficult to get a job, he was often disregarded due to his speech impairment - furthermore he found it difficult to form

friendships out with already established groups of friends and he equally found it difficult to form intimate relationships. For Sam, one of the key ways he could participate and felt included was through participating in CP football - this was one of the crucial ways in which his citizenship was embodied. Secondly, for disabled athletes - often access to accessible sports facilities and impairment specific sports clubs means travelling far afield. Unlike his non-disabled peers, Sam could not play football in the Local Park, local team or sports facilities. Sam had to travel to different cities in order to participate in sport; as such his motability car became the way in which this participation was facilitated:

I need the car to go play football and horse riding, and the football can be in Renfrew or Stirling so I wouldn't be able to go without the car.

(Sam, 29)

The 2012 London Paralympic Games have shown how access to sport is crucial for inclusive citizenship. Furthermore, Paralympians spoke openly about their DLA and how this facilitated not only their doing of sport but also their independence. Former Paralympian medallist Ade Adepitan remarked in the *Guardian* newspaper '*without DLA I would not have been able to do what I did or be a top athlete*' (Butler & Pring 2012). Discourses around 2012 London Paralympic Games and the promotion of competitive sports and active citizenship through sports exists in tension with similar neoliberal discourses of benefit cheats, shirkers and scroungers that pervades media discussions of disability welfare reform (Garthwaite 2011). There is a lack of recognition that good inclusion in sport is also facilitated through appropriate welfare and provision for disabled people whether you are a Paralympian or not. The additional need and support that can be a result of impairment requires a material component to level the playing field as it were.

8.1.4 Additional cost and other uses of DLA and ILF

As has already been discussed, welfare provision was primarily used to get around and for personal support services. I have already explored the ways in which participants used their funding to attend university, assisted and supported living, getting to work and having adequate mobility. The last section

explored both the practical and nuanced ways that good support facilitated citizenship and participation.

Participants also discussed the ways in which welfare provision was used to facilitate being able to buy basic necessities; things that are often taken for granted. Shoes were discussed in previous chapters and like many of the experiences documented by participants; shoes are multidimensional - not only do they represent the 'maintaining of sameness' (as discussed in Chapter Five) but they show the additional costs that disabled people often face. It has been well documented that it costs more to be disabled (Smith et al. 2004). Participants discussed how often they used their benefits to meet these additional costs.

While shoes are not always viewed as a necessity in the same way that accessible transport or adequate mobility is - some participants talked about their need to buy shoes frequently due to the nature of their impairment. Furthermore they could not just buy any shoes, they required shoes that fit properly, were comfortable and durable. As such, for some participants, this meant buying shoes every few weeks. The needing and requiring of shoes allows us to unpack the experiences of disabled young people more thoroughly. Lots of young women want to buy shoes frequently, but for some of the participants and Cara (20) particularly - buying shoes was not only about consuming fashion but about being able to afford necessary footwear so that she could walk comfortably every day:

I think it is a matter of equality because yeah I think it's hard for someone sitting in an office deciding on benefits to understand all the extra costs because it's things that you don't think about like shoes and taxis and petrol and parking. It's things that you don't think about you know someone who doesn't have a disability doesn't have to think about this but when you have a disability you're constantly worrying about other things so it's like having that is one less thing to worry about.

(Cara, 20)

Cara's example shows the importance of welfare provision for some disabled people to be able to meet the extra costs of having an impairment. While this is well known in terms of mobility, transport and so on, being able to afford accessible clothing and footwear is not always so well documented. This example, as previously discussed in chapter five, explores how the more intimate experiences of clothing and dressing are related to wider discourses of citizenship - without adequate footwear that supported comfortable walking Cara was restricted in how she could go out and about every day and this meant an additional cost which she met with her DLA.

In the same vein, Meg discussed how she required financial support to meet the additional costs of having an impairment:

That money really helps me because you know maybe I have to pay a higher mortgage because I have to buy a house that was more accessible for me so to not have that extra money would really affect me and just silly things like maybe I have to stay in a more expensive hotel if I'm away because other ones aren't accessible...

(Meg, 29)

Meg captured the ways in which additional costs impact on disabled people. Participants were confronted with additional costs in almost every aspect of their lives from 'higher mortgages' to 'accessible hotels'. Meg's narrative brings to the fore the notion of 'redistribution' (Fraser 2008). It costs more to be disabled, therefore good and adequate support for disabled people requires positive material and financial contributions and changes in order to level the playing field. Citizenship for the participants was realised through the materialisation of financial support to enable their participation and this was clear from their support in getting dressed, washing, toileting, clothing, going out, having a home, and working and so on all being facilitated by the provisions that they received.

The participants' experiences were historically constituted through and by the legacy of exclusion, discrimination and battles for equality that were taken up and fought by the disabled people's movement over the past thirty years (Oliver

1996 see also Goodley 2010). The participants, as a result, had come to enjoy and expect a level of inclusion and participation that they did not always realise, in many ways, were contingent upon the support that they had received and had always received. The proposal of welfare reform by the current coalition government represented an overwhelming upheaval and shock to the participants.

While this section explored the diverse and varied ways that participants used their welfare support to enable their participation, the next section will focus on participants' fears and worries over what the removal of this support could mean for their citizenship. Crucially, the support that participants received throughout their lives enabled them to reach a level of independence that means they can participate in mainstream spaces. This independence is now becoming the yardstick by which their removal of support is being measured. The threat of removal of benefits from disabled people was a threat to the citizenship that they embody and enact daily. The next section will explore the notion of independence and its restriction through the potential UK cuts.

8.2 Facing the 'cuts'

The last section looked at the avenues of support accessed by the participants and how this was integral to their inclusion and participation and how bodies are linked to broader social structures and how this was mediated by welfare provision. This section will focus on the discussions I had with participants in 2011/2012 concerning the proposed coalition sponsored welfare reforms and in particular the reassessment of disabled people for provision of DLA and the ILF. While at the time of the interviews, in 2011, many of the reforms were impending, two participants had experienced actual consequences of 'the cuts'. However, in 2012 the Institute for Fiscal studies maintained that 88% of the cuts were yet to come (Institute for Fiscal Studies 2012)¹⁵ and by February 2014¹⁶ they estimated that over half were yet to be implemented. Participants' discussions were largely focused around their worries and fears over what the proposed Coalition reforms could mean for them; they talked about this in conjunction

¹⁵ IFS 2012 Report can be accessed at: www.ifs.org.uk/budgets/gb2012/12chap3.pdf

¹⁶ IFS 2014 Report can be accessed at: www.ifs.org.uk/budgets/gb2014/gb2014ch2.pdf

with how this might change the way or limit the way that they lived.

This section will explore participants' fears and worries about the potential consequences of welfare reform; how they worried it could limit citizenship and participation and completely alter the lived experiences of the participants and disabled people more broadly.

8.2.1 Cutting Independence: the catch-22

The single biggest threat to the participants' experiences vis-a-vis the cuts was the reassessing of the mobility component of the DLA and the announcement that the ILF would tighten its criteria, would not be taking on any more recipients and would be facing major cuts. Since the time of interview, decisions were taken to remove the ILF completely whilst the Scottish Government took the decision to retain a Scottish Independent Living Fund (UK Government March 2014). The move towards PIP and the suggestion through Government consultation documents (Department for Work and Pensions 2010) that there would no longer be an 'indefinite' award for people with chronic or severe impairments along with the implications over what counts as 'mobile' posed huge threats to participants' current and future lived experiences (O'Hara 2014, Patrick 2012, see also Wood and Grant 2012).

In the same way that the mobility car proved to be one of the most enabling features in the participants' lives - the threat of its removal was the single biggest worry for participants. The removal of the mobility car not only meant that their capacity to 'get around' would be hindered partly in relation to psycho-emotional disablism but also in fulfilling the social expectations associated with traditional forms of citizenship such as employment.

As established in the previous section; for most of the participants their cars, mobility payments and welfare provision allowed them to live independently and allowed them choices and freedoms that their able bodied peers enjoyed:

I think they're going to say 'oh you live on your own you're a teacher', well not that I live on my own but what they'll class as independently and I live an active lifestyle and I know that if they did that my whole life would be reverted. I

wouldn't be able to be a teacher if they took my car away, I would be more reliant on benefits rather than less even though they wouldn't be available to me so that really scares me...I am petrified, I could live without the care allowance if I really had to I probably could but if they took away my car then that would be it, I wouldn't be able to live. That's how I live so independently.

(Anna, 23)

Anna's narrative highlighted the complexities of the proposed welfare reforms and their impact. Firstly, for Anna, being a teacher, living independently and 'active lifestyle' are all enabled and facilitated by the state support that she receives; it is through this support that she has achieved a high level of independence. Anna's fears, like most of the participants, were that her level of independence would be scrutinised and would be the thing that would count against her when her time comes to be reassessed. The removal of her car, primarily, would be the removal of her independence and she fears would leave her 'more reliant on benefits':

My physio said the minute I got my car my life transformed, I was able to live independently and if they took that away it would take my independence away and it worried me because I do think they'll look and go...cause I'm not living off benefits they're going to think I'm fine.

(Anna, 23)

This is the catch 22 that participants found themselves confronted with. Removal of the DLA, for Anna, would mean that she could not participate in the ways she wanted to and furthermore that she could not live 'an active lifestyle' it would see her unable to fulfill many of the 'rights and responsibilities' associated with more traditional forms of citizenship. She feared that it would be because of her independence and 'success' that she would be deemed an illegitimate or inappropriate recipient or claimant of benefits despite the DLA not being an 'out of work' benefit. The purpose of the DLA has always been to enable disabled people to lead full and inclusive lives.

In the same vein, and in many ways similar to their non disabled peers, participants' expressed worries over having to become dependent on their families again. Given the most of the participants were in their mid twenties they were reluctant to have to rely on their parents money, assistance and support where they had previously had been independent from them. This raises a number of issues; not only does it render young disabled people dependent in ways that could be avoided but it renders ageing parents as the only available sources of support; financial or otherwise (Melrose 2012). It impacted on how participants felt as many of them often discussed feeling like a burden if this were to come to fruition:

The more they cut back the more we will have to depend on our families again. We've striven to become independent, I've striven to become independent all my life and I hate phoning up and going 'I can't pay this bill can you help me out' you know? It's not fair.

(Ella, 26)

It is important to explore, at this juncture, that the coalition welfare reforms will impact on young people disabled or not. The 'cuts' represent an attack on youth more broadly (Melrose 2012 see also Slater 2012). Changing policies on housing benefits, tax credits, employment are making citizenship precarious for all young people. However, given that many disabled young people and certainly the ones who took part in this research, require an additional level of support - they are facing multiple attacks as a result of welfare reform. While their able-bodied peers may be forced back into the parental home, disabled young people require complex layers of support through adapted housing, personal support assistance (Melrose 2012).

One of the key points here relates back to discussions in the previous section about additional costs. While use of a car represents independence to most young people - for many of the participants it was the key to accessing employment, further education and leisure activities. Participants discussed that public transport would not be a sufficient alternative to them as it is either inaccessible or requires that they walk further than they can:

P: If they are considering reassessing everybody for DLA how much would it impact you if you couldn't have your car?

J: That would just be the end of my life because I wouldn't be able to use public transport...

(Jane, 25)

The words that Jane used were typical of the kinds of examples given by participants - many participants articulated the removal of their benefits as resulting in 'the end of my life' because it would mean the end of their lives as they knew them and this is how the participants felt about it. In the same vein Cara (20) said "The car is my life line". They conceived of the cuts as having such power as to entirely transform and alter their lives just as they had expressed that the use of benefits in the first place had transformed their experiences into more participatory ones.

8.2.2 Intersectionality and other avenues to (in)dependence

While most of the participants cited additional costs as a major reason for why they required financial support from the state, independence could be achieved through other means. A minority of participants discussed the consequences of having their DLA or accessible car removed. For Tim the removal of his car would not have such an all-encompassing impact as other participants. Tim discussed how his parents would buy him another car if it came down to it

P: How would it impact on you if they took away your mobility component?

T: So my car basically? Right so if I lost my car I'd buy a car and I'd have to get my dad to pay tax and insurance but it's fine for me obviously cause I've got that.

(Tim, 19)

Tim emphasised that 'disability' is not always the defining or master category; intersectionality, and in this case perhaps class, wealth poverty and impairment,

highlight that disabled people are not a homogenous group. There is the danger that Tim's circumstances could be seen to be the norm for all disabled people - which as the other narratives have shown us it is not. Removal or 'cutting' of DLA for all disabled people would create further inequality by removing support from those who require it and have no other means of financial support. Here, in Tim's narrative disability meets with class and wealth but also impairment. Tim did not have complex support needs and so the level of adaption to his car was minimal, for some of the participants their impairments or income (even when middle class) meant that they required financial support in having and adapting their cars. The financial requirement for adaptation and buying the necessary aids to facilitate mobility is very high indeed, which for Tim's family and Tim was possible.

However alternatively, this relates to what was explored at the beginning of the chapter - that in many ways families facilitate participation and for Tim his mobility would no longer be dependent upon the state but upon his parents' finances. Tim would be moving into another kind of dependency albeit with more economic power than some of the other participants. In the same vein, the removal of the DLA, even for Tim, removed independence and agency. It also feeds into current Conservative discourse around youth whereby parents are regarded as the 'safety net' for their children which is in itself fundamentally unequal. Some disabled young people would be able to achieve 'participatory parity' through their parents while others would not. However, despite restricting independence in some ways, Tim cannot be seen as the norm for disabled young people - the impact of removal for the other participants would be qualitatively and quantitatively different. This example examines the importance of considering disabled people not as a heterogeneous group with diverse backgrounds and experiences.

8.2.3 Removal of DLA for those in residential care

Late 2010 and early 2011 saw the proposal of the complete removal of the mobility component of the DLA for people living in residential care with its introduction to commence imminently. While the coalition government has postponed its introduction - at the time of the interviews the threat of this particular reform was impacting on Daisy's life. In order to save money through

the cutting of the mobility component of the DLA, through the coalition government's comprehensive spending review it was announced that this would be removed from those living in residential care. It became clear, through a project that I was involved in, that disabled people and their organisations challenged the view that local authorities or care homes themselves would meet the costs of residents' mobility needs¹⁷.

For Daisy, the only participant in residential care, this would mean the complete removal of her mobility and her capacity to go out, get to university, socialise and go shopping, for example:

I know that one of the cuts is to cut the mobility part of the DLA benefit if you're in residential care and at the moment I am in residential care and they want to remove that benefit in the hope that people living in residential care will get their transport paid for by where they stay. I know from where I stay that that just isn't possible because there's too many residents and too many needs and there's only one vehicle. I just think it's shocking and obviously they're just thinking about saving money they're not thinking about people's lives or quality of life or the individual needs of people, they're just grouping everybody together.

(Daisy, 25)

Daisy described the danger of the homogenization of disabled people; Daisy linked the mobility component of the DLA with quality of life, need and individuality and that having access to mobility through the DLA allowed her to have independence and individuality within her residential care. Daisy's experiences more represented the consequences of DLA removal for disabled people and particularly those in residential care. Within her transitional housing, the DLA enabled Daisy to exercise her agency, to achieve participatory parity and experience inclusion and belonging through doing her PhD. In the same vein as many of the other participants, the DLA was bound up in a complex network of relations between participants' and social spaces and participation in

¹⁷This project was undertaken by the Strathclyde Centre for Disability Research in conjunction with Capability Scotland and Margaret Blackwood Housing Association. The resulting report "How am I going to put flowers on my dad's grave?: Care home residents' use of the mobility element of the Disability Living Allowance" (Ferrie, Robertson-Rieck, Watson: 2011)

citizenship.

8.2.4 Restricting participation

While I have explored how independence would be limited and, for some participants, removed by restricting and removing the use of a car; Vicky discussed the cuts to the ILF which was critical to her attending University in another city. Vicky attended higher education. Again, for young disabled people attending further and higher education has become much more accessible. For many young disabled people going to university would not be possible without use of their benefits to enable and support them to do so. Vicky described how her ILF had come under review and how this might impact on her life:

If they cut that [ILF], then I have to go home and I probably won't be able to finish my degree and I probably sort of, won't be able to have the social life that I have at the moment because I'll be home all the time.

(Vicky, 26)

The participants' narratives have shown the myriad ways that they felt included and able to participate in the mainstream. However the welfare reforms, if realised, could see the removal of disabled people from mainstream spaces by restricting and eliminating the necessary tools to participation and independence:

Well I mean I think at the moment a lot of disabled people are very independent and I think that if they cut that then we wouldn't be very independent anymore we wouldn't be able to do the same things and we wouldn't have the same quality of life as we have now.

(Vicky, 26)

Like most of the other participants, Vicky connected independence with quality of life. Vicky's narrative demonstrated the notion of contingency and she described the 'glass roof' by establishing that disabled people have come to enjoy a high level of independence and it is because of good support that this is

the case.

The cuts to integral disability benefits demonstrate firmly the relationship between the spaces that people occupy and the policies that direct and shape how, when and where these spaces are occupied (Bacci & Beasley 2000, 2002). A number of participants, like Cara (20) and Vicky (26) discussed the cuts as forcing disabled people back into their homes; as removing people from participation and eliminating means to accessing the more formal places where citizenship is done (Lister et al. 2007, 2010). The narratives prove good examples of Fraser's three dimensions of social injustice - through the lack of recognition, the potential (and in some cases actual) removal of the economic means and resources that satisfy participatory parity and through the denial of status and equality it would render the participants and disabled people more generally, increasingly unequal (Fraser 2003, 2008).

Actualising the removal of benefits

As previously discussed most of the participants had not yet been reassessed or cut. The majority of participants' fears were in response to the potentiality of the cuts or that they had received letters notifying them that reassessment was impending.

Sam (29) lived in assisted living accommodation whereby all the residents' were required to volunteer hours helping in the accommodation. Sam talked about and described how important this was to all the residents' in the accommodation; that it helped build a sense of community and belonging amongst those that lived there; it enabled Sam to live independently. This community was very important to Sam; Sam's CP meant that he had a profound speech impairment which he said left him feeling isolated as he found it very difficult to make friends or get a job. The accommodation that he lived in enabled him to be independent:

P: Are you worried about all these cuts?

S: Yeah, it will restrict what I can do.

P: Do you get your house through a housing association?

S: Yeah, my social worker got it for me. I am more independent here. It's all people with disabilities here.

(Sam, 29)

Sam was one of the only participants who had experienced concrete outcomes of the cuts.

I have been cut but it's sad. My mum said she would help me. My hours have been dropped from 55 to 35 hours and I help in this accommodation because we all have to contribute hours and I contribute 7 but I've been cut.

(Sam, 29)

The restriction of Sam's 'hours' removed his ability to contribute to the community that he belonged to and lived in. In order to maintain his ability to contribute he had to rely on his mum to enable and support him. Again, this exemplifies the ways in which the participants were being forced or potentially forced into dependency and reliance on their families, removing their independence and the inclusion that they were used to. Sam's sense of contribution, of value and productivity were bound up in the pride that he felt over taking part in his accommodation and this had been removed. He had been removed from a vital role in the community that he was used to. This coupled with Sam's earlier narrative (in section one) around the potential for him to not be able to take part in disability sport saw a systematic disruption of the ways in which Sam participated. Furthermore rather than talking about his benefits being cut, he said '*I have been cut*' showing that for Sam the benefits he received were not something external to himself - they were bound to him and a crucial part of how he lived his life.

This section has focused on the complex ways in which welfare provision is bound up with citizenship and independence. It has explored participants' fears and worries over what cuts could mean for them and what they could do - the section examined how participation, inclusion, independence and belonging

were all achieved through and bound up with the material support that enabled this 'doing' and 'being'; it enabled participants to both do things independently but also be independent people and feel independent and able to make choices about their everyday lives.

8.3 Citizenship, worth and value; a complex interaction

This section will focus on participants' feelings about the cuts and how this made them feel about themselves, how they felt others viewed them and how they felt that the proposal of cuts had begun to target disabled people as scroungers and shirkers. Within the context of legitimate claiming of benefits, I will explore participants' narratives around their experiences of the process of applying for benefits and how this impacted on their lives. This section will then go on to explore the 'body sensations' felt by participants in relation to the cuts in order to explore the embodied experience of the cuts.

8.3.1 Legitimacy and scrounging: applying for benefits

It has been documented (Shildrick 1997) within Disability Studies literature and through disabled people's own accounts that the process of applying for disability benefits is an arduous and time consuming one that involves the disclosure of intimate and often personal information.

Within the context of the current coalition government welfare reforms, disabled people have been portrayed in the media as 'scroungers, lazy and shirkers' (Garthwaite 2011). Part of the justification for the reforming of the DLA has been to protect it from fraud and abuse by illegitimate claimants. Research into newspaper reporting of disability in 2011 found that 'Articles focusing on disability benefit and fraud increased from 2.8% in 2005/5 to 6.1% in 2010/11' (2011).¹⁸ The participants had been impacted by the kinds of articles they were reading in newspapers and discussed their feelings towards the view that disabled people might be illegitimate claimants and were keen to distinguish themselves as legitimate and in so doing often reproduced the very

¹⁸ Taken from report 'Bad News for Disabled People': How the newspapers are reporting disability (2011) issued by the Strathclyde Centre for Disability Research and the Glasgow University Media Group

same discourses they were trying to remove themselves from. Some participants felt targeted and felt that they had to prove that they were entitled to the benefits that they had; in many ways the current political and economic climate forced participants into these kinds of justifications.

Firstly, a large number of the participants talked about ‘feeling accused’ and needing to prove themselves as ‘legitimate claimants’ of benefits. This was an uncomfortable topic for participants as recipients of benefits, for example Cara (20) not only identified receiving benefits as ‘controversial’ but also curiously made a point of noting that she was ‘legally entitled’ to them.

Many of the participants talked about their benefits in this way and made points of rejecting socially imposed labels such as ‘scrounger’:

I don't like the way they're going about changes to disability benefit. I've not really looked into it but from what I've been hearing it's more medically done and it's terrible. I realise the system gets abused but is it right to penalise those who genuinely have a disability because of some scrounger who will illegally claim benefits?

(Gavin, 18)

Like Gavin, many participants throughout their narratives sought to separate themselves from ‘some scrounger’ as they felt that with reform had come the homogenisation of all benefits claimants as such. It is not only the receipt of welfare that supports equality that is precarious but the status that one is afforded which comes to characterise ‘citizenship’ for the participants. As Fraser notes, one of the key dimensions of social injustice is status inequality or misrecognition as hierarchies that remove or deny ‘status’ or ‘standing’ in social interaction (Fraser 2008).

Furthermore, participants’ felt that the actual process of applying for benefits impacted on how they felt; the process of application often made participants feel like they had to prove themselves to not be a fraudster. Cara repeatedly affirmed that she did not lie on her forms and that she was entitled to what she gets:

I am quite reliant on benefits and I know that I am absolutely truthful in all of my claims and that I've never lied on any of my forms and they've said that I'm eligible for it. I do worry that criteria maybe will change to tighten everything up and maybe stuff maybe won't be so available or handed out - not that it was before because anybody's who's been through the benefits system will know how difficult it is to get any of these things you have to jump through so many hoops.

(Cara, 20)

Like many of the participants, Cara felt that she was forced into proving legitimacy and that the difficult process of application often left participants feeling deflated, tired and accused and this can also be particularly tiring for people with impairments.

The political and economic climate, in 2010 - 2012, at the time of interview led participants to continuously feel uncertain about their status as claimants. This, in turn, led them to worry about whether they would be seen as legitimate or not. In order to manage this fear they became entrenched in a process of constantly separating themselves from public discourses of fraudsters and scroungers.

8.3.2 Worth and self-value

Worth emerged as a key theme when participants explored their feelings towards the cuts. It became clear that not only did the proposed cuts impact on the practical aspects of participants' lives but it significantly impacted on their sense of self and their feelings of sameness.

Feminist citizenship scholars such as Werbner & Yuval - Davis (1999) and Lister (2003, 2007) have sought to construct a model of citizenship that at its core is founded on 'pluralisation' and 'equal moral worth', and the valuing of difference (Lister 2007, 52). Feeling of equal value is integral, Lister (2007) and Werbner & Yuval-Davis (1999) argue- to inclusive citizenship. It can be seen that the cuts represented a devaluing of the self and enforced a feeling of low worth onto participants:

P: How do the cuts make you feel?

E: Yeah that we're not worthy of being part of society. We are not worthy of being part of this society. It is an infringement of our citizenship.

(Ella, 26)

Ella formed links between not feeling worthy, being marginalised and restriction of citizenship, which demonstrated that citizenship was, for participants, bound up with value, worth and inclusion. Ella maintained that her value was dependent on her being seen to be someone who did not need government funding and who did not require additional support. The cutting of benefits for participants made them feel out with society and out with citizenship; physical difference became the marker for how included or not included a person felt - the body thus became the landscape upon which citizenship was forged:

It makes me angry because I'm not the kind of person that lives off the government, I'm trying to make a life for myself and if I wasn't born the way I was then fair enough but I need that extra help to make me fair in this society and if they take it away then I won't be I will be at a complete disadvantage forever.

(Anna, 23)

Anna's experience echoed Ella's and she too formed the relationship between the cuts and her physicality; between citizenship and her body. Anna highlighted that being born with an impairment required additional support and that that additional support made her feel equal or 'fair' in society. At the time of interview, the proposal of cuts and realisation of cuts removed the feeling of equality that participants had come to enjoy and remove the feeling of belonging and participation that is necessary for the full enjoyment of citizenship.

Self-esteem and value emerged as inextricably linked to the avenues of support that participants received. The proposed cuts significantly impacted on how participants felt in general often citing feeling depressed, low or upset about

what their future prospects might be. Participants became worried about the impact that the removal of financial support could have on them and their family; this feeling of constant worry and uncertainty took its toll:

It's really terrible so it is. You feel like shite to be honest because all your money's just getting cut and you cannae dae the things you would usually do and it can affect your family as well. I wouldn't have enough money to get anywhere.

(Jamie, 19)

Jamie's example exposed the impact that the cuts have had on him; he talked about the practical implications of not being able to do the things he usually did but also how this made him feel. The removal of support meant that he had low self esteem and felt down and of low value. Good support does not only enable good inclusion through facilitating access to spaces, assistance and so on but it allowed participants to feel valued, worthwhile and important members of society. The cuts represented the exclusion from these categories; it made participants feel removed from belonging or being valued and they linked this to the fact that their impairments required a level of support over and above those of their able bodied peers. In reference to this Cara (20) said:

I think it kind of suggests that they [disabled people] aren't worth the money spent on them.

(Cara, 20)

Furthermore, a number of participants talked about their relationship to the government; they discussed feeling like they did not matter - that the government did not care about them and this added to their feeling over being of less value and worth:

See all this rubbish of well ‘we’ve got tae cut benefits back here and there’ for the good of people... you’re like ‘you [David Cameron] don’t understand what it’s like with your expenses cover, your healthcare, private carers’. The government doesnae care, they don’t care.

(Adam, 19)

The embodied experience of the cuts and of contingency was experienced not only by the prospect of limitation of ‘doing’ but through the emotions that participants felt when confronting and considering the possibilities of the cuts; by feeling undervalued and not cared about by the state. Participants discussed being angry, scared, feeling undervalued and this was their bodily experience of the cuts (Lyon & Barbalet 1994).

While emotions and how participants felt was one of the ways that they experienced and were impacted by the current economic climate - participants experienced a number of body sensations when confronting reassessment and the potentiality for having their support limited or removed altogether.

8.3.3 Body sensations

Considering the body sensations that participants felt in relation to the welfare reforms allows us to consider the embodied experience of the cuts. Participants talked about the fear of receiving DWP (Department of Work and Pensions) letters through the letterbox and often the body responses of receiving these letters were commensurate with the feelings of fear that they had. Participants discussed feeling ‘shocked’, ‘sick’ and ‘anxious’ when they received their letters. They were afraid of receiving the letters because they likened it to a lottery not knowing when they would receive notice that they would be cut or reassessed:

You know whenever I get a benefits letter I cry. I’m scared that they’re going to take away the money that I live my life on...It causes me so much stress.

(Ella, 26)

The body sensations that Ella felt when she received a letter was crying; she described how stressful it was to be confronted with the possibility that her benefits would be taken away. Participants felt like they had an axe hanging over their neck and not knowing what the future might be or the outcomes of the cuts was incredibly stressful. The body sensations that participants felt highlight the relationship between bodies and broader social and economic structures and they demonstrate that the cuts were felt and experienced in intimate ways by participants (Malacrida 2012).

In the same vein, the ‘not knowing’ became an arduous process for participants. Participants felt that they had no-one to go to about ‘the cuts’ and that they were left alone to deal with it themselves. Anna talked about the body sensations that she felt when worrying about the cuts:

I’m losing sleep over it. It worries me that much. It’s all going to happen at the same time. I don’t know what to do. I feel totally isolated at the moment; it’s not a very good time for me.

(Anna, 23)

Feelings of anxiety and isolation meant that Anna could not sleep at night; policies around welfare reform began to pervade the most intimate experiences for participants such as sleep.

These narratives show the embodied experience of welfare reform in the UK, it coalesces with broader notions of embodied citizenship and illustrates the myriad ways that citizenship is experienced, felt and mediated through the body. Body sensations also show the ways in which contingency impacted on participants’ experiences of themselves. The negative ways in which the welfare reforms impacted on body sensations allows the examination of the multiple and layered ways that material support and ‘benefits’ impact on practically every aspect of participants’ lived experiences.

8.4 Conclusion

This chapter has aimed to examine the numerous and complex ways that support was accessed, used, facilitated and impacted on the lived experiences of the participants. The focus of this chapter was to explore the ways that their inclusion, participation and enjoyment of citizenship was precarious and conditional upon the continued receipt of support from family but also by means of state funded benefits such as the DLA, the ILF and mechanisms such as the 'motability car hire scheme'.

Support from families often facilitated participants in overcoming barriers to participation and inclusion and most of these examples were from participants' experiences of school. Looking at familial support highlighted the nuanced and subtle ways that 'doing' was dependent upon, often, parents who would fight for good inclusion if they had the resources to do so.

The rest of the chapter focused on more formal avenues to support and throughout the interviews - benefits, the cuts and the DLA arose time and time again as incredibly important to participants' lives.

Firstly, the chapter aimed to look at the ways that almost every aspect of participants' lives were affected by the policies concerning financial support, mobility and personal support services. This section explored the fact that for disabled people to have good inclusion it demands a state-provisioned financial foundation; it is expensive to level the playing field and participatory parity requires not only recognition of the rights to good inclusion and equality but the economic and redistributive power to achieve it (Fraser 2003, 2008).

Participants discussed the 'transformative' nature of the financial support that they received; it facilitated independence, freedom and choice - it enabled participants to be in control of their worlds and experiences by being able to access a car, go to university, get to work and live independently.

The second section of the chapter examined participants' fears, worries and thoughts over the coalition led welfare reforms that were introduced in 2010. The second section explored the negative impacts that removal or restriction of support could have for participants and particularly for their independence.

Participants' narratives uncovered the complex ways that policies around welfare and reform were related to their everyday lived experiences; their bodies, what they could do and the kinds of people they wanted to be. It became clear that independence, for participants, represented a catch-22 whereby experiencing the independence hard fought for by earlier generations of disabled activists would be the very thing that counted against them when it came to be reassessed but it was by virtue of benefits that participants' had achieved that level of independence. Benefits also mediated many of the relationships that participants had; by being independent participants felt that they would not be a burden on families or friends. A number of participants' discussed how if they felt that they had to rely on other people then they would feel dependent and like burdens on others. Participants' articulated that their capacity to be 'active' and 'productive' members of society was dependent upon and intrinsically bound with their right to access support to enable this. They felt that through the removal of welfare they would become more dependent upon benefits and government agencies.

This third section focused on how participants felt about disability welfare reforms. This section explored the impact that the threat of removal of welfare had on their self-esteem, self worth and self-value. It highlighted that how they felt about themselves were inextricably linked to the policies that directed the support that they received. Their selfhood and self-esteem was bound to the avenues of support that they received. This was evidenced through the narratives provided; feelings of low value, low worth and negative body sensations all served to reinforce the relationship between bodies and citizenship, good inclusion, participation and psycho-emotional wellbeing. The threat to the support that they accessed represented not only barriers to doing and being (Thomas 1999) but evidenced a form of psycho-emotional disablism that pervaded all aspects of participants' lives.

Chapter 9. Discussion and conclusion

This study has sought to explore disabled young people's experiences of and thoughts and feelings towards citizenship in their everyday lives. The research aimed to examine how disabled young people felt about themselves and citizenship and the extent to which they felt that they were included. However it became apparent during data collection that the young people who took part spoke about their citizenship in relation to more intimate, seemingly 'private' activities; citizenship, for them, was intrinsically linked to their selves and emotions. The study also sought to explore the notion of 'embodied citizenship' by focusing on not only how participants felt but also restrictions to their participation and inclusion. Citizenship, conceptually, has been challenged for preferring the seemingly 'public' sphere and has historically resulted in the marginalisation of those who are associated with the 'private' sphere such as women, children and disabled people (Bacci & Beasley 2000). Throughout data collection it became clear that participants' intimate feelings and activities were a site of their everyday citizenship and further that they faced restrictions in being able to participate in social citizenship. The restrictions that participants faced had negative impacts on their psycho-emotional wellbeing (Thomas 1999), their self-esteem and feelings about their bodies; often seeing themselves as not belonging in wider social communities. Restrictions not only came in the form of poor access but also negative attitudes towards disability, damaging interactions with non-disabled others and a lack of representation in mainstream culture.

The findings revealed that while disabled young people felt more included in everyday life and often, ontologically, did not see themselves as disabled, they had to manage their precarious feelings of 'sameness' and 'difference' on a daily basis. Further, at times feeling 'different' was a result of impairment effects (Thomas 1999) and not always psycho-emotional disablism. Participants' sometimes struggled with having a body they felt was incompatible with dominant discourses of corporeal appropriateness and subsequently felt that this resulted in their exclusion and lack of visibility in popular representations of youth and beauty, sexuality and parenting, for example. It also became clear that those participants with less severe or 'obvious' impairments felt more

included, to some extent, and experienced the least intervention and control from the state, whereas the data revealed that those participants who had more severe impairments or less 'control over body' (Bacci and Beasley 2002, Hughes 2009) experienced more control over them by the state through avenues such as local authorities, social welfare providers and social work. The social model of disability has focused on citizenship for disabled people as a matter of the structural and material barriers that restrict disabled people from participating in society favouring the association between 'public' participation and political and social equality. However, as discussed in chapter two, the model has been critiqued by feminist disability scholars for failing to make visible the ways that citizenship is also comprised of disabled people's lived experiences in the 'public', 'private' and further that how disabled people experience their bodies as intertwined with citizenship (Bè 2012, Garland-Thompson 1997). This research has found that there is a complex interplay between the 'public' and 'private' the personal and political and the body and participation which is particular salient when considering the lives of disabled people whose marginalisation and inclusion is experienced both as a result from having an impairment but also from being physically excluded from sites of citizenship.

This chapter aims to bring together the key research findings from the data, the emergent themes and the wider literature discussed in chapters one and two. The chapter is divided into three main sections and begins with an overview of the data chapters; it then goes on to present the key themes that emerged from the data. The key themes to emerge from the data were 'sameness' and 'difference' and reconciling 'private' and 'public'. Within these themes, the notion of control over body, psycho-emotional wellbeing and precariousness will be explored in understanding embodied citizenship. The final section of the chapter will look at the limitations of the study and future research.

9.1 Overview of thesis

This section presents an overview of the findings that have been discussed in the previous four data chapters; this section will highlight the key themes and concepts to be discussed in the following section. The study set out, initially, to look at rights and how disabled young people exercised these rights in everyday

life. Over the course of data collection and the analysis of the data it became clear that participants were not just talking about rights but their everyday experiences of citizenship; their ability to participate in social life, their feelings about themselves in relation to others and society more generally and their social positioning were all key areas that built up a picture of their citizenship. The study then turned to citizenship as the foundation of understanding participants' everyday experiences. The study sought to explore the relationship between the individual and the social and in so doing was keen to look at participants' feelings about themselves and how feelings were shaped by the people and structures around them. The relationships they had with others affected how they identified themselves and where they positioned themselves in relation to non-disabled others. Research has found that it is not uncommon for disabled people to not identify with disability; it is difficult for some disabled people to relate to a collective 'disabled' identity when experience of impairment is so diverse and in the case of these participants they have had very little or no contact with other disabled people (Watson 2002, see also Shakespeare 2006).

The data revealed that while epistemologically, participants knew they were disabled, ontologically they often did not see themselves as disabled (Somers 1994). The first data chapter explored the overarching theme of 'sameness' and 'difference' in the lives of the participants. 'Sameness' was constructed by participants as feeling the same as 'everybody else' or non-disabled peers, whereas 'difference' was understood as being confronted with impairment, being treated unfairly or differently by others and being made to feel unattractive. The data showed that participants managed these feelings everyday and often simultaneously. Feeling the 'same' or 'different', it was revealed, was often dependent on the psycho-emotional impacts of encounters with others. Families and friends, mostly, had a positive psycho-emotional effect on participants which helped them feel confident, equal, valuable and 'the same'. However psycho-emotional wellbeing was often compromised in interactions with others where psycho-emotional disablism (Thomas 1999) compounded feelings of 'difference'; this was almost always in conjunction with relationships or sexual encounters with non-disabled peers.

Psycho-emotional disablism often resulted in ‘barriers to being’ (Thomas 1999) especially where participants felt that others’ assumptions about their capabilities or bodies were made. Disablist comments, stares and exclusions had far reaching impacts on participants and negative experiences often had the capacity to undo the positive efforts made by family and friends.

The second data chapter looked at sex and sexuality in more detail. This data chapter looked at participants’ experiences, thoughts and feelings towards exercising rights to sexuality and relationships as a vital part of their citizenship. This chapter focused on the notion of sexual or ‘intimate’ citizenship as a way to challenge the otherwise ‘thin’ understanding of citizenship as collective belonging (Smyth 2008). Further this chapter focused on intimate citizenship as a way to reconcile the personal and political by focusing on participants’ narratives of sex and sexuality (Plummer 2003). The notion of recognition was key to participants’ who felt that there was a lack of recognition that disabled people were sexual beings. Participants understood and articulated sexuality and reproduction as a part of their citizenship; all felt that family and friends expected them to exercise these rights however they faced barriers to doing so. Research focusing on sex and disability has shown that disabled people face additional barriers to this aspect of everyday citizenship (Shakespeare et al. 1996 see also Sanders 2010). Lack of good access was a key issue when it came to sexual health clinics, however exclusion from sex education, a lack of representation in mainstream culture and the invisibility of disabled people as active sexual beings and parents are bound up with a historical, social and cultural construction of ‘sexiness’, attractiveness and bodies worthy and capable of sex. Finally this chapter looked at participants’ worries about having a family in the future. Feminist disability scholars have been critical of the invisibility of disabled women in sociological literature on mothering (Malacrida 2012 see also Thomas 1997). There is a lack of visibility and recognition of disabled people as potential mothers and fathers. Female participants, in particular, worried about how they would ‘cope’ with becoming pregnant or having children in the future and very few of the participants had any knowledge or information on disability and parenthood; as a result women believed that it was not possible at all and further worried that they would not be ‘good’ mothers because of impairments.

The third data chapter (chapter seven) was concerned with participants' experiences of 'private' and 'public'. Chapter six showed that social forces in 'public' life shaped participants' 'intimate' lives. Chapter seven sought to explore notions of 'public' and 'private' even further and the way in which they intertwined. The chapter began by looking at participants' experiences of toilets, how toilets and going to the toilet could foster feelings of inclusion or exclusion and further how the notion of the 'bladder's leash' compounded how participants' bodies were subject to the construction of toilets. Chapter seven also explored how, for participants, state intervention and support impacted on their 'private' experiences. One of the key themes was control; it became apparent that participants who required the most support from the state also had the least control over their own 'private' lives and activities, the state impacted and shaped these experiences. Participants spoke about requiring adaption to their homes and how this shaped how they could access their homes. Some participants felt that they lost independence because they required adaption and thus were subject to the state where others felt that poor adaption meant that they could not access their homes at all. This section of the chapter sought to understand the way in which the seemingly 'private' domestic sphere was impacted by 'public' decision making. Finally the chapter explored the lives of participants who experienced the least control because they required the most intervention and support. Participants' experiences showed that citizenship was not, for them, just about 'public' life; it showed that participants' bodies, intimate and personal experiences were intrinsically linked to the 'public' or 'political' sphere.

The final data chapter (chapter eight) was concerned with the most traditionally 'public' aspects of participants' citizenship. Given the tumult of the economic climate, in 2011, at the time of interview and the then proposals for welfare reforms, participants were keen to discuss their benefits and the support they accessed. While the other data chapters showed how, for the most part, participants did not have a collective political 'disabled' consciousness it became clear that the level of citizenship they had come to enjoy was under threat. Participants reflected on how the benefits they accessed removed many of their 'barriers to doing' and 'being' (Thomas 1999), as they felt able to participate on an even playing field. This chapter looked at 'precariousness' and

the ways in which for disabled people, citizenship is not fixed, predictable or secure. In this sense participants represented the social 'precariat' as their futures were uncertain. The notion of 'participatory parity' was used to understand how benefits were crucial in enabling participation, belonging and self-worth amongst participants (Fraser 2008). Chapter seven highlighted how for some participants everyday life was supported through access to benefits such as the DLA and ILF, chapter eight looked at how almost all participants accessed some form of benefit. Participants spoke about how their lives as they knew it were connected to these benefits; mobility cars in particular were understood as 'life lines' that meant that social and economic participation was possible. Further, access to benefits and participation promoted feeling valued and 'worthy; removal of these benefits could have, and have in some cases, detrimental consequences for participants and their everyday citizenship.

Having presented an overview of the key themes that emerged from the data, this chapter will now discuss these narratives within the context of understandings about citizenship, embodied citizenship and disability. It starts by looking at 'sameness' and 'difference' through the exploration of psycho-emotional wellbeing and psycho-emotional disablism and the impact that these had on participants' sense of self.

9.2 Discussion of key findings

The following section will present the conclusions that have emerged from this study. The study originally set out to look at rights and embodiment and the extent to which disabled young people exercised these rights. However, through the data analysis it became clear that how participants' felt about themselves in relation to others and wider social structures, the impact that this had on their bodies and selves emerged as crucial to their everyday experiences of citizenship. The overarching theme that came out of the data was that of embodied citizenship; that everyday citizenship was not an abstract concept but a lived experience that spanned both 'private' and 'public' life. Within this three subsequent themes emerged; the notion of 'sameness and 'difference', 'private' and 'public' and 'precariousness'.

There has been limited focus on citizenship and disability; where citizenship has been focused on it has been conceptualised rather thinly (Smyth 2008, Bacci & Beasley 2000, Lister 2007). The social model of disability (as detailed in chapter two) reaffirmed citizenship as a matter of access to 'public life'; this was founded on removing barriers to voting, equality of opportunity in employment and access to 'public' spaces, for example (Oliver 1992, see also Oliver 1996). While these are significant and meaningful aspects of participation it has limited the ways in which citizenship and disability can be understood. Increasingly citizenship research has come to focus on identity, belonging, and self-esteem as fundamental to understanding the lived experience of citizenship (Lister 2007 see also Bacci & Beasley 2000, 2002, Werbner & Yuval-Davis 1999). This study also sought to look at the relationship between the body and citizenship particularly because disabled people are excluded precisely because of having 'different' bodies. However, the body has been removed from citizenship as citizenship increasingly became focused on political and 'public' life (Bacci & Beasley 2000). Similarly disability became associated with the political while impairment and matters of the body became increasingly 'private' and personal and to some extent invisible; as Shilling writes the body became relegated to the 'back-regions of social life' (Shilling 2012, 166; see also Bè 2012 and Hughes 2012, 2012a). This dualistic thinking has restricted the ways in which we can understand lived citizenship and the way citizenship is afforded. The data showed that for the most part participants' felt that they had access to the places they wanted to go, they could go to university and they could go to work however it was the more 'private' and personal aspects of their lives that impacted on how they could access the 'public' and further the state actively shaped how they experienced their 'private' lives. The body recurred throughout the data as participants' spoke about how they felt about their everyday citizenship, their feelings towards their bodies and their exclusion from spaces where embodied practices were managed. This emerged throughout the data in relation to sex, sexuality and sexual health; participants felt that they had limited access to these spheres of everyday life.

How participants' felt about themselves and their construction of identity was critically linked to feeling included and excluded. As Watson writes, identity from a Disability Studies perspective is founded on the notion of a 'shared

experience based on common interests' (2002, 513). However, the majority of participants had no interactions, friendships or relationships with other disabled people and so this 'disabled identity' was not something they related to. Identity was complex and fluid, with some referring to a political identity in relation to their benefits and rights but rejecting a 'disabled identity' when they felt it highlighted them as 'different' and this was often due to the psycho-emotional impact of being made to feel different or unworthy (Thomas 1999 see also Reeve 2012). Having negative feelings towards their own bodies or how they looked was often a result of being exposed to only images of supposedly 'normal' (able) bodies; their citizenship was 'other' to able bodied people who enjoyed full citizenship and participation thus striving for 'sameness' was key. Often this was linked to attractiveness resulting in hiding the body. Participants felt that they struggled to find relationships because they were worried they would not be found to be attractive by others. Being seen to be capable of sex or relationships was something that participants required recognition for; either from family and friends, partners and lovers or medical practitioners. However, this was often in opposition to a society, that they felt, distanced disability from sex and kept disability and sex invisible (Sanders 2010). Epistemologically participants knew that they had rights to relationships 'like anybody else' whilst ontologically there were considerable barriers to realising or exercising these rights through the construction of eligible sexual beings or bodies manifest in inaccessible spaces and a lack of representation or visibility.

The body came to the fore again where participation in everyday activities were managed and structured through the state and the relegation of certain activities to the 'private' sphere apart from citizenship. Toilets were one of the key areas where this emerged in the data. The data showed that toileting, whilst not usually considered to be linked to citizenship, was one of the fundamental ways that participants were or were not included. Significant research into disabled toilets has explored the consequences of poor or no accessible toileting facilities for disabled people often resulting in barriers to accessing 'public' life (Kitchin 2000), work (Manderson 2011) and feeling valued. The research found that they were often tethered by 'the bladder's leash' whereby the body becomes inextricably bound to the construction and constitution of disabled toilets.

Participants felt and were able to participate as a result of the financial support that they received. The research revealed that the economic climate, at the time of interview, put participants in a precarious place where they were uncertain of how 'the cuts' might affect them. Given the immediacy and ongoing nature of the Coalition Government's proposed reforms to welfare, there is very limited literature relating to this (for examples see Patrick 2012, Wood and Grant 2010, 2012). However, citizenship was understood to be under attack and this led participants to question their worth and value in society. The following section will discuss in more detail the distinct thematic areas that contributed to the overarching theme of embodied citizenship.

9.2.1 'Sameness' and 'Difference': psycho-emotional wellbeing

This section discusses the notion of 'sameness' and 'difference' and psycho-emotional wellbeing in participants' lives. The data revealed that participants were always walking a fine line between what they saw as being the same and being different. 'Sameness' and 'difference' was constructed as being the same as or different to non-disabled people and in some cases constructed as being the same or different in relation to other disabled people. 'Sameness' and 'difference' was inextricably tied to how participants constructed their sense of self, self esteem and how they located themselves in relation to wider society. 'Sameness' and 'difference' was one of the most pervasive aspects of participants' narratives and spanned all aspects of their discussions. There is a shortage of Disability Studies literature that explores how disabled people feel about themselves; rather research tends towards a social model understanding of disabled people's feelings in relation to the material barriers they face (Watson 2002 see also Shakespeare 2014). The data showed that participants' feelings towards themselves reflected wider mainstream attitudes towards disability and often participants were rejecting a 'disabled identity' underpinned by emphasising difference or singling out. Carol Thomas' (1999) work has been crucial in understanding participants' experiences of 'sameness' and 'difference'.

The data showed that participants' feelings about their selves were co-constructed in relation to others. Friends and family had positive psycho-emotional impacts on participants' self-esteem. Thomas (1999) and Reeve (2012)

have explored the notion of psycho-emotional disablism, both direct and indirect, while little focus has been placed on the reverse of this and how positive psycho-emotional effects can both directly and indirectly promote feelings of worth and equality. The data revealed that families and friends had a crucial role in providing a foundation of equality for participants; parents in particular instilled feelings of 'sameness' in participants by encouraging them to participate, by having meaningful expectations for their futures and expecting that they would have intimate relationships. Further the data showed that friends promoted feelings of 'sameness' by rejecting narratives of difference, therefore participants were able to construct ideas about their bodies as beautiful, attractive and worthy. Friends and family forged the beginnings of their citizenship by promoting self-esteem. The data showed that the psycho-emotional impact of this was that participants' felt equal in relation to their non-disabled peers, they felt able to participate, they felt they were valuable and in this sense saw themselves as 'the same' as 'everybody else'. However, it became clear that while families' and friends' efforts bolstered an ontological narrative of 'sameness', participants were often faced with 'difference'. As presented in chapter two, the negative perceptions of and interactions with others can impact on sense of self and 'place limits on our psycho-emotional wellbeing' (Thomas 1999, 47) and as Reeve writes this has a detrimental effect on self esteem resulting in 'barriers to being' and the restriction of who a person feels they can be or become (Reeve 2012, see also Thomas 1999). The data showed that in instances where they were confronted with their bodies, or when their bodies 'dys-appeared' (Leder 1990, 1992) they felt 'different'.

The data revealed that participants felt 'different' mostly when it came to relationships, intimacy or sex. While all participants felt that they were 'worthy' of intimate and sexual relationships they were worried they would not be found attractive by others. Participants often questioned why their able-bodied friends had intimate relationships and they did not. Sanders (2010 see also Shuttleworth 2012) argues that disability and sex have been historically distanced from one another, disabled people have been denied the rights to sexual expression and attractiveness and the body-beautiful have been constructed on the basis of youthful, able bodies. This is reflected in the data where participants internalised these cultural expressions of sexual potential and capacity and

often believed that they would not be found attractive. Reeve (2012) identifies this as a form of indirect psycho-emotional disablism as structural inequalities have historically excluded disabled people from sexual citizenship. However this becomes direct psycho-emotional disablism as structural disablism is reproduced by non-disabled others. The data showed that in some instances encounters with sexual partners had negative impacts; in one example (Ella, 26) the sexual partner confirmed Ella's 'difference' by only having sex with her because she was in a wheelchair. However, her ability to 'show him the door' reflected the positive psycho-emotional impact of being surrounded by caring friends and family. The data in chapter six showed that participants often felt that sex and disability were framed as something specialist, other or exceptional and rarely included in mainstream representations of sexuality. This left participants feeling excluded from sexual citizenship and aware of their own bodies, often questioning their desirability and attractiveness. As Mollow & McRuer (2012) write, the fact that sexiness is associated with able-bodiedness is self-evident whilst disability and sex are framed through lenses of 'tragic deficiency or freakish excess' (2012, 1); it is evident that attractiveness comes down to how bodies are constructed and impairment lies outwith these ideals. Difference was felt in relation to sexuality and relationships because it related to something far more visceral than accessing a building, it related to participants' bodies and feeling like their bodies were different or abject was very upsetting to participants. As Hughes (2012a) writes, those deemed out with acceptable, normal bodily function are 'regarded as objects of disgust' as disability becomes invalidated (2012a, 30). This was evident where some participants set themselves apart from 'other disabled people'. Some participants associated unattractiveness with disability, the way disabled people dress, looking untidy or being overweight and they went to great lengths to demonstrate how they were different from these disabled people by affirming their thinness, wearing makeup and 'dressing well'. These examples showed how participants seemed to have internalised mainstream representations of disabled people as unattractive thereby perpetuating the exclusion of disabled people from sexual citizenship.

Psycho-emotional wellbeing was further at the crux of feeling the same or different when it came to how participants identified themselves. A more direct form of psycho-emotional disablism was found in participants' descriptions of

being identified by non-disabled others, as disabled. As Watson (2002) writes in reflection of his own research with disabled people:

Being disabled, for many of these informants, is not about celebrating difference or diversity, pride in their identity is not formed through the individuals labelling themselves as different, as disabled, but it is about defining disability in their own terms, under their own terms of reference.

(Watson 2002, 521)

In many instances participants felt that they were not able to define disability 'in their own terms'; rather they felt they had labels ascribed to them by non-disabled others. Often participants rejected a disability identity, for example in Pete's experience he felt that it was easier to say he had an impairment because of a military injury rather than saying he was born with it. For Pete this was a way to manage difference and coping with probing questions from others, he could construct disability on his own terms. The psycho-emotional impact of stares and questions from non-disabled people led participants to lie about or hide their impairments in attempts to pass. The data also revealed that participants often felt the negative psycho-emotional impact of having a narrative of 'triumph over adversity' ascribed to them by virtue of having an impairment. In this sense participants talked about achieving their goals in spite of impairment thereby separating their self from body in order to reject others' assumptions. As Manderson notes, participants attempted to 'separate corporeality and self' (Manderson 2011, 122). Feeling the same or different was fragile and complex. Sameness and difference often reflected able-bodied assumption or representations of what was 'normal', attractive or acceptable as Paterson and Hughes write the disabled body is 'stunned into its own recognition by its presence-as-alien-being-in-the-world' (1999, 603)

In order to feel valued and included participants had to negotiate psycho-emotional wellbeing on a daily basis. For participants, feeling included and equal was inextricably tied to their feelings about their bodies which in turn were shaped through interactions with others. Negative psycho-emotional forces had the capacity to undermine participants' feelings of belonging or inclusion

and these were most often brought to the fore where they were confronted with difference.

9.2.2 Reconciling the ‘private’ and ‘public’: embodied citizenship

Throughout this study it became apparent that participants’ citizenship was explicitly bound to their personal, ‘private’ and intimate everyday experiences. As discussed above, their feelings of inclusion and their position in society was constructed in relation to their personal relationships with friends and family, their feelings about their self and body and, at times, their intimate sexual encounters with others. The data has shown that the relationship between participants’ so called private and public lives and activities were interlinked and mutually dependant and their bodies were at the centre of this. Again and again, participants’ discussions focused on their personal lives and feelings; sexuality, relationships, their homes, their friendships and even toileting all formed the basis of their narratives. Whilst the discussion above and in chapter five focused on participants’ feelings about themselves and ‘sameness’ and ‘difference’, chapter six focused on the experiences they had that had shaped these feelings. Whilst citizenship studies has developed to critique the public/private dichotomy this has been founded on the notion that women have been excluded from ‘public’ life due to their association with the ‘private’ sphere (Bacci & Beasley 2000, see also Smyth 2008). So much of disabled people’s citizenship and fight for equal citizenship has been founded on the right to participate in ‘public’ life and as such the everyday personal experiences of disabled people have become depoliticised and made invisible (Garland-Thompson 1997, see also Bè 2012). I approach citizenship from a different perspective; whilst the notion of embodied citizenship has been directed towards women’s experiences, sexuality and LGBT movements (see Plummer 2003, see also Grabham 2007), the ‘private’ lives of disabled people have been given less attention and the relationship between the body and citizenship has been afforded even less.

The data showed that much of the exclusion that participants felt and faced were tied to activities associated with the private sphere. Chapter six explored participants’ feelings about sexual rights and citizenship and it emerged that they all felt they *should* have equal rights to sexuality but discussed how they

were often restricted from exercising them. The data showed that participants experienced barriers in being able to access sexual health education and sexual health clinics often making them feel as if they were not welcome in these spaces and not recognised as sexual beings. Feelings about sexuality were shaped by exclusive practices and a social construction of sex as an able-bodied activity. The data showed that participants often questioned their capacity to have sex because of having an impairment despite never having any evidence to suggest this. Richardson (2000, 109) argues that the social construction of sex has had negative impacts on female sexual citizenship, she argues that this is because sex has been constructed through a 'heterosexual drive' defined by penetrative vaginal intercourse with partners of the opposite sex, further this has been characterised as a male drive. However, the data presented also shows that this construction of sexual citizenship is not only damaging for female sexual citizenship but also disabled people's sexual citizenship. The data revealed that participants' linked their right to have sexual relationships with being able to exercise them and this was often built upon an able-bodied construction of sex that lead them to feel negatively about their own bodies.

It was not just feelings about and experiences of sexual rights that demonstrated the comingling of the private and public spheres; participants talked about toilets as being crucial to their feelings of inclusion and exclusion. The notion of the 'bladder's leash' compounded how participants' were often restricted by the lack of provision of good disabled toilets; this placed limitations on the way that participants could socialise, access public places and how much food or fluid they could consume. Whilst citizenship is not usually associated with toilets, as toileting is framed as a 'private' activity, Kitchin & Law (2001) describe the long history between citizenship and public toilets as being underpinned by the rise of modernity. Further Elias' (2000) explains how the products of bladder and bowel were, over time, 'tidied away' and privatised through the process of civilising. Here participants' experiences offered a way to demonstrate toilets as a fertile site of citizenship. The data showed that participants felt good about themselves when good toilets were provided; good toilet facilities promoted inclusion and participation in social life, education and employment, for example. Further still, participants felt that lack of provision of toilets, toilets being used as store rooms, and the composition of toilets meant that they were

not considered as citizens at all. Perhaps the most compelling form of exclusion is not creating spaces where disabled people can participate in a process that all beings have to participate in; it is here that the body emerged as the 'fleshy substance of citizenship' as Bacci and Beasley (2000) maintain.

The reconciliation of the 'public' and 'private' further emerged as participants spoke about their need for support in order to manage their everyday lives. As discussed in chapter seven and eight, the data showed that participants who required greater support had to relinquish more control over their own lives and bodies and were, in many ways, subject to the state. Hughes (2009) discusses the notion of the 'wounded' being those in society who can be characterised as 'vulnerable' and as such have limited, if any, control over their own bodies and are under the paternalistic thumb of social welfare. The data presented in chapter eight showed that the young disabled people who participated in this study largely did not have a political association with the disabled people's movement; disability was seen as 'uncool' or not related to who they felt they were. However, this was brought into question when participants discussed proposed welfare reforms and cuts to disabled people's benefits. It became clear that citizenship was becoming precarious and contingent. Participants felt that they were going to be beaten with the very stick that facilitated their living independently. This catch-22 demonstrated how the level at which participants had come to feel included like being able to go to work, get to university, socialise with friends, and live away from their parents was under threat.

Bacci and Beasley (2002, 326) also discuss the notion of out of control bodies framed as lesser citizens than those who have control over their bodies. The data showed that participants who required the most support or who had the most severe impairments had the least control over their everyday citizenship. This was particularly salient in the examples of those participants who required personal support and assistance. One participant in particular, Daisy, needed support to get dressed and go to the toilet and this became structured through personal assistants showing up on time or structuring her toileting around four daily visits. However, control emerged in complex nuanced ways. While disabled people are seen to have 'out of control' bodies it emerged that participants had to exert high levels of control over their bladders, for example, where toilets were not accessible or they had to structure toileting around when carers were

available. Further, control was often forfeited in some areas in order to have control in others, for example Daisy had to give up control of her finances in order to exert control over her education, similarly in order to gain access to his home through state funded adaptation. Jack had to relinquish control over where he could live and when. What emerged was that those participants who required the most support from the state were restricted from decision-making and control over most aspects of their lives. These narratives expressed how intimate aspects of life were shaped by state interventions and control but also how citizenship was bound with embodied experience and not a mere abstraction. While Lister (2007) writes, citizenship is a 'lived' experience rather than an abstract concept the data shows that lived experience is fundamentally always an embodied experience.

9.2.3 Precariousness

Uncertainty, precariousness and contingency were key themes that emerged throughout all aspects of the participants' lives. Precariousness could be seen in the everyday management of 'sameness' and difference', uncertainty characterised participants' thoughts and feelings about sexuality and parenting in the future as has been discussed above. However, precariousness really came to the fore when participants spoke about their feelings about the cuts. The data revealed that only one of the participants had, in 2011 - at the point of interview, been substantively impacted by the proposed welfare reforms and the rest of the participants talked about their worries about what the cuts might mean for their lives and participation in social life. Nancy Fraser (2008) discusses the notion of participatory parity as being the centre for inclusive citizenship; the data highlighted that parity of participation was experienced for participants through the support, adaptations and benefits that levelled the playing field. Given the immediacy of the welfare reforms, the fact that they are ongoing and many are yet to come into force this study provides a unique lens through which to view how disabled people internalise and have their sense of self threatened by 'cuts' prior to their occurrence.

The data presented in chapter eight showed that participants' self-esteem and feelings of worth were tied to the mechanisms that facilitated their everyday participation. The use of cars through the 'motability car hire scheme' was

discussed as vital as a 'life line' upon which both 'public' (employment, education) and 'private' (friendships, socialising and self-worth) aspects of citizenship were all dependent. This data bolstered the notion of redistribution; chapter six demonstrated how participants required recognition from others that they were capable sexual beings whilst chapter eight demonstrated that inclusive citizenship was dependent on the redistribution of goods and wealth in society to enable parity of participation. However, independence was the stick with which participants were beaten. The data highlighted that the participants feared that the more independent they were perceived to be the more the state may decide they did not need the benefits they received. Participants talked about feeling worthwhile and valued and the cuts, for them, represented the devaluing of their citizenship. Participants discussed having to legitimate their claim to equal citizenship by proving that they were not 'benefits cheats'; in this sense their bodies were called to question as illegitimate claimants of benefits. The data showed how participants' citizenship was always subject to the control of the state and that their movements, relationships, housing, eating, education and employment were all bound up with state relations. This further challenged the private/public dichotomy as their seemingly private and intimate lives were always already shaped and dependent on the political sphere (Bacci & Beasley 2000, 2002; see also Plummer 2003, Smyth 2008).

9.3 Limitations and future research

The previous section discussed the key findings that emerged throughout this study. This section will discuss the limitations of the research and this study as a platform for future research before concluding the thesis. This study aimed to be an exploration of disabled young people's lives and how they felt about rights and citizenship. The research design was constructed in such a way as to allow for participants to direct the research and gave them the space to discuss what was meaningful for them. Chapter four explored my own identity as both a woman and a disabled person and how this shaped the research that I carried out; it became apparent throughout the analysis that the key themes and experiences presented were gendered. My own gender, as well as being close in age to the participants, appeared to have impacted on the kinds of responses male and female participants felt comfortable giving. As discussed in chapter

four, talking about one's body is not an easy thing to do and perhaps even more exposing for disabled young people. Needless to say, male participants often gave very short answers to questions exploring sexual citizenship as they may not have been very comfortable talking about intimacies with a female peer. Upon reflection, replicating this study with a male researcher may have gotten a different male perspective. However, this study has highlighted that there is a limited focus on masculinity in sociology more generally as male bodies are not constructed as deviant in relation to women's. Similarly while Disability Studies has been critiqued for its underrepresentation of disabled women's experiences and 'private' bodily experiences it can be seen that there are aspects of masculinity that require greater exploration (See Bê 2012, Garland-Thompson 1996 and Malacrida 2012).

The thesis took an embodied perspective from the outset. However talking about the body proved to be a challenging task. Chapter four discussed the difficulty in writing the body without reproducing dualisms of mind/body. While not reconciled here, this study has shown that there is a need for further empirical research that focuses on the body and everyday embodied experiences in order to overcome these dualisms in writing and talking about the body.

The previous section and chapter six found that disabled women in particular felt very uncertain and insecure about the potential to become mothers in the future. Male participants largely were not worried about this; their corporeal insecurities were bound to their capacity to perform penetrative sex. The one male participant who talked about having children at any length did so in relation to support from the spinal injuries specialists in being able to ejaculate rather than worrying about parenting. It became clear that women worried about their fertility, capacity to carry a pregnancy, give birth, carry a child and look after a child in their daily lives. This was tied exclusively to corporeal insecurity with none of the female participants having any knowledge or information about support or adaptations to support disabled parents. It became clear that there is a lack of research in Disability Studies focusing on the sexual health and reproduction health and support that disabled people get. The invisibility in mainstream social life of disabled parents and disability and pregnancy had a negative impact on how the young participants felt about themselves and in some cases participants had already decided that having

children and being disabled was too difficult a task and had 'written it off' as an option. The private and personal lives and experiences of disabled people in the sphere of parenting requires development through research that focuses on the kind of information disabled people have access to as well as the kinds of treatment and support disabled women get throughout pregnancy. It brings to light the need for further development of the concept of psycho-emotional wellbeing and the ways that psycho-emotional disablism is inextricably bound to corporeality. Malacrida (2012 see also Thomas 1997) writes about the scrutiny that disabled mothers face and the social and economic barriers that disabled mothers face. However there is little focus on how disabled women become disabled mothers and the process that they go through in pregnancy and becoming mothers. This study has shown that this needs considerable attention and development in order to give voice to disabled women's experiences and to highlight the lack of information and support for disabled women who may want to have children.

Toilets and toileting came to light as a result of this study as being a key site of disabled people's everyday citizenship that would benefit from further development and research. Kitchen & Law (2001) have explored the relationship between inclusion and the use of public spaces for disabled people in which toilets were highlighted. Goldsmith's (1963) *Designing for the disabled* and Serlin's *Pissing without Pity* (2010) have given meaningful historical accounts of the construction of disabled toilets and their often exclusive character. However, this study has shown that further development of empirical research exploring experiential dimensions of toileting and disability would further contribute to the reconciliation of 'public' and 'private' in constructing a more inclusive framework for lived citizenship for disabled people. Developing research into disabled toilets has the potential to impact on the policy that informs the designing of disabled toilets.

Finally, this study found that participants were deeply fearful of the potential effect that cuts to disability welfare provision and support could have on their everyday lives. As these cuts are ongoing and will continue to have far-reaching impacts on disabled people's lives then future longitudinal research on how cuts affect disabled people as they 'roll out' is essential to understanding and documenting the changing landscape of everyday citizenship for disabled people.

9.4 Conclusion

This thesis set out to explore disabled young people's thoughts, feelings and embodied experiences of citizenship in their everyday lives. Previous research has focused on the social barriers that disabled people face and has developed to place emphasis on the political relevance of personal experience (Bè 2012). This research looks at the private sphere as a legitimate site of everyday citizenship for disabled people; it also focuses on the body as the 'fleshy substance' of citizenship. In addition to exploring everyday citizenship for disabled young people, it became apparent that there were other emergent themes that sketched out a more nuanced picture of citizenship than public participation and access. We are our body; every experience of inclusion, exclusion, participation, love, sex, going to the toilet and getting to work are corporeal experiences. Citizenship is more than an abstract concept; it is encapsulated in our everyday lived experiences. Disability Studies and the disabled people's movement have been reluctant to incorporate the body into illuminating disabled people's exclusion from mainstream social life. However, the social construction of citizenship, as discussed in chapter three, is built upon the ideal citizen as ideal body being male, rational, complete and functional (Bacci & Beasley 2000, see also Hughes 2009 and 2012). Further still citizenship's association with the public sphere has been founded on the tidying away of the messiness of the body from public life thus excluding disabled people in its wake.

The research reveals that citizenship is comprised of nuanced and complex relationships between bodies in both public and private life. The research has revealed that when asked about their everyday lives, participants were most keen to discuss their intimate, personal experiences and how these were the key areas in their lives where they felt most excluded, restricted and not valued. The research shows that although participants did not see themselves as disabled people and the inclusion that they had felt was built upon the battles of older disabled people who had fought for access to education, employment and independence, participants felt different, unequal and invisible in matters of relationships and sexuality. Further still access emerged as of great importance to participants when it actively restricted fundamental bodily activities like

going to the toilet or accessing sexual health. The data showed that psycho-emotional wellbeing was integral to feeling like a valued and valuable person, any further research into disabled people's experiences would benefit from the development of the psycho-emotional dimensions of disablism but also the effects of positive psycho-emotional wellbeing. In relation to this the data showed that positive psycho-emotional effects were the result of positive influences and relationships with friends and families who lay the foundations for feeling equal. Similarly psycho-emotional disablism reproduced negative feelings about the body. There is a need for disabled young people to have access to meaningful information that represents a more diverse and inclusive picture of everyday citizenship. Disabled young people would benefit from positive representations of disabled people in relationships, as sexual beings and as parents. The data showed that exclusion from the spaces and places where sexual citizenship was managed led participants to question their capacity for sexual expression.

In order for citizenship to be inclusive the body must be recognised as the site of citizenship and the seemingly 'private realms' of everyday life must be understood as comingling with so-called 'public life'. The data has emphasised that for disabled people, access to the public sphere is often contingent upon social relations in the private sphere; access to good toilets enables social participation in all areas of life and access to adequate provision enables inclusive citizenship. The data revealed that citizenship, for disabled people in particular, is never fixed or given; the cuts to welfare reform have the capacity to significantly alter the landscape that these disabled young people have become familiar with. The provision of social welfare enabled a degree of inclusion that participants had come to expect and suddenly this has been challenged. Although only one participant had been affected by the cuts, participants' worries highlighted how disabled people's citizenship is not secure.

This research has shown that a fuller understanding of disability, a more holistic representation of disabled people's experiences depends on the reconciliation of the 'public' and 'private' spheres. The frontiers of disabled people's citizenship exist in the so-called 'back regions'. The research has revealed that disabled people's citizenship is comprised of a complex interplay between the embodied

self that is invariably bound to and at the basis of private and public social relations.

Appendix 1: Participant Information Sheet



Researcher Information

This research is for the purposes of a PhD, which is being done in School of Social and Political Sciences in the Department of Sociology at the University of Glasgow. The research project is focusing on the experiences of disabled people and their opinions, thoughts and feelings about rights, inclusion and participation in everyday life.

The research is being carried out by Phillippa Robertson-Rieck¹⁹ who is currently a PhD student at the University of Glasgow; Phillippa will be conducting the interviews and carrying out the analysis for the purposes of her PhD. Phillippa's PhD is being supervised by Professor Nick Watson (nicholas.watson@glasgow.ac.uk) and Dr. Lucy Pickering (lucy.pickering@glasgow.ac.uk), at the University of Glasgow. Phillippa can be contacted by phone (0141 330 xxxx) or by email (p.robertson-rieck.1@research.gla.ac.uk) if you have any questions concerns or queries.

1. Invitation to participate

You are being invited to take part in a research study. It is important that you understand the research taking place and what will be asked of you. Please take time to read the following information carefully and discuss it with me or anyone else if you would like. Please contact me if there is anything you are unsure about or has not been made clear.

2. Purpose of the research study

The interview portion of the research will take place between October 2010 and September 2011. The research study sets out to gain insight into disabled people

¹⁹ Now Phillippa Wiseman

aged 18-30 (with physical impairments only) and their experiences; it is particularly interested in disabled people aged 18-30's thoughts, feelings and opinions about rights in their everyday lives. Therefore participation will involve participants giving information about their lives; their employment, education, social lives and views on issues that are relevant to their lives such as access, participation and equality.

I am asking around 30 disabled people aged 18-30 to participate in the research. I will interview each person twice with around three months break in between the two interviews. The interviews will last as long or as little as you feel comfortable with, but I don't anticipate that interviews will last much longer than an hour.

3. Is participation voluntary?

Your participation in the research project is on a voluntary basis and you are able at any time to withdraw from participation without reason.

4. What will taking part involve?

If you decide that you would like to participate in the research project I will contact you to arrange a time for you to be interviewed. You will be essential in deciding where and when the interview will take place. The interviews should not take much more than an hour, but will last as long as you are happy and comfortable. The interviews will be taped using a digital audio recorder, unless you are not comfortable with this and would prefer not to be taped. Using an audio recorder will allow us to represent what you have said properly. Participants can expect to be asked questions about their education, for example whether they are in further education or not, similarly participants can expect questions about their social lives, employment and their thoughts and views about rights and disability rights such as access to the places they like to go, equality and inclusion.

Only I will have access to the recordings and they will be safely kept in a locked filing cabinet or on a file in a password protected computer. After the research project is finished the recordings will be destroyed. They will not be labelled so you will not be identifiable from the recording.

5. Confidentiality

All the information that is gathered throughout the course of the research project will be made confidential. You will be given a pseudonym to make sure that your identity is kept anonymous. Any information about you including your consent form, name, audio recording and so on will be stored securely on either a password protected computer or in a locked filing cabinet.

6. Contact Information

If you have any questions, concerns or queries about the research then please do not hesitate to contact me. Participants are welcome to raise any concerns or complaints about the research or the way it has been carried out with me, my supervisor or my head of department all of whose contact details are listed below. Participants should feel free to provide any feedback, questions or concerns and are most welcome and invited to do so.

I can be contacted via telephone on 0141 330 XXXX or via email p.robertson-rieck.1@research.gla.ac.uk. My primary supervisor can be contacted via telephone on 0141 330 XXXX or via email nicholas.watson@glasgow.ac.uk. Furthermore you can contact the Head of Department for Sociology, Anthropology and Applied Social Sciences²⁰ at the University of Glasgow Professor Satnam Virdee by telephone on 0141 330 XXXX or via email: s.virdee@lbss.gla.ac.uk

Thank you for taking the time to read this information sheet.

With Many Thanks

Phillippa Roberston-Rieck

²⁰ Now the Sociology subject are in the School of Social and Political Sciences

Appendix 2: Participant Consent Form 1



Project Title: 'How do disabled people aged 18-30 experience rights?'

(Working Title)

Researcher: Phillippa Robertson-Rieck

I confirm that I have read the information sheet provided to me, that I understand the nature of the research project and I have had the opportunity to ask questions about the research taking place.

- I consent to being interviewed for the purposes of this research project; I consent to the interviews being audio-taped on a digital voice recorder.
- I confirm and understand that throughout the project I will be referred to by pseudonym and in any publication that comes out of this research.
- I fully understand that my participation is entirely voluntary and can withdraw from the project at any point and I am under no obligation to give a reason for doing so.
- I consent/do not consent to participating in the above project (please circle).

Participant name:

Signature:

Date:

Researcher's name:

Signature:

Date:

Appendix 3: Participant Consent Form 2



**Project Title: 'How do disabled people aged 18-30 experience rights?'
(Working Title)**

Researcher: Phillippa Robertson-Rieck

Interview 2:

I confirm that I have read the information sheet provided to me, that I understand the nature of the research project and I have had the opportunity to ask questions about the research taking place.

- I consent to being interviewed for the purposes of this research project; I consent to the interviews being audio-taped on a digital voice recorder.
- I confirm and understand that throughout the project I will be referred to by pseudonym and in any publication that comes out of this research.
- I fully understand that my participation is entirely voluntary and can withdraw from the project at any point and I am under no obligation to give a reason for doing so.
- I consent/do not consent to participating in the above project (please circle).

Participant name:

Signature:

Date:

Researcher's name:

Signature:

Date:

Appendix 4: Participant Biographies

Adam, 19	Adam is 19, he lives with his mum. He has Cerebral Palsy, he uses a wheelchair. Adam goes to College; he had special education in both primary and secondary school. Adam has a girlfriend and plays wheelchair sports. Adam is from a particularly deprived area of North Glasgow. Adam is concerned about his mortality because lots of his friends have died as a result of their impairments.
Anna, 23	Anna is 23; she lives in a flat that she shares with friends. She lives in Edinburgh. Anna went to mainstream schools for both primary and secondary school although her mum (who was very young when she had her) had to fight hard to get her into mainstream school. Anna does not use any mobility aids but experiences a lot of pain getting around. She uses her DLA to fund a car. She went to University and recently qualified as a teacher, she has been experiencing a lot of discrimination in the workplace. Anna is single. Anna has Cerebral Palsy. Anna hasn't really met any other disabled people and has no disabled friends.
Cara, 20	Cara is 20 and is originally from Northern Ireland although she now lives in Scotland and goes to University. Cara lives with her friends who do not know that she has Spina Bifida, only her friends from home (NI) know that she has SB and it is only with them that she really feels comfortable. Cara has a partner, she misses quite a lot of University and social life because she often has to go into hospital because of the complications of her SB. Cara does not use any mobility aids. Cara places a lot of importance on being seen as normal, and hiding her impairment. She went to mainstream schools and said that she

	had a positive experience of schooling. Cara does not really know any other disabled people and has no disabled friends.
Daisy, 25	Daisy is 25 and lives in residential housing for young disabled people who are waiting to find accessible and more permanent accommodation. Daisy went to mainstream school for primary education and then chose to attend special education at secondary. Daisy also chose to go into residential/supported accommodation rather than stay at home. She is in a lot of conflict with Social Work about this. Daisy went to University and is doing a PhD. She is single. Daisy has CP and uses a wheelchair.
Ella, 26	Ella is 26 and is from the Highlands and Islands. She always attended mainstream school and for the most part has been treated equally, although her mum had to fight to get her into mainstream education. She is single and goes to university and does Counselling. She also does a lot of volunteer work. Ella uses a wheelchair; she lives in a flat on her own. Ella wants to be a counsellor. She is particularly scared and worried about the current government, cuts and what this could mean for her. Ella does not have any disabled friends and does not really know any disabled people.
Gavin, 18	Gavin is 18; he is from Glasgow and lives with his family and his sister who, like him, has cerebral palsy. Gavin does not use any mobility aids and is quite a successful gymnast and plays football on a CP team. He went to mainstream school but had support throughout. He is single and goes to University. He feels that people assume that he is stupid because he is disabled and strives to show that he is not. He has lots of nondisabled and disabled friends.

Greg, 28	<p>Greg is 28. He lives in Scotland. Greg has used a wheelchair for 11 years after a spinal cord injury as a result of a motor cycle accident. Prior to that he was really keen on building cars and engines - he's can't do that anymore, not because he can't (he still puts cars together all the time) but because health and safety means he can't work in a garage. Greg experienced some depression and drug use because of his injury and finds that taking part (semi-professionally) in disability sports makes him feel useful. He is a very successful athlete. Greg is single and lives at home with his parents (his mum doesn't want him to move out). He is unemployed at the moment and is currently focused on taking part in the commonwealth games.</p>
Jack, 22	<p>Jack is 22. He lives with his family in Stirlingshire. He is a sports coach and although he is a successful athlete and works in sports (part time) he is trying to and struggles to find a job. He is really concerned that this is because he is disabled. He went to mainstream school and had really negative experiences of discrimination by staff and bad bullying from pupils. He doesn't really have a lot of friends and has very little confidence. He is single and uses a wheelchair. Jack went to college to study sports coaching which he found much more inclusive.</p>
Jamie, 19.	<p>Jamie is 19 and from Glasgow. He lives in a very deprived area in social housing with his dad. His house is really inaccessible and he struggles to get around it in his wheelchair. Jamie has had special education all his life and now attends a college where he has assisted learning and does woodwork. He often goes to the community centre for disabled people and most of his friends are disabled. He gets quite a hard time in the area he lives in and also finds it hard to access places in his wheelchair. Jamie is single.</p>

<p>Jane, 25.</p>	<p>Jane is 25 and lives with her mum in Glasgow. She is a twin and has always felt that she has to live up to her sister. She has CP but does not use any mobility aids. Jane had special education all her life, she is also deaf. Jane is single and actively does not want a partner (especially a disabled partner). She does a lot of outdoor activity and fundraising/campaigning for disabled charities and organisations. She has quite a grim view of other disabled people and wants to prove herself as very capable. She has had a lot of media attention. She has always struggled to find a job and feels this is because of her disability.</p>
<p>Kate, 28.</p>	<p>Kate is 28 and lives in a flat on her own in Glasgow. She is single. She has CP although does not use mobility aids. She went to mainstream schools and found that difficult although always had lots of friends. She is an only child. She used to get disability benefits and a blue badge etc. However she stopped getting these as she felt that she did not really need them. She is single and worries that this is because of her disability. She went to Medical school and found that she was under scrutiny during the application process but she knew there was a girl with SB that had graduated as a doctor and so this motivated her to do it. She really does not identify or associate with disability at all. She is a qualified doctor and works in geriatrics.</p>
<p>Meg, 29</p>	<p>Meg is 30 (29 in the first interview). She lives on her own in a flat that she bought and had to adapt. Meg was born without any legs and uses a wheelchair. She always went to mainstream school and has one sister. She went to University and now works in admin. She is single. Meg has travelled around the world a lot and is a very independent person. She worries that she looks so different from everyone else and thinks her being single is because of this, she recently started internet dating. Meg often</p>

	finds that there are physical barriers to her being able to do things. She does not really know any disabled people but has a big diverse group of friends.
Molly, 18	Molly is 18 and lives with her parents in Stirlingshire. Her dad came to the interview and her parents are very protective of her. Molly has Spina Bifida and uses a wheelchair. Molly is a very successful wheelchair athlete and competes nationally and internationally. She was single at the start of fieldwork but had started seeing someone by the end. She went to mainstream schools and was very badly bullied, she did not make any friends at school and so felt that she really only wanted to be friends with disabled people because they had similar experiences to her. She started college by the second interview and found that was much more inclusive and her peers were very friendly and supportive. Her parents get respite from her (which I never really understood).
Pete, 26	Pete is 26 and is from Edinburgh. Pete lives alone in a flat and has a girlfriend. When Pete was 16 he started the process to have his leg amputated because of his SB. This happened at 18 - he wanted to get it amputated because of how his leg looked but also because he got infections in it. He is happier now it is amputated but more for aesthetic reasons as he still gets infections and pain in the site. Pete used to do a lot of disability sports and now he does sports coaching. Pete went to mainstream schools and was bullied and had negative experiences at school.
Ruby, 25	Ruby is 25 and lives in her own flat that her parents live in with her. She has Cystic Fibrosis and is quite unwell. She uses oxygen all the time and her mobility is badly affected so she uses a mobility scooter. Ruby always went to mainstream schools and

	<p>because her CF did not really affect her until she left school, impairment did not really impact on her life until that point although she often had bouts of being unwell. CF started to impact on Ruby when she went to art school and she started using oxygen then. She works in various community projects doing art and works in art and mental health. During fieldwork she started working for an art gallery doing PR and admin. Ruby had a boyfriend at the start of the fieldwork but this broke down by the second interview. When I first met Ruby she had been in and out of hospital for 4 months and was concerned about her life expectancy. Her health has improved quite a lot and she was able to start her job.</p>
Sam, 29	<p>Sam lives in assisted housing in a deprived area of Glasgow. He chose to live away from home as he felt he would live more independently in the assisted housing. He gets personal assistance and lives there with his dog. Sam has CP and his speech is quite severely affected (more than his mobility). He feels his problems with his speech means that he cannot get a job and so he volunteers with kids. He had special education for primary and secondary. Sam is single. Sam went to college but was not really interested in it. Sam is has competed in the Paralympics and is a very successful athlete. The cuts to his benefits are now making it difficult to attend his sports clubs and training. Sam is single but attends a dating organisation for disabled people.</p>
Tim, 19	<p>Tim is 19 and lives in a flat with his friends from Uni. Tim broke his spine in 2007 and took a year out of school. Tim says that his life hasn't really changed since breaking his spine, although he now uses a wheelchair. Although Tim feels that his friends are really inclusive he talks a lot about how he gets left behind and then never go to accessible clubs. Tim is single and has never</p>

	<p>had a girlfriend so he does not know if he can attribute this to being disabled. Tim went to mainstream schools and now goes to University. He is from a very well off family and so he's not too concerned about benefits cuts because his parents will support him. Tim faces a lot of physical barriers but says that this does not really bother him.</p>
Vicky, 26	<p>Vicky is 26 and is from the West of Scotland. She has CP and has quite poor speech; she uses a wheelchair and gets personal assistance. She lived with her family until she moved to Uni and now she lives in Uni accommodation and gets personal assistance. Vicky went to mainstream school and had a really bad time. She finds that it's hard to meet people/get to know people because of her speech and this has a huge impact on how people see her. She feels that since she started Uni this has improved. Vicky meets a lot of physical barriers and feels that if her benefits are cut that she will not be able to go to uni anymore, will have to move back in with her parents and will not have the same independence.</p>

Appendix 5: Topic Guide for first Interview

Introductory Questions:

1. Please could you tell me a bit about yourself?

Possible prompts:

- Name
- Age
- Where do you live
- Who do you live with
- Are you in education (Where) - Is it accessible? Do you feel included/not included?
- Do you work (Where do you work) - Is it accessible? Do you feel included/not included?
- Are you single/ in a relationship? (If so, for how long, where did you meet etc.)
- Did you go to a mainstream school/special needs school?

2. Could you tell me, what's the most important thing to you in your life at the moment?

3. What do you get up to?

Possible prompts:

- Activities
- Sports
- Clubs
- Hobbies
- How did you get in to it?

4. What do you do to socialise?

Possible prompts:

- What do you do on the weekends?
- Where do you like to go out
- Is it accessible/not accessible?
- Do you feel that there is access to places?
- When you are there do you feel included? How do you feel?
- Do you go out with your friends?

- What kind of friends do you have?
- Where did you meet them?
- Are they the same age?
- Are they disabled?
- Are they in to the same things as you?
- Do you feel that being disabled affects how you make friends?
- Are there places that you feel excluded from? (How does this make you feel? Would you act on it/do anything about it?)
- Do you think that your social life affects how you meet people? (At uni/clubs/ orgs etc.)
- How do you think you are treated by people
- Is it easy making friendships?
- How do you think people react when they first meet you? Is it an issue?

5. Is having a relationship important to you?

Possible prompts:

- Has being disabled impacted on having a relationship? Meeting people?
- Do you meet people when you are out? Is it easy meeting people?
- Do you think that having a relationship is a right?
- Do you ever feel you are being denied that right?
- Is it easy to make intimate relationships?
- Do you think that having a sexual life is a right? Is it something that's important to you?
- Is it something that you have wanted or expected in your life?
- Has it been expected of you?
- Do you feel that you are included in relationships?
- Have you had access to and information on sex, sexuality and sexual health as a disabled person?
- Did you get that at school?
- Have you ever attended a sexual health clinic? Is it accessible? Was there information on sex and disability?
- Is more information on sex, sexuality and sexual health something you would want?
- Do you think it's a right to get married and have a family?
- Is this something you might want?
- Does being disabled affect that do you think?

6. Do you think there is a right to support?

Possible prompts:

- Is it something that's important or that matters to you?
- Do you get support?

7. How do you feel about the situation for disabled people at the moment?

Possible Prompts:

- The economy?
- Benefits?
- Mobility?
- Equality
- Inclusion

8. Where do you see yourself in five or ten years?

Appendix 6: Topic Guide for Second Interview

1. What have you been up to since we last met? What have been the important things that have happened?

Possible prompts:

- Work?
- Education?
- Family?
- Relationships?
- Activities?
- Health?

2. How does it make you feel when you don't have access to a place? Or when you are included/ can participate

3. How does it make you feel when you do have access to a place? Or when you are excluded/ can't participate

4. Do you ever feel excluded in your own house (the physical environment), by professionals? At work?

5. Do you think disabled people experience hate crime?

Possible prompts:

- Have you ever experienced anything like this?

6. A lot of people mentioned that relationships can be a really tricky area when you're disabled and how do you think this is?

7. What do you find easy/hard about being in a relationship? Does disability impact on this?

Possible prompts:

- Attractiveness? - People's notions of their own beauty/ attractiveness/body.
- Would you be happy to be in a relationship with a disabled person?

8. What kind of information on parenting/pregnancy, if any, would you as a disabled person want?

9. Have you heard any more about potential cuts?

Possible prompts:

- Have you been impacted by these at all?
- How do the cuts make you feel?

10. What do you think it means to be a citizen?**Possible prompts:**

- Do you feel like a citizen?

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