Writing the Disabled Self: An Autoethnographic Study of Disablism in England 2015-2018

by

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RESEARCH STUDENT DECLARATION FORM

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Abstract

Writing the Disabled Self is an autoethnography based on my lived experience of disablism in England. This thesis is grounded in a social model of disability, situated within the field of Disability Studies, and employs an Emancipatory Disability Research paradigm (EDR). My research documents and analyses the disablist nature of the relationship between society and self in the areas under study and highlights the human impact of disablism. The underlying premise of my thesis is that disablism exacerbates the experience of living with impairment. My thesis documents this experience in detail using an analysis of a personal journal I kept between 2015 and 2018, supplemented by research by disabled people from a range of sources. My research contributes to existing literature and theory by developing and illustrating the idea of psycho-emotional disablism. I apply Kitchin's conceptualisation of 'knowing our place' and 'being out of place' to the experience of disabled people. I illustrate the exclusionary, sporadic, and conditional nature of accessibility for many disabled people including those, like myself, who are wheelchair users. I develop the concept of 'decrepitification' to describe and explain the process that claimants must engage in to have a chance of being found eligible for disability entitlements such as Employment and Support Allowance and Personal Independence Payment. I apply Garfinkel's concept of degradation ceremonies to understand and conceptualise the psycho-emotional impact of disability related assessments. Given the enduring nature of disablism, I suggest that disabled people need strategies to help us mitigate its psycho-emotional impact. Therefore, I analyse and explore my use of gaming, humour, and comedy as a form of self-care. My thesis illustrates that disablism is socially embedded, widespread, and commonly unrecognised as a tangible aspect of the lives of many disabled people.

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List of Abbreviations

DWP: Department of Work and Pensions

DLA: Disability Living Allowance

EDR: Emancipatory Disability Research

PIP: Personal Independence Payment

PED: Psycho-emotional disablism

RADAR: Royal Association for Disability and Rehabilitation

UPIAS: Union of the Physically Impaired Against Segregation

UNCRPD: United Nations Convention on the Rights of People with Disabilities

WCA: Work Capability Assessment

WRAG: Work Related Activity Group

Chapter One

Introduction

Given that the focus of the thesis is the disabled self, it feels appropriate to start by providing an understanding of my disabled self, and to describe the key life events that have influenced my decision to write a disability-focused Ph.D. The specific motivations to write this thesis in this context are repeated experiences of inequality, inaccessibility, discrimination and hostility, which, over time, have become a source of increasingly undeniable and acute frustration and distress. In this thesis, I am specifically documenting and analysing my experiences of disablism. My experience often brings me to the conclusion that impairment, and how society views it, is a key factor in poor or inadequate social responses to me and to other disabled people. This autobiographical commentary is written partly chronologically and partly thematically. It highlights issues relevant to living as a disabled person in the UK and provides a personal context to my thesis, in which my own experience is a central part of my research. My primary impairment is visible and physical, and therefore, my research focuses predominantly on impairments that can be seen. This chapter serves as my thesis introduction. It begins with chapter overviews. I then cover the following topics, my birth and early family life, adolescence and adulthood, education and employment.

Chapter Overviews

Chapter two entitled, a social context for disablism, provides a context for my thesis, conceptualising disablism, neoliberalism, and austerity. Here, I provide background information and define these key terms. I have included sections that explore the impact of austerity on the broader population and on disabled people specifically. I understand that austerity is not the only context relevant to my research: broader neoliberalism and disablism also influence my experience, but it is a key factor, so these areas are covered in some detail.

Chapter three describes my methodology and explains the key methods, concepts, and ideas that influenced both my research and me as a researcher. It features sections explaining the key principles of Emancipatory Disability Research, psycho-emotional disablism, and my central method of autoethnography. It also explains my rationale for using these. I discuss the journal I kept between 2015 and 2018 (a defined political period of austerity in the UK), which constitutes the ‘raw data’ of my research thus providing a catalyst for my subsequent analysis. I offer autoethnography as a form of Emancipatory Disability Research (EDR) and give examples of how I applied autoethnography to my work.

Chapter four (my first core chapter) the excluded self: a personal documentation and critique of accessibility in everyday life, documents the spectrum of my everyday life experience of accessibility in public spaces. This chapter includes sections on accessible toilet provision (lack or inconsistency thereof), train travel as a wheelchair user or person requiring assistance to travel, access to shops and restaurants and ticketing and venue accessibility.

Then follows chapter five, the assessed disabled self, which explores my and other disabled people’s experiences of various assessment processes such as for Employment and Support Allowance (ESA), Disability Living Allowance (DLA) and Personal Independence (PIP). In this chapter I identify and theorise my idea of ‘decrepitification’, it describes the steps claimants are required to take to have a chance of being found eligible for ESA or PIP. For example, it involves representing yourself in the most deficient terms possible and then providing medical evidence to support the representation.

Chapter six, the psycho-emotional disabled self, explores disabled people’s experiences of what disability scholars have referred to as psycho-emotional disablism. I apply Garfinkel’s work on successful degradation ceremonies to the assessment processes for ESA and PIP. I also use Garfinkel’s work to explain how it feels and what it is like to be assessed doing so from the perspective of people who have been through these processes; I explore its psycho-emotional impact. As someone who has experienced disability hate crime, I also dedicate a portion of this chapter to exploring, highlighting, and critically commenting upon the psycho-emotional effects of this, drawing upon current research.

Chapter seven addresses caring for the disabled self: mitigating the impact of disablism. Here, I discuss and define self-care in the context of a neoliberal, austere, and disablist society. I talk about the caution with which I approach the concept of self-care because it maps well onto the ideas and principles of neoliberalism and has been used as a vessel for their progression. However, despite the fact that I find the concept of self-care practically problematic, I also consider self-care, as I understand and define it, to be a necessity in terms of my own self-preservation and survival as a disabled person in a society that is neoliberal and disablist in character. I look in detail at two activities that might not be commonly considered as examples of self-care yet, for me, serve as such: employment and gaming. I look at the ways in which for me these activities function as self-care and help to mitigate disablism.

The final core chapter, chapter eight the comic disabled self, explores my love of comedy. First, I look at how I employ comedy as a viewer through which I can manage and endure experiences of disablism. I use examples of the work of Stewart Lee, Mark Thomas, and Nina Conti; further, I discuss how dark comedy acts as a form of release allowing me space to laugh at social perceptions of ‘disability’ and how society sees me as a disabled person. I also explore my own personal use of comedy and humour to help me manage and endure experiences of disablism in my everyday life.

My concluding chapter, chapter nine, draws together the main arguments of my thesis: that the impact of the social on the experience of impairment is often absent from understandings of disability. Furthermore, the social aspects of living with impairment often absent from mainstream understandings of disability can make the experience of living with impairment more difficult. In this concluding chapter I also highlight contemporary forms of disablism, I explore the contribution my research makes to existing literature, I offer a framework for change and examine some of the limitations of my research.

A Note on Language

As discussed throughout this thesis, as a person, I have a preference for social model understandings of disability and impairment and the core idea of the social model that society disables people with impairments (Oliver, 2009). However, the nature of my research sometimes meant I had to engage with and use medical model language, which frames disability and impairment as a problem of and for the individual (Cameron 2014). Where this occurs in my thesis, I have placed terms or phrases in inverted commas to convey when I am using medical model language. The applies to the terms, 'disability', (where indicated), 'my disability', 'declaring disability', 'decrepitification' 'persons with disabilities', 'people with disabilities', 'medical condition', 'primary medical condition' 'chronic illness' or 'chronic impairment'.

Birth and Early Family Life

I was born on Christmas Day 1983. I was premature, my mother was diabetic, and the hospital where I was born did not have an incubator to put me in, so my brain was left without oxygen. No one has ever been held accountable for this. My medical record cites my mother's diabetes as the sole cause of my impairment. My parents did not find out until months later that I had Cerebral Palsy. The hospital where I was born had a high rate of Cerebral Palsy births. The personal circumstances of my birth have shaped my life and the person I have become, and I am still dealing with the consequences. It is highly unlikely I would be writing a Disability Studies Ph.D. were it not for my overarching perception that being impaired has either prevented me from doing things I wish to do or has made particular life aims harder to achieve. Society's response to impairment makes an already challenging situation even harder. Having said this, the detrimental impact of society upon the experience of impairment is often absent from public discourse about disability. Highlighting and understanding the detrimental impact of society's response to impairment is one of my main motivations for writing this thesis.

My mother's diabetes meant that as a family we spent a lot of time travelling back and forth to and from hospitals. Mum needed regular dialysis treatment to filter her kidneys, which at first could only be done in hospital. Later, equipment that meant dialysis could be done at home became available. Our garden shed and kitchen cupboards were full of the required medical supplies. This was an improvement because it gave my mum and us as a family greater freedom; it also meant fewer visits to hospital. Mum was not always ill; her health fluctuated. She took every opportunity she could to be with me. She would take me to my hospital appointments, and when I went to school, she and Dad would be there to pick me up. I remember my mum as a good cook, as someone who enjoyed buying me clothes, someone who liked to take care of her appearance and enjoyed going out, (bingo and clubbing were her particular favourites). As a child I was close to both my parents, but I was my mother's daughter and I never went to bed without a hug. I have always loved Mum and still do. She always believed in me as a person despite the various negative viewpoints people expressed about me, often because of my impairment. The negativity people expressed has left me with reoccurring feelings of being 'written off' and is part of the reason I find it difficult to imagine a decent future for myself. Looking back, I feel that Mum understood me better because of what she had experienced. I have vivid memories of my mum in hospital. For example, on one occasion she nearly died of starvation because the nursing staff neglected to feed her. My dad took the decision to discharge her and cared for her at home, and on that occasion she recovered. Situations like this have given me what I consider to be an understandable mistrust of the medical profession.

My mum's condition deteriorated to the point that she needed a kidney transplant and she was placed on the waiting list. The first potential kidney was not a close enough match, but eventually a suitable kidney was found, and my mum went ahead with the surgery. She came through the initial operation, but a few days later, on 1st March 1992, aged 39, she died. Her heart was apparently too weak to withstand the demands of surgery. I was nine at the time, and Mum's death came as a shock to us all. I did not expect my mother to die and I did not get to say goodbye. Mum's death is one of the few times I have seen my dad cry. It feels as if my mother took the ultimate gamble with her life in an effort to improve her quality of life, and lost. I remember crying a lot, often spontaneously, for a long time afterwards. When my mum died, I was allowed a long time out of primary school. On the day of Mum's funeral, I remember my aunty standing at the gate of our house and waving us off as we left for the funeral in a large estate car, with my manual wheelchair in the boot. I remember returning to school, and some people who had never talked to me before being overly nice. I remember others who had been kind before my mum's death remaining so. I think I coped better with Mum's death as a child than I do as an adult, because a child cannot really comprehend the gravity of the phrase 'never coming back'. It increasingly dawns on you over time. I am acutely aware of all the things we did not get to do together as a family. My dad is without the woman he still loves; her death meant that he became a single parent.

I am the youngest of three children, I have a brother and a sister, and both my parents had already been married before they met each other. I am a white, disabled female. My family were relatively poor and working class. Whilst it is fair to say that coming from middle-class family may have mitigated some of my experience of disability. I am writing from a Disability Studies perspective because I consider impairment the primary marker of my identity and influence upon my life. Being impaired has impacted upon and shaped almost every area of my life. If I were not impaired, I would literally be a totally different person. It is realistic to say life would be easier. I consider my gender to be an important but secondary aspect of my identity. I think that my impairment and how society responds to it, plays a more prominent role in shaping my life than my gender. Primarily, I am a disabled person living with an impairment first, and a woman, second. The lifelong nature of my impairment forms the basis of this view and explains why my work is not predominantly intersectional. I was aware that I was from a poor background because we often could not afford to pay the electricity bill, and had to rig the electric meter. Additionally, many of my clothes and Christmas and birthday presents were bought on Hire Purchase, or as it is now known, ‘Buy Now Pay Later’.

As children, all of our holidays were taken in caravans in the UK. The lack of money was not the only reason for this: it was a key factor. My experiences of caravan holidays as a child have meant that now I cannot tolerate the thought of going away in a caravan ever again. One of quite a few reasons I do not like caravanning is the lack of flushing toilets and decent, modern washing facilities. I did not enjoy going for days without a proper wash, and as an adult I need accessible toilet facilities and a proper bed in which I can stretch out and relax.

Primary Education

I began my educational life in a special school. My parents made this choice on the premise I would receive extra physiotherapy, and whilst I did receive weekly physio, the extra sessions never materialised. It was left to others, nursery nurses and my family to do such tasks as putting on and taking off my splints, stretching me as well as strapping (restraining) me in a diverse range of standing frames and in chairs designed to control my posture. They often had to do this for hours at a time. I worked really hard and did as I was told, but much of this was painful: it dominated my childhood.

As the term ‘special school’ implies, my schooling at this point was segregated. I was surrounded by other disabled children who had a range of impairments, many of whom became my friends. The time I spent in segregated schooling means that I feel comfortable around people with impairments. On reflection, though, it has also given me a strong personal conviction that educational segregation is harmful. My attendance at a special school made me feel like an aberration and anomalous. Being educated separately from non-disabled children was a factor in this, and perhaps marked the beginnings of the sense of alienation from society that I still have today. I feel that segregated schooling sent a message that I was different, and this difference was undesirable, as it was acceptable to regard and treat me as inferior on this basis. It is also where I became socially conscious of being regarded by others as inferior because of my impairment. School was one of the first places I learnt that anything was ‘wrong’ with me. To begin with, I didn’t understand what all the fuss, sadness, and negativity that surrounded me was about. In the whispers and hushed tones, or in the conversations had about me while I was present, which those involved incorrectly assumed, I could not understand. I learnt that it was bad to be me.

Initially, little emphasis was placed upon my teaching and education. There was a persistent presumption that, because I was physically impaired, I was also mentally impaired, and therefore incapable of learning. I owe much of my educational success to one particular teacher, and to a couple of supportive nursery nurses, who chose to test this assumption. Upon discovering I had cognitive ability, Miss Holly put a lot of her time, effort and energy into helping me understand the basics. She taught me reading, writing, and maths. I went to school at the age of four earlier than other, non-disabled children.

Later, thanks in part to the 1980 Education Act, I was given the chance to transition to a mainstream primary school. However, the choice of schools to which I could transition was limited: the majority of schools were not wheelchair accessible. I remember being taken around another special school I could have attended where some of the children, as did I, had Cerebral Palsy. However, even as a child I knew it was not the right place for me. The children were kept occupied and their basic needs attended to, but I got no sense that they were being prepared for a future. I also visited a local primary school. As part of the transition process, I had to take, and pass, additional academic tests to ensure I could meet and keep up with the standards expected of my non-disabled peers. I passed. However, had I not been labelled as ‘disabled’ and ‘Special Educational Needs’ (SEN), and come from a special school environment, I would not have been required to pass such tests. These tests were a barrier to many of the disabled friends with whom I grew up and was taught alongside, because they required literacy, language, and verbal communication skills, which some did not possess. The parents of these children argued with the local authority for their right to a mainstream education, many keeping this up for years, but were denied what they wanted for their children. I still feel a strong connection to the children with whom I began my education. At the time, people around me were debating whether disabled children should be educated in mainstream schools: I was aware of a degree of scepticism. These debates still continue today.

I passed the test and was allowed to attend a local primary school. However, I did not enjoy the first primary school I went to. I did not get on with the teaching assistant who was hired to support me. I felt like an experiment, and I stood out because I was the only pupil in the school with a physical impairment. I had a better experience at the second primary school I attended. In preparation for my arrival, the headmaster reduced the size of the class I was in, so that I was not as overwhelmed by the environment or by the other pupils. Unlike the previous school, I was not the only pupil with a physical impairment and I had a very loving and kind support assistant who, as part of her job, helped with my physiotherapy and stretching, and with the academic demands of attending a mainstream primary school. As was Miss Holly before her, Marion Ferns was influential in my success. Wherever she could, she made sure that I had a good experience, and took care of me practically and psychologically. Rarely since have I felt to such an extent loved, protected, and supported. Marion’s work with me was a factor in her choice to train as a physio therapist’s assistant after I left that school. I made friends and most of the other pupils accepted my presence.

Despite this, I do not wish to suggest that my time at this primary school was entirely straight forward and without incident. There was a point when the headmaster, who had been so accommodating left, and a new headmistress was appointed. It is fair to say she took a different philosophical approach, both to me and to the act of school governance. Activities I had done before her arrival, with nobody questioning my right to do them, were suddenly deemed to be unsafe and no longer open to me. My parents and those who worked with me did object, but their objections were ignored. In practice this meant I was prevented from swimming with my classmates, as I had been doing for some time. Instead, I was sent back to the special school to swim on my own, instead of as part of a group with people I knew. I was effectively segregated again. I was also prevented from walking around school on my walking frame because the headmistress considered it unsafe. If she had reached this conclusion in response to a particular incident it might have made some sense, but I had never fallen or sustained the slightest injury. Her decision meant I had to use my manual wheelchair as my main method of mobility around school. This did little to help my chances of walking, because as a child you spend a lot of your day at school, and a considerable degree of that walking around school, and this was removed from my daily routine. This negatively affected my physical fitness. I was not the only one who had problems with this headmistress. She was so difficult that eventually her entire staff revolted, and she was removed. To this day, I find it hard to believe that she made these decisions with absolutely no conscious knowledge of their negative impact on me. If this headmistress taught me anything, she taught me the extent to which one person can have a detrimental impact on those around them. Towards the end of my time there I could not wait to leave.

Secondary Education

I went to a mainstream high school. I had no choice of which high school I attended because only one local high school was wheelchair accessible. By this point I used an electric wheelchair for mobility. As in my primary school, I was not the only pupil with a visible impairment, and this helped me feel more comfortable. Even though this high school was my only option, it turned out to be great for me. I had a lot of good times there, and the staff that worked with me put a lot of effort into helping me achieve my academic potential. I had excellent in-class support. I was even encouraged to do physical education, although some of my PE lessons were taken with another impaired pupil. However, this only happened when it was obvious to all concerned that I could not participate in the lesson scheduled for my non-disabled peers. Good examples of this, were cross country running and javelin. A degree of thought was put into the replacement lessons. For example, I did dance as one of my PE lessons with the rest of my classmates and for this I was allowed to transfer from my wheelchair. I also got the opportunity to try disability sports such as Boccia, a game played with rules similar to those of bowls. I competed in the Merseyside youth Games as part of the Boccia team and won gold. I was also part of a team that won a disability 'kwik' cricket tournament and I was a Kielder Challenge team member. One year we reached the final and I went away for the weekend. Although we did not win, I did not mind. I had spent part of my weekend going boating and hanging between trees on ropes, and these were not activities I had done before. I also got to participate in swimming galas, which felt good, given the previous swimming experiences I described earlier. I also went on a school trip to watch a Premier League football match between Blackburn Rovers and Chelsea. In recounting these experiences, I want to emphasise the importance of staff taking a holistic and inclusive approach to working with me. I firmly believe that one of the reasons many of my high school experiences were so good is because some of the teaching assistants who supported me were themselves parents of disabled children. In addition, those who were not still understood the importance of inclusion.

I studied for a number of GCSEs.[1] I was given extra time and a scribe for any exams I took. The amanuensis and I were invigilated for every such event, of course, to ensure that examination conditions were maintained. In addition, because of the way I had to communicate with my scribe when taking my exams, I was always placed in a separate room from my peers. I achieved good grades. My lowest was a C in mathematics: paradoxically, this was the result I found most satisfying because I struggled with mathematics and, although I was given extra tuition, I still was not sure of achieving a passing grade. I was in the top classes with my friends for most of my other subjects and particularly enjoyed English and History. Most of my teachers spoke highly of my academic ability, yet I remember

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[1] General Certificate of Secondary Education, are exams taken by fourteen to sixteen year olds in England, Wales, and Northern Ireland. *See https://www.nidirect.gov.uk/articles/gcses*

my Home Economics teacher's telling me in the days leading up to this examination that I would fail. Despite having little culinary aptitude, I passed the theoretical exam.

After my GCSE results, I had to decide where I wanted to study for my A.S. and A-levels.[2] I looked around a local sixth-form college, but I was put off going there when I saw what I would have to do if I wanted help with practical tasks. I would not have had my own support to help me get around college or study. Instead, the disabled students were required to ring staff on mobile phones the college supplied when help was needed. I decided it was not best suited to me and instead chose my high school sixth form. As a member of the sixth form, I had access to the same quality of classroom support I had recieved during my GCSE studies. I had free periods throughout the week, which meant there were some days I could go home early and relax or study at home. I appreciated this: it was great for my body and only made me work harder. I was also taught in smaller classes alongside many of my friends, which made the experience more enjoyable. I undertook A-levels in History, English, Media Studies, and General Studies: my lowest grade was a B. Whilst studying for my A-levels I began the process of applying to university. At the time this felt like a major personal achievement because of the issues other people had forecast for my life, and the degree of negativity I had up to this point encountered as a disabled person. I was sad to leave my high school as some of my best memories were made there.

Higher Education

I was awarded my university place on merit. I was the first member of my immediate family to go to university. I chose a local university and wanted to stay in halls. As it happened, I was the only one

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[2] A-levels are advanced level, post-sixteen qualifications studied in England, Wales, and Northern Ireland. An AS level refers to the first full year of an A-level. A-levels are usually studied over two years. *See https://www.theuniguide.co.uk/advice/a-level-choices/how-are-my-as-and-a-level-studies-structured#whatisanaslevel*

who wanted this, and I had no help to achieve it. I could not obtain any funding for the support needed for me to live away from home. I missed out on this aspect of student life and therefore travelled in every day from home instead, a fact which still bothers me today. I wanted to study Journalism and applied to do a Journalism degree, but I was advised by the course leader that I would not be able to do the shorthand, a compulsory aspect of the degree, to the standard required to pass. This felt discriminatory because I had a very strong impression that his view was derived from the fact I was impaired and he simply did not want the responsibility for me on his course. I was not even given the opportunity to try and see whether I could indeed do it. I wish I had challenged the course leader's view, but I did not because I knew well the stress that came with making such challenges. I had no psychological or financial support and just wanted to get on with studying. Instead, I switched to a similar course, Media and Communication with English. Unfortunately, unlike the journalism degree I wanted to study, it did not include a professional qualification with the backing of an official body, and the career path on completion was less clearly defined. Despite these initial challenges, I enjoyed studying for my undergraduate degree. In 2002, when these undergraduate studies began, I was not required to pay tuition fees. I took out a student loan and used this to buy the items I needed. I bought a second-hand electric wheelchair, a double bed, and a computer. I took out the loan because I knew the extra money would be useful: the interest rate was very low, and it was made clear that I would not have to begin repaying it until I was earning over £21,000. Nearly 20 years later, I have not yet been in a financial position that requires me to begin repayments.

At University, I applied for, and was granted Disabled Students Allowance (DSA), and received good in - classroom and study support. I particularly enjoyed building a website as part of my Web Design module, and writing a case study on the subject of the Iraq war, which occurred under Tony Blair's Labour government. I completed my degree and graduated with what is colloquially referred to as a Desmond, (after the late Archbishop Desmond Tu Tu) a (2.2). After a lot of planning and organisation I managed to attend my graduation ball. I managed to arrange transport through the University, and travelled to the venue in a minibus with a couple of friends. I also attended my graduation ceremony, which was an enjoyable day, I was very happy to be a part of it. Two factors, though, stood out. First, robe manufacturers do not make robes in my size, so even the smallest robe available swamped me. Second, upon reaching the platform to collect my degree, I was required to reverse my wheelchair backwards down a ramp, in front of what was a very large crowd of people, to return to my spot in the audience. I did not enjoy these aspects of the day.

In 2007, I returned to University to study for an MA in Women's Writing on a part-time basis. I used some of the student loan I had taken out as an undergraduate to fund my tuition fees. One reason I returned to study was to take a break from the stress of applying for jobs. I also felt that, alongside widening my social network, a further qualification might improve my chances of securing employment. As with my undergraduate degree I travelled in from home I applied for and was again awarded DSA. Similarly, I had one-to-one in-classroom and study support. While studying for my MA, I did so with what were, by that point, very painful kidney stones. I had to take an official break from study just as I was about to begin writing my required dissertation in order to have keyhole surgery on my right kidney. The break from study to undergo surgery meant that my MA took three years to complete instead of the planned two years. It also meant that I did not graduate with my class. I achieved my MA in 2010, although this time I chose not to attend the graduation ceremony.

My mainstream education has given me opportunities I would not have otherwise had. For me, one often unacknowledged, yet implicit, value of learning is to gain understandings and knowledge that helps me not only to understand other people, but also to tolerate, challenge and/or resist poor attitudes or discriminatory perspectives to disability and impairment where applicable. Without education, I would be less likely to question the unjust nature of my predicament, and the role that being impaired plays in it. This is important psychologically because it helps me to live within a society that I feel often displays an uneasy relationship to disability and disabled people.

Adolescence and Adulthood

In comparison with my childhood, my adolescence was fairly stable. I lived at home with Dad and my sister, as I still do. I made friends at high school and university and had an active social life. Throughout my adolescence, and for the greater part of my adulthood, I have had very heavy periods, and alongside having Cerebral Palsy this has negatively affected my energy levels. Over the years I have also acquired secondary impairments common in people who have Cerebral Palsy. I have contractures in both knees, and curvature of the spine due to years of sitting in wheelchairs not suitable for me, which have little or no postural support. Until fairly recently, despite applying for and needing an electric wheelchair, I could not obtain one on the NHS.

Then, as now, the practical support I need was predominantly provided by my sister and Dad. I feel that the fact this support has been provided by my family has adversely affected my development. The nature of the support my sister provides means that socially she would be referred to as my 'carer'. Having said that, this is not how I would describe her, because the term has acquired too many negative connotations for me. I perceive it to be a reductive social imposition and particularly affronting given that I live in a society that fails substantively to support my right to independent living.

My life lacks psychological and emotional privacy, and my right to live independently is not supported. I find living at home to be particularly inhibiting when it comes to forming friendships and intimate relationships. I am acutely aware that I do not manage to live as I wish. For example, I live at home and my family members provide my support. I would not choose to live with my family at my age. Being transported almost everywhere at age 35 by my Dad does little to help my self-image. It feels important to say that nothing contained in this section is intended to express anything other than appreciation for my family. Rather, it expresses my deep dissatisfaction with many aspects of my own life over which I have little or no substantive control. For me, the interaction between being impaired on the one hand, and how society responds to my impairment, on the other, plays a key role in that. I did not, for example, envisage how difficult it would be for me to find a job that pays enough to live on; nor did I imagine being denied the health treatment I need. I feel that I live in a society that punishes me for being impaired then sends the message I should be grateful for that punishment.

As I have got older, the sense I am not living in a way I would choose has intensified. Five years ago, I tried to move out of my family home. I approached my local social services and made a housing application. I spent a few years on the housing list and discovered that there is a lack of accessible housing in my local area. One 'accessible' house I was sent to view had a step at the front door and no room to turn my wheelchair inside. I looked at a local supported living development, which felt too much like an institution, and not as if it were 'my own place'. I did not want to exchange one undesirable situation for another. After spending approximately three years on the housing list, I took myself off the list. Experiencing situations such as those described above, the pressure of managing relationships with social services, housing, and my family's lack of support for my desire to live independently became too frustrating. I never felt that I had any control over the process of moving out. Even if I could find an accessible place to live, I am neither in the financial position to fund it, nor to pay for the personal assistance I would need in order to live my own life there.

Employment

A specific area where my impairment has a detrimental impact on my life is in finding employment and developing opportunities to earn money. I know from experience that my chances of getting and retaining a job are reduced because I am impaired. Actively seeking employment places me in direct competition with people who are either non-disabled, or, if their impairment is not visible, might gain from the option of being perceived as non-disabled.

When I first left University, having completed my undergraduate degree in 2005, I had an initial and to some extent unexpected success: I found a part-time Christmas job at a local supermarket, working on the perfume counter. The woman who interviewed me for this position had a son who was impaired, and indicated that she had a considerable understanding of the barriers faced by disabled people in the context of employment. It is not hard to conclude that her experience was most probably pivotal in my being offered the job. It happened that my contract ended just before Christmas, thus I was again unemployed.

In the following two years I made several attempts to obtain employment. For example, I joined schemes designed to assist disabled people into employment, on one occasion undertaking the same course twice in an attempt to progress towards finding a job. I undertook voluntary work in hospital radio and achieved a volunteering award while still applying for jobs. Initially, I kept list of the numbers of jobs for which I applied, but at some point, during these two years, I stopped, because the number of rejections was beginning to have a negative impact on my mental health. During the course of my attempts to find a job, I experienced everything from poor organisation on the part of employers, to discrimination and highly prejudicial attitudes. Some of the employers and organisations I approached for employment were not savvy enough not to cite 'disability' as the reason I was unsuccessful. As such, I feel confident in making the assertion that in some cases I was discriminated against. I was asked, among other questions, if I was a cripple, or if I did stairs. At one interview I was carried upstairs by bellboys because the chosen venue was not wheelchair accessible, even though I had 'declared my disability' in advance. On another occasion, I was interviewed in the bakery next door because the potential workplace was inaccessible, (again, I had 'declared my disability' in advance). The cumulative effect of these experiences on my mental health was a factor in my decision to return to University to study for an MA in 2007. At different times, whilst studying for my MA, I managed to get two *ad hoc*, part-time, jobs. The first involved talking to health and social care students about my experiences of their chosen professions from a user perspective: this is known as service user involvement. The second job was as a student guide, which involved showing prospective students and their families around the University, facilitating group discussions and helping visitors to locate the correct venues for talks and presentations. Understandably, to be a student guide you had to be a student at the University, so when I finished my MA that particular employment ended. I continued with the service user involvement role on an *ad hoc* basis after completing my MA.

After my MA, I started actively applying for employment again. I wanted to keep my work history current, so I negotiated my own volunteering opportunity with a Liverpool-based theatre company and began volunteering there as an administrative assistant. The psychological support provided by those I worked with was crucial in giving me the impetus to keep applying for jobs. The staff there were also instrumental in helping me to obtain the part-time, paid employment I now have, which is working as a sales assistant in a theatre box office. It took me four years to get this current job. I tend to have long periods of unemployment and go a long time between jobs, and I think my impairment is one of the reasons why.

In 2012, I began volunteering for a service-user-led writing group called Reading the World. As the theatre company did before it, Reading the World provided me with much appreciated psychological support. My membership of this group was pivotal in getting the chance to study for a Ph.D., and I also had the chance to travel and perform my creative work. In addition, since beginning my Ph.D. I have been given the opportunity to teach at UCLan, also on an *ad hoc* basis.

Whilst the descriptions I have provided in this section may have created the impression that I applied only for part-time jobs, I actually applied for a number of full-time jobs. However, if a post was full-time, I was less likely even to be invited for an interview. Many failed to respond at all. At one point I chose not to 'declare my disability', and as a result I was invited to more interviews, yet was still unsuccessful. There were many occasions on which I was interviewed as practice for the interviewer and my application, my desire to be employed, had not been taken seriously. For me, sourcing meaningful, financially viable employment remains an on-going issue.

Ph.D. Study

I began studying for this PhD in 2015. Until embarking on it. I chose not to study topics that were specifically focused on disability. When I was younger, I did not want to study what I was living with and through; however, as I have become older, this has changed. To study anything in detail you must be prepared to acknowledge your own social circumstances, which previously I did not feel ready to do. Over time, however, I have come to understand the importance of talking about disability and impairment in the society in which I live. To put it more frankly, I feel a compulsion to write about my experiences because, as I have explained, there is too much that I cannot do and too much that is made more difficult because I am impaired, and because of the way society responds to impairment. My lived experience of impairment and how others respond to disability has led to my developing a personal preference for applying the social model of disability as a way of understanding impairment and disability. I recognise it is not the orthodox way that disability is understood in England, where disability is commonly conceptualised as a problem of individual deficiency or failure of the body (Thomas; 1999, Oliver, 2009; Cameron, 2014). Nevertheless, I have a preference for this as a way of understanding my experiences, because it breaks the link between disability and impairment. By recognising that society disables some within it by failing to provide equity of access for disabled people and reframes disability as a social rather than individual problem, the social model gives disabled people a framework from which to argue for substantive equality and improved access. Unfortunately, I did not discover the social model of disability until studying as an undergraduate. Had I been aware of it earlier, its principles and values may have helped me to challenge some of the discrimination and poor responses I have encountered throughout my life.

I knew from the outset of my Ph.D. studies that I wanted to include my personal experience in my research. I wanted to give space and consideration to my own perspective which, in my experience, is often ignored in or erased from my daily life. With the possibility of including some critical analysis of autobiographical narratives, I read texts such as *My Left Foot* by Christy Brown, a man with the same impairment as myself, Cerebral Palsy, who grew up in Ireland in the 1930's. *My Life in My Hands*, by Alison Lapper, a disabled woman born in 1960's Britain with no arms and legs and *Don't Worry, He Won't Get Far on Foot* by John Callahan, an American quadriplegic, who acquired his impairment in 1972 following a car accident. Although I found sufficient commonality and divergence of experience in these texts to produce what would have been an interesting and potentially valuable analysis, I did not pursue their use as primary texts in my research because I felt they were too far removed in time, space and culture from my own experiences. Therefore, I felt they would not have been a good enough fit to analyse my own experience of living in the UK during a time of austerity policy, a situation that it felt more pressing and important to understand and write about given what was happening to me during this time.

At the suggestion of my Director of Studies I began to keep a journal. I titled this "Fucked: Diary of a Disabled Ph.D. Student". The provocative title both reflects how I felt about my social position and situation as a disabled student at the time and how I felt about the position of many other disabled people under austerity. My life and the material conditions as a disabled person with a 'chronic impairment and 'medical condition' were difficult enough before the imposition of austerity, and austerity only made them more so. My journal ended up, at least in part, documenting the impact of this policy on myself as a disabled person. I kept my journal over a three-year time period from 16 March 2015 to 26 December 2018, during a recognised period of socio-political austerity enacted by the Coalition and Conservative Governments. As I shall explain, this journal forms the basis of my autoethnographic thesis.

My Ph.D. might not change or improve my own situation in any way; still it is my attempt to increase understanding of the barriers disabled people face. Moreover, this thesis is my contribution to Disability Studies, and to the Disabled People's Movement, which exists, among other reasons, to remove some of those barriers.

Chapter Two

A Social Context for Disablism

Introduction

This chapter provides a context for my thesis. In it, I define and conceptualise disablism, neoliberalism and austerity. As my research was conducted during a defined political period of austerity in the UK, I have included sections on the background to austerity, the broader impact of austerity, and the impact of austerity on disabled people. Neoliberal principles, policies and practices underpin both my experience of disablism, and of austerity and I explain why I think neoliberal austerity is disablist.

Defining and Conceptualising Disablism

Disabled activist, - Pam Thomas defines disablism as: 'The practice of not taking account of people with impairments, (thus creating a false notion of normality, pressure to conform to this false notion and the separate development of people with impairments)' (Thomas, 2004: 2). For disabled activist Carol Thomas, 'disablism … refers to the social beliefs and actions that oppress/exclude/disadvantage people with impairments' (2007: 13). Contrastingly, in making the prejudicial nature of disablism explicit, Miller *et al.* (2004: 9) define it as being 'discriminatory, oppressive or abusive behaviour arising from the belief that disabled people are inferior to others'. The understanding of disablism I wish to advance encompasses all of these elements. When I reflect on my lived experience they are all relevant and readily identifiable. Disablism is comprised of the failure to take account of people with impairments. It is the creation of false notions of normality and pressure to conform. It does lead to the separate development of people with impairments. It is a combination of (and embedded within) social beliefs and actions that oppress, exclude, and disadvantage people with impairments. Disablism is discriminatory and much of it is founded on the conception that disabled people are inferior to others. The social disadvantage, marginalisation, and exclusion experienced by disabled people is acknowledged by many (*see* Imrie and Wells, 1993; Oliver, 1996; Kitchin, 1998; Watermeyer, 2016). Miller *et al* highlight the broad social scope and impact of disablism in commenting that:

> Disablism blights our society. From getting an education to getting around, building a career to becoming a parent, going out with friends to using the Internet, disabled people face many more challenges than their nondisabled fellow citizens and are routinely discriminated against and excluded. Nobody could seriously suggest that disabled people should have fewer opportunities than nondisabled people but somehow we find ourselves in a situation where the reality, as lived by disabled people today, would suggest otherwise (Miller *et al.* 2004: 19).

As Goodley (2014: 7) contends, people with impairments will commonly experience disablism, the conditions of disablism are 'material', 'real' and 'potentially fatal'. One purpose of disability studies, in highlighting disablism, is to oppose the individualisation of disability, and to acknowledge that disablism, similarly to disability, is a collective experience (Goodley 2014). Whereas some forms of disablism such as disability hate crime are more overt and obvious, applying race theory to disability and disabled people Deal (2007) developed the concept of aversive disablism, suggesting that much of the prejudice expressed in relation to disability and disabled people is subtle and covert. This notion of aversive disablism builds on the race theory of Gaertner and Dovidio (2000) who argue that aversive racists hold ambivalent attitudes towards black people that are 'rooted in the tension between feelings and values' (2000: 13) and that: '[t]hese negative feelings do not reflect open hostility or hate; instead, the feelings involve discomfort, uneasiness, disgust, and sometimes fear' (2000: 14). As such, an aversive racist is someone who, while not openly hostile or hateful to someone of a different race to them, may respond to people of different races with discomfort, uneasiness, disgust, and fear. Applying this to disabled people, Deal suggests that such feelings are:

> [L]ikely to cause the attitude holder to avoid contact with the attitude recipient. Support for well-meaning social policies that reduce the possibility of meaningful interactions between disabled people and others are therefore likely to be supported by aversive disablists, for instance: supporting segregated schooling due to the belief that it can offer a higher quality education to disabled children, rather than mainstream education with appropriate backing within the school; the continuation of Day Centres, rather than providing the same services and support within an integrated environment; the use of residential care homes rather than community-based housing schemes; supported/sheltered businesses rather than job coaching schemes assisting disabled people to work in integrated work environments. (Deal 2007: 96)

Deal's point here is not that the settings identified are inherently bad: indeed, he suggests that some settings may be appropriate in some instances. Rather, it is that: 'these approaches will inevitably reduce contact and, therefore, the opportunity to forge meaningful relationships between the disabled person and the wider community will be severely hampered' (Deal, 2007: 96). In addition, Gaertner and Dovidio (2000) argue that aversive racists are not anti-black but pro-white. Applying this in the context of disablism, Deal suggests:

> Aversive disablists may not be anti-disabled, but rather pro non-disabled. This theory may hold true for both disabled and non-disabled people, bearing in mind people do not on the whole choose to be disabled, but not choosing to be disabled does not mean the person will automatically be anti-disabled (Deal 2007: 97)

Referring to the critical race theory of Gaertner and Dovidio (2000), Deal recognises that the consequences of aversive racist, pro-white behaviour can be as damaging to black people as are more overt forms of racism and, although not directly stated, one key implication of his work is that the same can be said of aversive disablism (Deal 2007). Deal's work on aversive disablism is illustrative of the following: that it provides a context for disabled people's being socially regarded as different, through separation and the lack of opportunity to form meaningful relationships with others. The resulting lack of contact plays a part in the formation and reinforcement of disablism itself. As Imrie (1996) argues, segregation, although promoted as a way of helping to assimilate disabled people into society, in fact perpetuates disablism by labelling disabled people as 'different', as needing specialised and segregated facilities. Segregation is thus a catalyst for reproducing the negative position and status of disabled people. As such, popular misconceptions concerning disabled people are consolidated and propagated.

Deal's work on aversive disablism is also illustrative of the ease with which disablist attitudes are rationalised and can be made to seem reasonable to disabled and non-disabled people alike. Disablist attitudes and perspectives that deny the existence of disabled people and commonly fail to take account of our needs and requirements form the basis of and are embedded within policies that govern access to the built environment and a whole range of public spaces (Imrie and Wells, 1993; Kitchin, 1998; Deal, 2007). For example, Imrie (1996) suggests that current urban planning is underpinned by a `design apartheid', adding how those involved are guilty of constructing spaces which `lock' disabled people out and prioritise the dominant values of the `able-bodied' community (Imrie, 1996: 2;19).

Policy and legislation with the stated aim of improving access for disabled people is often voluntary and the wording vague and flexible. For example, Section 4 of the 'Chronically Sick and Disabled Persons Act' (1970) requires developers to provide access to buildings only if it is 'practicable and reasonable' to do so, and refers only to the provision of access in new buildings and where 'substantial improvements are made to existing ones' (CSDP Act 1970). The Equality Act 2010 requires that public bodies, organisations, businesses and service providers make 'reasonable adjustments' to accommodate disabled people (Equality Act 2010). Such wordings make it fairly straightforward to justify failings in providing access or a particular type of provision since it can easily be argued that a requirement or need is not practicable and reasonable or else is an unreasonable adjustment. Simply put, there is little or no compulsion within policy and legislation to provide access. The bodies vested with responsibility for the oversight of rights and entitlements under equalities legislation have progressively lacked powers and resources to effectively enforce compliance (Dickens 2007). In addition, and in my experience, health and safety legislation and policy can act as a cloak for disablism in the sense that my exclusion from a range of activities and environments has been justified on such grounds. For example, I have been barred from swimming with my non-disabled peers at school: prevented from taking part in physical education classes and denied entry to a cinema, as well as being denied access to a wide range of events, leisure venues and attractions. When my entrance is permitted, my movement is commonly restricted to certain areas, predicated on my willingness to hold my bladder and remain in my wheelchair. This is because of the usual height and design of public seating, alongside the reactions of others to the ordinary act of transferring from my wheelchair in public that is on occasion perceived as a risky and transgressive act. Perspectives and attitudes held in the context of health and safety are rarely questioned or critiqued and can be hard to challenge. They function as disablist because they are employed to rationalise and justify many disabled people's exclusion from a range of activities, environments and locations. Arguably, health and safety policies are also oppressive, because disabled people's occupation of spaces is predicated upon conditions which many non-disabled people would not tolerate, such as the restriction of free movement and the necessary control over full bladders and bowels. Mutua (2001) summarises the social predicament disabled people find themselves in during the course of our daily lives:

> Consider the wheelchair user dwelling in a city with an inaccessible built environment. Unlike everyone else [he or]she knows, her admission to public transport, shops, restaurants, the homes of friends and colleagues, beaches, travel and public amenities of all sorts is simply barred. (Mutua, 2001 cited in Watermeyer and Swartz, 2016: 270)

Awareness of this predicament influences most decisions I make in relation to my daily activities and my life as a whole. Most transport is not accessible to disabled people and where it is accessible, many disabled people say they are fearful of travelling on it. Many consider a private car to be the only form of transport that is convenient and accessible (Miller *et al*., 2004). In Britain, people with physical and sensory impairments report that the main barrier to accessing goods and services was physical access to premises (Miller *et al*., 2004). In addition, getting an education is made difficult by inconsistent and sometimes non-existent physical access to campuses, classroom spaces and facilities (Be, 2019). Moreover, I know from experience that the attitudes of staff to disability and impairment and lack of substantive support and provision for disabled students are further barriers that disabled people can and do encounter. I have experienced disablism at every stage of my education, including whilst studying for this Ph.D.

In addition, given their purpose, i.e., to provide medical care to sick, ill, or injured people, it might be reasonable to expect environments such as GP surgeries and hospitals to have improved accessibility, yet, in my experience, they are some of the most inaccessible and disablist environments. As a result, I often feel like a 'fish out of water' when in these settings. Some reasons for this include a general lack of space, proximity to others, and lack of accessible toilet facilities (my wheelchair either does not fit through the door or handrails are in the wrong place). The height and un adjustable nature of equipment often make independent transfers from my wheelchair impossible. I have also commonly experienced ignorant and prejudicial attitudes of staff to disability, impairment, and also to my wheelchair as a mobility aid.

Simply put, systematic disablism detrimentally impacts most areas of my life (Miller *et al*., 2004). As I shall illustrate in detail in chapter four, the tangible effects of disablism are inaccessible or partially accessible buildings, inaccessible or partially accessible public transport, difficulties in accessing education or healthcare, and general social exclusion. These prevent disabled people from living as they wish in any actual sense. Contemporaneously, disabled people are experiencing and dealing with the consequences of a historical apathy, a failure to account for our needs and existences. This amounts to a tokenistic, fragmented, and disablist approach to providing for our inclusion. Disabled people are coping with the results of policies and legislation which are voluntary, unenforced and embedded with disablism. I consider disablism to be influenced and impacted by the neoliberal character of society, which I define and conceptualise in the following section.

Defining and Conceptualising Neoliberalism

Disability scholar Deborah Stone (1981) noted the importance of the body and the imperative of bodily categorisation for sustaining modern capitalism. The disabled body is deemed to be a health and financial risk to the general citizenry and a burden on the state (Gothard, 1998). The regulation of the social order requires the state continually to create broad social consent to emergent political/economic structures and it is here that the state regulation of bodies through a plethora of sophisticated classification regimes is necessary (Foucault, 1977). Bodies marked out as ‘exceptional’ are powerfully held out as a moral deterrent to other citizens from resisting the ideals of the prevailing social order (Peck, 2001). The social meanings of disability have been key to this process. Historically fluid, social classification regimes contribute to particular ideological, political, and economic projects. The remaking of social categorisation therefore becomes pivotal to maintaining the hegemony of the historical moment, where the state formation is set in time and space. Shifting state formations in turn, mesh with emergent material structures, as Gleeson observes:

> [S]ignalling a potentially profound change in the course of social embodiment, involving new forms of freedom, prestige and wealth for some, and new types of restraint, discrimination and deprivation for others. (1999: 70)

Soldatic and Meekosha (2012) argue that disabled people can speak to the fluidity of these state regulatory structures as their bodies continually undergo a process of re-classification, stratifying their disability status into new hierarchical formations. The ideas that underpin neoliberalism adapt well to contemporary capitalism and are themselves projected or inscribed upon populations and bodies. Contemporary capitalism has become predominantly neoliberal in character and on occasion what is attributable to capitalism and/or neoliberalism can be indistinguishable. Neoliberalism has multiple interpretations and meanings. As Willis *et al*., suggest (2008: 3) whilst it 'is not a coherent or homogenous ideology', it functions as an overarching ideology, political economy and state formation. According to Leitner *et al*. (2007: 1) neoliberalism is 'spatially differentiated and the historicity of spaces and places mediate its sweeping force'. Its key principles and ideas include unregulated, unrestricted capitalism, the privatisation of public assets and services and the reduction of state interventionism in economic and social activities (George, 1999; Navarro, 2007; Chomsky and McChesney, 2011; Slorach, 2016). Neoliberalism is characterised by the primacy of the free market as the key organising principle of society, the elevation of the individual as a free autonomous agent, and a regression of the prior Keynesian welfare state consensus (Harvey, 2005; Willis *et al*., 2008; Peck, 2001). According to Harvey (2005) Neoliberalism can be defined as:

> A theory of political and economic practices that proposes that human well-being can best be advanced by liberating individual entrepreneurial freedoms and skills within an institutional framework characterized by strong private property rights, free markets, and free trade. (Harvey, 2005: 2)

Similarly, Navarro (2007) characterises neoliberalism as an ideology which:

> Postulates that the reduction of state interventions in economic and social activities and the deregulation of labor and financial markets, as well as of commerce and investments, have liberated the enormous potential of capitalism to create an unprecedented era of social well-being in the world's population. (Navarro, 2007: 47)

What is striking about both these definitions is the reference to the assumption of proponents of neoliberalism, that its principles are the best way of progressing human well-being. Yet in arguing that neoliberal austerity policies cause preventable harm, research by Stewart (2019) presents a strong challenge to the view that neoliberalism is the best way of progressing human well-being. Soldatic and Meekosha (2012) chart the ascendancy of neoliberalism as a world view from the 1980s with what became known as the 'New Right' through the Parliamentary election of Margaret Thatcher in the UK and Ronald Reagan in the USA (Chomsky and McChesney, 2011; George, 1999; Minford, 1987). It is often assumed that neoliberalism is the only option and this influenced the belief in the maxim that 'There Is No Alternative' (TINA). As 'the vanguard of the global 'New Right' Thatcher and Reagan:

> [U]ndertook a process of change in positioning the state, the market and society. The unfettered workings of the market were signalled as paramount and the role of the state was radically restructured to ensure that the market was given free rein from all social constraints (Soldatic and Meekosha 2012: 196).

As Leys (2001) contends, under neoliberalism state and representative politics are secondary to the market and public interest is solely framed within market terms. Giroux (2004: xiii) argues that neoliberalism is 'wedded to the belief that the market should be the organizing principle for all political, social and economic decisions and wages an incessant attack on democracy, public goods, and non-commodified values'. These understandings of the market have become normative and shape the relationship between state and citizen (Soldatic and Meekosha 2012). In this context, the individual is cast ‘as a market agent pursuing advantage in competition with others’ (Connell 2008: 247). It is suggested that the importance placed upon individual responsibility has become ‘endemic’ in Western liberal democracies (Soldatic and Meekosha 2012: 197). As such, states have undergone a transformation process to normalise the discourse of individual responsibility within civil government and political constitutions, and espousing the benefits of competitive individualism as a central aspect of day-to-day life (Rose 1996). As Soldatic and Meekosha (2012) note, joining the ideologies of the free individual and the free market is paramount to neoliberal understandings of the self in which:

> The individual is represented as an active autonomous agent, free from all constraint in pursuing their own individual interests. The free market individual, freed from all social and moral restraint, is empowered to make their own individual choices and, consequently, free to experience their own individual failings. (Soldatic and Meekosha 2012: 197)

Leitner *et al*. (2007: 4) refers to this individual responsibility in neoliberal terms as ‘capacity for self-realisation’. For Soldatic and Meekosha it is predicated ‘upon a set of government technologies that reposition the individual as a self-defining entrepreneur, engaging in a range of activities to build their human capital so that they are an effective resource, highly sellable, within the marketplace’ (2012: 197). Accordingly, they argue that the role of the neoliberal state is ‘to propel the ‘willing’, and coerce the ‘unwilling’, into adopting, practising and regulating their individual behaviour in favour of ‘free’ market competition’ (2012: 197).

Although neoliberal faith in unregulated free markets and privatisation are powerful contemporary orthodoxies, they are not without criticism. Critical economists point both to deleterious impacts and fallacies associated with foundational beliefs and assumptions. For example, Pearson (2020: 21) plausibly observes:

> The pretence that the free market decides the most efficient and effective allocation of resources is hugely damaging. First, there is no such thing as a free market; and markets free from government interference do not remain competitive for long. Without the benefit of extraneous regulation, competitive markets inevitably mutate towards cartel and monopoly, where financial players are focused on the predatory extraction of value, rather than investing in the long-term future … that is damaging to business, to the overall economy, and to wider ecological and social systems.

One obvious context to which neoliberal beliefs and assumptions are applied is employment and the labour market. Writing initially in the context of employment in the Australian state, Soldatic and Meekosha contend that the neoliberal state has co-opted the disability movements collective demands for the right to work by harnessing individual ‘employability’. This state strategy for de-collectivisation has been compelling for many within the disability movement who see the labour market as integral to their struggle for equality. However, Soldatic and Meekosha note that the gendered nature of disability means that men are more employable than women. This situation is similar in a British context, where notions and schemes of individual employability exist and where the employment rate is lower for disabled people compared to that of non-disabled people. However, in Britain, disabled women are marginally more likely to be in employment than are men (EHRC 2017; House of Commons Library 2021). Soldatic and Meekosha summarise the position of many disabled women living in Western democracies:

> Across Western liberal democracies … state co-option of the right to work as an individualizing discourse, has had detrimental consequences in real terms, where a segment of the disability population has been extensively targeted and is now forced to look for work in low waged and unskilled labour markets to maintain access to a range of social entitlements. Disabled women,

> in particular, when they do obtain employment are more likely to be in low paid, part-time, short-term casual jobs Soldatic and Meekosha. (2012: 198)

In line with this, they note that the representation of the fit and healthy person as the epitome of embodiment within neoliberalism has important implications for disabled people's collective ability to challenge exclusionary and discriminatory structures:

> As legitimizing discourses, neoliberal State measures not only individualize, but also directly blame, those who are suffering from structural disadvantage by harnessing moral discourses of individual responsibility. This is particularly onerous for disabled women, who often have caring roles that limit their employment opportunities. Structural and systemic disadvantage remains hidden, [and] discrimination in the workplace often remains covert; disabled people are considered less 'able' and less reliable. (2012: 198)

In other words, disabled people are made personally responsible for the disadvantage they experience, the organisation of society plays no part and disadvantage and discrimination in the workplace remains unacknowledged and unaddressed. State responsibility for enabling people's rights and entitlements are reduced to the moral worth of the individual and moral worth is inexplicably linked to competence and ability (Soldatic and Meekosha 2012). The idea that the inequality people experience is solely their own fault has been challenged by several writers who argue that Neoliberalism itself is a central driver of inequality (Azevedo *et al*., 2019; Chomsky and McChesney, 2011; Navarro; 2007). Representations of disadvantaged individuals and groups as being in some way blameworthy for their own predicaments has helped sustain complementary narratives that justify austerity policies attendant upon crises of neoliberalism, where the victims of austerity are deemed complicit in its necessity. In this distasteful paradox, the poorest within society carry the burden of economic measures designed to remedy catastrophic failings of unfettered market forces whilst preserving the advantages of the richest within society. Austerity is thus a key feature of neoliberalism and in the following section I define it and explore a key aim: the reduction in size and scope of the state.

Defining Austerity

Mary O'Hara employs the Collins Dictionary definition of austerity as: 'difficult economic conditions created by government measures to reduce the budget deficit, especially by reducing public expenditure: a period of austerity' (O'Hara 2015: viii). Similarly to O'Hara, Ryan (2019), a disabled journalist, looks at austerity in a British context. For her, as for O'Hara, austerity in a UK context begins with the election of the Conservative Party as part of a Coalition Government in 2010. Also, as did O' Hara, she understands austerity as a programme of cuts and a 'hollowing out' of welfare, public services, and council budgets: 'as part of a Coalition Government in 2010, the British Conservative Party under David Cameron oversaw a programme of cuts not seen since the 1920s … hollowing out welfare, public services and local council budgets' (Ryan 2019: 3). Similarly, disabled writer and member of the disability activism group *Disabled People Against Cuts* (DPAC), Ellen Clifford asserts that the purpose of welfare reform under austerity is:

> [N]ot to get rid of the welfare state altogether but to reshape it through cuts and privatisation and by entrenching punitive approaches; welfare reform is being used as a weapon against benefit claimants while serving to discipline the workforce in the interests of business. (2020: 7)

Additionally, Cooper and Whyte define austerity by commenting that:

> Austerity is a word that is used to describe a period of fiscal discipline in which governments make significant cuts to public expenditure as a means of reducing public debt. The principal ideal underpinning austerity is that governments, by cutting expenditure, will encourage more private consumption and business investment and therefore more sustainable economic growth. Austerity, then, built on the logic of expansionary fiscal consolidation, whereby cuts to public expenditure are preferred over maintaining public expenditure and/or implementing tax increases. (Cooper and Whyte, 2017: 4)

The definition of austerity provided by Cooper and Whyte acknowledges that austerity is both a social and an economic policy. My understanding incorporates all of these definitions; it sees austerity in Britain as encompassing a wide range of cuts to public services, inclusive of a reduction of the welfare state, and the conception of austerity as an economic policy implemented to reduce public debt. In the next section I look at the background to the introduction of austerity in the UK.

The Background to the Introduction of Austerity in the UK

The imposition of austerity in the UK is predicated on the idea that as a nation we have spent too much on public services, yet the predominant cause was the global banking crisis in 2007/2008 (Blyth, 2013). It is important to note for the sake of clarity that when discussing austerity some writers refer to debt and deficit interchangeably, whereas debt makes reference to money owed as a nation and deficit refers to the gap between the amount owed and the capacity to pay back in terms of what we produce, commonly referred to as our Gross Domestic Product (GDP) (Cooper and Whyte, 2017). The 2010 Coalition Government argued that austerity was necessary to reduce public debt. As Cooper and Whyte (2017) observed, 2008 marked the beginning of a:

> Consistent theme in political discourse that has endured for a decade following the global financial crisis: that austerity can be understood as a rational response to soaring levels of both

> personal and public debt, which in turn have resulted from a combination of reckless government spending and debt-fuelled personal consumption. (2017: 5)

Benstead (2019) provides a comparable explanation of the Coalition Government’s justification for the cuts:

> The cuts to social security, social care and the wider welfare system form part of general efforts to achieve a closer balance between government spending and tax receipts following the 2007/08 global financial crisis. The government elected in 2010 considered the social security budget to be particularly bloated and a large contributor to the deficit it inherited. Therefore, there was, it alleged, an economic need, as well as the moral need … To reduce spending on social security. (Benstead, 2019: 103-104)

For Blyth (2013) what the government framed to the public as a problem of state debt was actually a result of the global banking crisis of 2007/2008, and the UK public is being made to pay for the mistakes of private sector banks. As Blyth notes, prior to the banking crisis of 2007/2008 the subject of state debt received scant public attention (2013). For Blyth, to argue that the situation is a sovereign debt crisis is a gross distortion of the facts:

> The way austerity is being represented by both politicians and the media-as the payback for something called the sovereign debt crisis, supposedly brought on by states that apparently spent too much-is a quite fundamental misrepresentation of the facts. These problems, including the crisis in the bond markets, started with the banks and will end with the banks. The current mess is not a sovereign debt crisis generated by excessive spending for anyone except the Greeks. For everyone else the problem is the banks that sovereigns have to take responsibility for, especially in the Eurozone. (Blyth, 2013: 5)

As Blyth points out, what was private debt, that of individual banks, has been made public debt by not letting the banks go bust:

> This is, as we shall see … why all of Europe needs to be austere, because each national state balance sheet has to act as a shock absorber for the entire system. Having already bailed out the banks, we have to make sure that there is room on the public balance sheet to backstop them. That's why we have austerity. It's all about saving the banks. (Blyth, 2013: 7)

According to Blyth, the national balance sheets of a number of global states, the UK included, are being conscripted into propping up the banking system. For Blyth, there is a sovereign debt crisis in Europe, but this is an effect, not a cause of the banking crisis. For him, austerity is predicated upon both preventing the banks from going bust and making the public pay for the banking crisis (Blyth, 2013). Making the public pay for the banking crisis has been referred to as the 'alchemy of austerity' (Clarke and Newman, 299: 2012) where, according to Cooper and Whyte 'the problem of the financial crisis magically becomes a public sector problem. The huge sums of public money used to save the banks from liquidation following the 2007/2008 crisis effectively turned 'a private sector problem into a problem of public debt' (2017: 7). For O'Hara, and Mendoza too, contemporary UK austerity is attributable to the 2007/2008 banking crisis rather than to an issue of national debt. (Mendoza 2015; O'Hara 2015). Benstead (2019) also notes how the governmental narrative that, as a country, we have overspent on social security to an excessive degree does not survive scrutiny:

> But the data does not support the contention that social security was excessive. Real-term per capita expenditure on working age people fell between 1995 and 2006, and even after the 2007/08 financial crisis per capita spending peaked at around the same level as during the recession of the early 1990s. Social spending as a percentage of GDP was below or very close to the average for developed countries from 1989 until 2007/08, and although the UK went slightly

> above average after the financial crisis this gap has now shrunk to half a percentage point. So, the pre-crisis benefit levels were neither excessive nor out-of-control. (Benstead, 2019: 104)

She notes that it is part of the government’s role to prevent unnecessary financial hardship at times of recession. She argues that the provision of social security has both moral and economic benefits, a point noticeably absent from the government’s stated reason for implementing austerity:

> The post-2010 governments claim of excessive social security spending ignores the importance of the government’s role in maintaining demand and preventing unnecessary poverty during a recession. During the recession, the private sector stopped providing an income for as many people as previously, as people are made redundant or otherwise have their pay reduced. This creates a downward spiral as people who have lost work have less money to spend, so demand for goods and services fall, so businesses have to let even more people go. Social security at this point provides both a moral and economic role by providing people who would otherwise have nothing with money that they can spend on basic living costs. (Benstead, 2019: 104)

As Mendoza (2015) adds, the amount by which, according to her own research, the national debt rose following the banking crisis could have funded the NHS for eight years. She continues:

> The decades preceding the crisis had seen long-term collusion between government and the financial services industry aimed at avoiding proper regulation of financial services in general, and the derivatives market in particular. There was intense lobbying in the US and the UK to maintain this position, with senior government figures on both sides of the Atlantic stepping in directly to prevent the commodity futures trading commission (in the US) and the financial services authority in the UK from ever coming close to putting the appropriate safeguards in place around these products. This left banks brokers and insurance companies free to expand their balance sheets rapidly by leveraging debt to almost infinite ratios. (2015: 18).

Decades of failure to regulate the banks left them free to do as they wished. The net result of this was that the banking system was propped up by debt as opposed to by capital. Arguably, failure to regulate financial institutions made the banking crisis inevitable, and if deregulation continues, it is likely to happen again because of the amount of debt they are supported by (Blyth 2013). As did Blyth and O'Hara, Mendoza attributes the root cause of austerity to the bank bailout 'instead of these corporations simply collapsing, this extraordinary mountain of toxic private debt was converted into public debt by the bank bailout' (2015: 19). There is, as I see it, an inherent unfairness in expecting the public to bail out the banks and pay for the mistakes of the private sector. To support why I favour writers such as Blyth, Mendoza and O'Hara, who attribute contemporary UK austerity to the banking crisis of 2007/2008 in preference to the view that as a state we have spent too much and need to reduce the national deficit. I shall provide an explanation of how the economy works. I use an example from Mendoza's work because she provides an accessible explanation of a complex concept. According to Mendoza most people understand how our economy works in the way represented in the following equation**: A Good Idea + Skill + Usefulness = Added Value**. She notes that this equation is also key to the social acceptance of the profit principle and inequality of wealth in that 'people feel that those who add value should be rewarded' (2015: 21). For Mendoza:

> The problem is, this has ceased to be the way our economy has actually worked for some considerable time (if it ever was) … The way most wealth is accumulated today is not based on this simple premise of adding value by creating something useful and being rewarded for that contribution. (2015: 21)

For Mendoza (and for Blyth) the securitisation food chain, (an economy founded on the pooling of debt), that aims to create increased profit rather than add value provides a more accurate representation of how our contemporary economy works. It looks something like this: **Debtor > Creditor > Investment Banks > Investors.** The chain is founded on debt and dependent upon a debtors' ability to make **Loan Repayments** (Mendoza 2015: 23). As an explanation of how this securitisation chain works in practice Mendoza uses the example of the utility, water:

> Water has immense value, but only as much utility as there are people who need to drink it or use it in other ways. So how do you keep increasing the profits on water in an economic system that demands infinite growth? First, as a water magnate, you can set out to buy it all and gain control over the total water supply and production. You succeed. Now you've increased your customer base. But, now what? You get people to pay you to have shares in the proceeds from what people pay for their water and the shareholders and others run the company. You succeed. You retain control over the company, you continue to receive profits … Now what? You can have people bet on whether the price of water will rise or fall you realise you can manipulate the price of water at will by creating scarcity or by a whole host of other methods. This means you can ensure the house always wins … In all this time, the price of water for those using it creeps continually upward. The consumers have to pay not only for the water, but the profits and losses all the way up this giant chain. They are getting no greater utility from the water. (Mendoza 2015: 22)

Mendoza asserts that this is how financialisation, the process by which financial institutions increase in size and influence, works. It takes something that has utility and without increasing the utility or adding value generates even greater costs to those using it and profits on a short-term basis for the owner (Mendoza, 2015). Mendoza refers to this process as a zombie economy, which is an economy founded on debt, one that relies on consumers paying increasing amounts for things they need, without any additional benefit to them. She argues that in effect, this zombie economy exists to overcome barriers to capital growth (profit):

> It creates financial instruments that increase the paper value of an asset (not its utility, which is finite) by financializing it. However, when this house of cards collapses, which is inevitable, it's

> the consumers that pick up the bill. The purpose of financialisation, the securitisation food chain and the zombie economy is for creditors, investment banks and investors to make maximum profits from lending. It is the same cycle that we witnessed with the Third World Debt Trap and the lead-up to the financial crisis. The purpose is to move people away from making money by producing things, towards making money from money. The problem is the debtors (consumers, taxpayers or nation-states) eventually exists solely to service these loans and production becomes secondary. This is the food chain that has moved into the fabric of the British state and is now feeding on our public services. (Mendoza 2015: 23)

The idea that austerity is needed because as a nation we have overspent is politically expedient because 'in a democracy you can hardly come clean about what you are doing and expect to survive' (Blyth, 2013: 87). Blyth includes an example of what a more honest statement from a Prime Minister of a European country might look like in order to explain why austerity is put to the public as a problem of overspending rather than a banking crisis:

> There is literally nothing we can do about this. We need to keep the banks solvent or they collapse, and they are so big and interconnected that even one of them going down could blow up the whole system. As awful as austerity is, it is nothing compared to a general collapse of the financial system, really. (Blyth 2013: 89)

As Blyth acknowledges, this is a speech you will never hear any politician give; if they represented the economic situation in this way it is unlikely people would vote for them, because the power of the banks and the unfairness of the system, the placing of financial institutions before people would be made clear. When people owe money, they are expected to pay it back. The same should be expected of financial institutions. For Blyth, 'the real reason' we have to be austere is we have to continually be in a position to bail out the banks. Recalling the example of securitisation chain and how the economy works, a financial crisis is likely to happen again, or inevitable, if you, as I do, accept Blyth and Mendoza’s interpretation of events:

> It is the real reason we all need to be austere. When the banking system becomes too big to fail, the moral hazard trade that started it all becomes systemic “immoral hazard”- an extortion racket aided and abetted by the very politicians elected to serve our interests. When that trade takes place in a set of institutions that is incapable of resolving the crisis it faces, the result is permanent austerity. (Blyth 2013: 90)

Blyth is one of a number of writers who have questioned the official government narrative and sees austerity as a conscious political decision, predicated on the financial crisis imperative of rescuing the banks (*see* also Ryan, 2019 and Clifford, 2020). In supporting this view, Cooper and Whyte (2017) cite the example of Iceland:

> One country that didn’t follow the austerity route was Iceland. Following the financial collapse in 2008, the Icelandic government initially developed a rescue plan to bail out the banks that involved compensating shareholders and foreign investors and putting the financial burden back onto the taxpayers and national bank. After several weeks of public protests, the government stepped down, the austerity package was abandoned and an alternative set of reforms were put on the table. In the end, Iceland did not bail out its banks, but allowed the losses of the financial crisis to fall more directly on to shareholders, foreign investors, bankers and the financial elite. (2017: 9)

This is one illustration of how there is nothing inevitable about austerity (at least not for Iceland). Despite initial statements made by politicians on its introduction that austerity was a temporary measure, cuts to public expenditure persist. As O’Hara (2015) asserts, quoting the then Prime Minister David Cameron’s own statement at the 2013 Lord Mayor’s banquet, austerity was intended to be permanent:

> He talked of forging "a leaner, more efficient state", and uttered the words many felt he had been holding back since 2010: "we need to do more with less. Not just now, but permanently." There it was-a declaration of permanent austerity. (O'Hara 2015: 8).

As Mendoza points out, 'the main consideration here (in not leaving the banks to go bust) has been the continued profitability of the biggest banks and corporations-not the socio-economic conditions of ordinary citizens. In fact, the public interest is often antithetical to the private interest' (Mendoza, 2015: 19). Similarly, Clifford (2020) suggests that 'deceit and distraction are imperative for maintaining a system geared towards achieving profit for an elite, where the accumulation of misery is a necessary condition for the accumulation of wealth' (2020: 221). In my view placing profitability above the welfare of ordinary citizens is inherent to austerity: this is what it does by design. In agreement with the writers I have chosen to include in this piece, I do not consider austerity to be a necessity: to me it is a conscious political choice. Even if I accepted the official government version of events that as a nation we have overspent and we did need to reduce the national deficit, this does not excuse the impacts of austerity on a large number of British people. In the next section I look at the impact of austerity on the broader population.

The Broader Impacts of Austerity

Organisations trying to address the issue of poverty have pointed out that the situation was bad for people living in poverty even before the government's austerity measures came into full effect. Oxfam was one such organisation urging the government to rethink its plans to cut public spending:

> The combination in the UK of economic stagnation and public spending cuts is causing substantial hardship to people living in poverty. This amounts to a perfect storm of falling incomes, rising prices, public service cuts, benefit cuts, housing crisis, and weak labour rights. By making different political choices, the government can both protect people in poverty and

> help to stimulate economic recovery in the short term, and set the UK on the way towards economic, social and environmental sustainability in the long term. The UK is the sixth richest country on earth yet one in five of its people lives in poverty. Before the financial crisis and the economic recession prosperity was not shared. The UK is one of the most unequal rich countries in the world, with the poorest 10th of people receiving only 1% of the total income, while the richest 10th take-home 31%. (O'Hara, 2015: 47)

In 2013, the Economic and Social Research Council (ESRC) published a report entitled *Impoverishment of the UK*, which looked at poverty and privation being experienced across the UK. It concluded:

> These results reflect the situation before the majority proposed benefit changes came into place and before benefits payments are revised to increase at less than the level of inflation. The impact of the current government austerity measures are set to hit hard those whose standard of living is already well below that seen by a majority to be minimal. (O'Hara, 2015:48)

I know from experience that poverty was an issue for many people before austerity, but austerity policies in the UK made things even worse. Many factors contribute to the detriment of people's living conditions and the entrenchment of poverty under austerity. As Mendoza asserts, the stagnation of wages plays a key role:

> In the period of austerity between 2008 to 2013, wages increased by just 10%. UK essentials index, which focuses on the kinds of everyday items bought by the U.K.'s working and nonworking poor, showed an inflation rate of 33% during the same period. This means that the poorest working people's wages are worth 20% less than they were back in 2008 and it's getting worse. (Mendoza, 2015: 128)

Furthermore, as Blyth states, when government services are cut because of 'profligate spending' it will not be the rich that are expected to 'tighten their belts'. Instead, he suggests: 'it will be those who lie in the bottom 40% … Who haven't had a real wage increase since 1971' (Blyth 2013: 14). In addition, quoting figures from the Office of National Statistics published in August 2013, O'Hara notes that prices rose faster than wages in all but one month from May 2010 and that no other G7 country saw workers' incomes decline as much as in the UK (O'Hara 2015). The suppression of wages and the rising cost of living has meant that more people are acquiring personal debt as they attempt to make ends meet. As Mendoza suggests, the availability of credit has been: 'masking the expanding gulf between the cost of living and the level of wages for decades' (Mendoza, 2015: 128). The combination of these factors is compelling people to use food banks. While food banks did exist before the banking crisis and the government's austerity policies kicked in, austerity has led to both an increase in the number of food banks, and an increase in their usage as many people's incomes are under pressure they cannot withstand (O'Hara, 2015). For her research O'Hara visited a number of newly established food banks. She sees food banks as an indication of the hardship austerity has brought about:

> The Braunstone food bank was just one of hundreds that sprang up all over the UK following the economic downturn that began in 2008. They became ubiquitous in some communities and were regarded by many people as one of the most potent manifestations of austerity and the hardship wrought. (O'Hara, 2015: 18).

A further indication of the negative impact of austerity policies is that a number of those using food banks are in employment:

> incomes are being squeezed to breaking point. We are seeing people from all kinds of backgrounds turning to food banks: working people coming in on their lunch breaks, mums who are going hungry to feed their children, people whose benefits have been delayed and people who are struggling to find enough work. It's shocking that people are going hungry in 21st-century Britain. (O'Hara, 2015: 22)

O'Hara noticed while conducting her research that:

> There was a growing awareness that something unprecedented was taking place, people who had lived on or near the poverty line their whole lives were telling me they had never seen anything like it, and how every week there seemed to be a new food bank opening up. It appeared to many that a creeping normalisation of food poverty was taking place and that the state was abdicating any responsibility for it. (O'Hara, 2015: 26)

It is a measure of the extent of poverty in austerity Britain that, according to O'Hara and to the subjects of her research, food bank usage has become a normal aspect of everyday living for many (Jenkins *et al*., 2021). It is also a measure of the broader impact of austerity that those in full-time work are also struggling to pay their bills and meet their living costs, including many who were not in debt before austerity policies were implemented. The comments of a Glasgow debt adviser from O'Hara's research provide a useful summary of the circumstances even those in work are facing:

> What we are seeing is an increase in people who may not be on benefits but are also experiencing debt problems. So even the people who are out working we are now seeing an increase in those types of people coming to see us. Basically, they are struggling with the amount of money they have to pay out for food and heating and stuff. The current economic climate even seems to be affecting people in full-time employment. Admittedly, minimum wage full-time employment, but we are definitely seeing an increase, which makes us think that the problem is a lot worse. (Martin, cited in O'Hara, 2015: 81)

A reduction in the disability benefits bill was a key stated aim of the government when its austerity policies were announced in 2010. Politicians took every opportunity to remind the public that as a country we were spending too much on disability benefits and talked of their ambition to cut two billion pounds from the budget (Ryan, 2019). It may come as a surprise to some that despite government rhetoric, which implies that most of the welfare budget is spent on people who are sick, disabled and/or unemployed, more is actually spent on in-work benefits and more benefits go to people who are actually working. Mendoza, for example, notes how in-work benefits paid by the taxpayer function to subsidise the wages of the lowest paid:

> The three most expensive benefit payments in the UK are not out of work benefits. Around 65% of the total spent on working age benefits is actually going to people in work. Tax credits, housing benefit and child benefit, totalling 56.4 billion a year has been effectively set up for the taxpayer to subsidise poverty wages. Instead of challenging the disparity between wages in our economic system, the Coalition Government perpetuates the war on wages for the lowest paid (Mendoza 2015:127-128).

O'Hara, too, notes the impact of changes to a number of in-work benefits on working families. She observes that many working families are now living in poverty, and many are even worse off than those who are unemployed or retired:

> There was a fundamental shakeup of the welfare state, including eradicating or reconfiguring a number of key benefits that had primarily assisted the working poor, while the introduction of a new tier of excessively punitive sanctions into the social security system thrust hundreds of thousands of people into extreme financial difficulty, destitution and in some cases, mental breakdown. For the first time ever in the UK there were more people in working families living below the poverty line than in workless or retired families combined. (O'Hara 2015: 3)

In addition, other researchers such as Stuckler *et al*. (2017) and Hamnett (2013) assert that the impact of austerity policies was not felt equally across the country, with the North experiencing greater unemployment and being disproportionately adversely impacted by the cuts when compared to the South and other areas of the country. It is important to note that many people in these areas were already experiencing deprivation and disadvantage prior to the implementation of austerity policies. Moreover, research by Pearson (2019), a 'Feminist Analysis of Neoliberalism and Austerity Policies in the UK', explored the impact of austerity on women, and found that its impact did not fall equally in terms of gender either. Pearson concluded that under austerity women were expected to carry out an excessive amount of unpaid and informal labour (Pearson, 2019). Having looked at the broader impact of austerity on the general population, the next section focuses on the specific impact of UK austerity policies on disabled people.

The Impact of Austerity on Disabled People

As Mark Blyth argues, if state spending is cut then those with the least income will be impacted worse because they have less to begin with:

> If state spending is cut, the effects of doing so are, quite simply, unfairly and unsustainably distributed. Personally, I am all in favour of "everyone tightening their belts"-as long as we are all wearing the same pants. But this is far from the case these days. Indeed, it is further from the case today than at any time since the 1920s … Austerity is, then, a dangerous idea because it ignores the externalities it generates, the impact of one person's choices on another person's choices. "We have spent too much," those at the top say, … Meanwhile, those at the bottom are being told to "tighten their belts" by people who are wearing massively larger pants and have shown little interest in contributing to the clean-up. (2013: 13-15).

In practice, the impact of the cuts is greater on many disabled people because we have less wealth to start with. As Benstead (2019) points out there has never been a "golden period" in which the majority of disabled people have received enough financial support:

> Improvements to social security in the 1970s and early 1980s have been countered since the start of the 1980s by cutbacks to not just the social security system but to the welfare state as a whole. Poor people have been increasingly blamed for their poverty without any consideration of the government's role in shaping the quality and availability of education,

> healthcare, housing and jobs ... Sick and disabled people have never received enough financial support and access has never been uniformly applied or universally available. (Benstead, 2019: 102)

Having acquired my impairment at birth, I know the veracity of the picture Benstead presents. At no point during my life have I ever received sufficient financial or practical support, and in my experience, access is not uniformly applied or universally available to me as a disabled person. Austerity has made already difficult life circumstances more difficult for both myself and for many other disabled people:

> In 2013 disabled people are already struggling to pay the bills. Living costs are spiralling, income is flat-lining. We know many are getting in debt, just to pay for essentials. What's the government's response? The same group of disabled people face not just one or two cuts to their support, but in some cases three, four, five or even six cuts… At the same time, disabled people who want to live independently are seeing the support they need to get up, get dressed and get out squeezed due to chronic under-funding of social care. It paints a frightening picture of the financial struggles affecting disabled people in 2013. (O'Hara, 2015: 143)

The Centre for Welfare Reform calculated in 2013 that disabled people would endure nine times the burden of cuts compared to the average citizen, with 'people with the most severe disabilities' being hit a staggering 19 times harder (Duffy, 2013). Whilst I cannot say that I have been affected by all of the cuts progressed under UK government austerity, I have had my share. The same factors that have impoverished many of the general population under austerity have a greater impact upon disabled people. Disabled people are more likely to be in debt than non-disabled people; research by Scope in 2013 found that: 'Half of disabled people (49%) have used a credit card or loan to pay everyday items in the past 12 months – most commonly to pay for clothing and food' (Scope ,2013). Research carried out in 2018 by Citizens Advice into payday loans found that nearly half (48%) of people struggling with home loan debt have a 'long-term health condition or disability' (Citizens Advice Bureau, 2018). Ryan

(2019) provides a useful summary of what the situation in respect of debt is like for many disabled people under austerity:

> This is not only a case of not having a cushion to cope with the sudden financial crisis-say a broken boiler or being made redundant-but of having an income so low that, week in week out, it won't even cover essential bills. It's a climate of borrowing money to survive … This is the double-edged sword of disability debt: while being more likely to face financial crisis, disabled people are shut out of ways to escape it. Disabled people are less likely to have a current account than the nondisabled; without a stable income, good credit is a phantom. (Ryan, 2019: 32-33)

As with the general non-disabled population unemployment is making the impact of austerity worse for disabled people. An Equality and Human Rights Commission report entitled *Being Disabled in Britain* (2017) found that just under half of disabled people aged 16 to 64 are in work compared to 80% of non-disabled people (Equality and Human Rights Commission, 2017). Ryan (2019) refers to unemployment amongst the disabled community as being an 'epidemic':

> This scale of unemployment isn't simply about not being hired; it's about shutting out disabled people from whole swathes of society. Engineering a system where disabled people are unlikely to find work means withholding their chance at economic independence or finding a place in the community and the social status given to paid work. Rather than the stability and higher living standards of a wage they are pushed into surviving on low-rate benefits. It's disabled people's exclusion from the labour market that in many ways is fundamental to perpetuating a disabled underclass while disadvantage is held up as a moral failing, in reality its structural causes are never more blatant than with disabled people's poverty … the barriers to a decent income are frequent and brutal: be it a deficit in an adequate safety net of social security, being too ill to work, or a labour market that discriminates and excludes workers who need adaptions

> to enable them to earn a wage. But when it comes to a disabled person staying afloat, the issue isn’t simply how little goes in but how much has to go out. (Ryan, 2019: 30-31;54)

Difficulties in relation to employment for me and other disabled people feature across several chapters of this thesis, most notably in chapter five, which explores my experience of benefits assessments under austerity and benefit cuts to Employment and Support Allowance, Disability Living Allowance, and Personal Independence Payment. The chapter intersects with issues relating to employment because being on benefits complicates the process of looking for a job due to the conditions imposed on benefit claimants (Hamnett, 2014). In addition, the context and conditions of employment mean that it is additionally difficult for disabled people to find a job that either matches or exceeds the amount they receive in benefit payments. As Clifford (2020) argues:

> Welfare reform policy is divorced not only from the daily realities of living with different impairments, but also from the material conditions of the workplace. Although the enormous diversity of impairment makes it difficult to generalise, there are numerous ways in which the modern workplace can broadly be seen to have become less accessible and more discriminatory towards disabled workers. Disability employment trends are understudied but what evidence there is suggests that it is actually more difficult for disabled people to be in employment now than previously. (Clifford, 2020: 234)

Unfortunately, I find little in my own experiences that enables me to contradict the picture Ryan and Clifford paint of the employment context for disabled people. As Ryan and Clifford acknowledge, my chances for economic independence are severely limited by the nature of the systems I am forced to operate within. The lack of accessible working environments that Ryan and Clifford cite features in my chapter about my experiences of accessibility. There are many places I just couldn’t work in because buildings are not to any degree wheelchair accessible. The range of attitudes I have experienced as a disabled person looking for work also form part of my chapter on psycho-emotional disablism (PED).

My experiences have led me to concur with Ryan and Clifford that the labour market discriminates against disabled people. The economic and financial situation for many disabled people is so dire that like their non-disabled counterparts they are having to access food banks. Joint research by the University of Oxford and the Trussell Trust in 2017 found that the majority of people accessing food banks are disabled or ill. Over half of households referred for emergency food parcels in Britain include a disabled person. Some 75% are experiencing ill-health (Loopstra and Lalor, 2017). Austerity policies enacted by government have been accompanied by their own justifying rhetoric, and disabled people have been a key target (Briant, Watson and Philo 2013). As Burch (2018) notes in her reflections on political rhetoric and media coverage of changes to welfare:

> To justify these changes to welfare, politicians and media outlets have adopted a strategic narrative. That is, they have expressed pity for 'hardworking taxpayers' who have been portrayed as the real victims of financial instability. At the same time, we have witnessed a surge in vitriolic welfare rhetoric that brands welfare recipients, and many disabled people, as 'scroungers', 'cheats' and 'scum'. (Burch, 2018: 393)

As Ryan (2019) highlights, disabled people have historically been exempt from this type of hostile rhetoric when compared to other groups:

> Even as anti-welfare attitudes festered over decades, disabled people have been traditionally exempt from such criticisms of dependency. While, say, the figure of the working class jobseeker or single mother was said to deserve contempt, disabled people-culturally seen as pitiable and passive-were widely viewed as the good recipients of state help … Damningly, as the post-2010 austerity era kicked in, even this faulty division didn't last. Disabled people and their social security not only became fair game in the vilification of benefit claimants-they became the prime target. Newspapers and television shows hunted examples of the disabled

> milking the state. Politicians talked openly of the bloated disability benefits bill. (Ryan, 2019: 28)

Citing research from a number of disability charities, Ryan draws a link between the prevalence of political rhetoric about disabled people (in particular those who claim benefits) and an increase in both hostility towards disabled people and disability hate crime:

> Two years into the Coalition Government in 2012, a group of disability charities reported a surge in hate crimes against disabled people, with public resentment over supposed mass abuse of the disability benefit system and negative media and government rhetoric said to be a key factor. Charities including Scope, Mencap and the Royal National Institute of Blind People (RNIB) reported that they were now regularly contacted by people who had been taunted on the street about supposedly faking their disability, with others saying the climate is so hostile they avoid going out. (Ryan, 2019: 29)

Ryan is not alone in drawing a link between political rhetoric in relation to disabled people and a rise in hostility and disability hate crime. The United Nations Committee on the Rights of 'Persons with Disabilities' has suggested that such political rhetoric which proliferated through mass media, may have contributed to a rise in 'disability' hate crime (CRPD, 2016: 14). From an experiential perspective, I feel such rhetoric does contribute to a rise in 'disability' hate crime, as reflected in my chapter 'Disability under Austerity: Do some forms of political rhetoric constitute disability hate speech?' This chapter was recently published in an edited collection on disability hate speech entitled *Disability Hate Speech, Social, Cultural and Political Contexts*. My chapter addressed how political rhetoric of the kind directed at disabled people under austerity can and does function as disability hate speech in specific contexts (Davies, 2019). I also refer to this in my chapter on psycho-emotional disablism and the disabled self in this thesis. The type of political rhetoric I discuss in relation to disabled people serves to make the expression of hate speech and hostility towards disabled people socially acceptable to some and may even function to encourage such behaviour. Indeed, I experienced ‘disability’ hate crime twice while keeping my journal and I experience the social world as a more hostile place as a result of these incidents; also I find it hard not to see the fact I am disabled as a key factor in my experience of hate and hostility. I feel that addressing the impacts of a neoliberal, austere, disablist society will require widespread social change of the kind articulated by Labonte and Stuckler:

> Re-regulating global finance ... rejecting austerity as an empirically and ethically unjustified policy, especially given now clear evidence of its deleterious health consequences … There is a need to restore progressive taxation at national and global scales … Redistributing work and promoting fairer pay. (2016: 312)

Alongside these proposals, I would also advocate for a meaningful enforcement of the Human Rights Act, which is legislation designed to guarantee universal human rights for all: however, its principles, in my view, often conflict with neoliberal values and aims (Human Rights Act, 1998).

In this chapter I have provided a broader context for my thesis, my experience of disablism as is austerity (which is disablist in itself) it is neoliberal in character. ‘Writing the Disabled Self’ is my attempt to theorise the impact of disablism on disabled people using my own autoethnographic writings as a basis for understanding. Each chapter that follows explores in greater detail specific issues that have adversely impacted many disabled people and still do. The political period of austerity under study spans January 2015 until December 2018, the time during which I kept my journal. I am articulating what it feels like at a personal and human level from the perspective of a disabled person to be subject to disablism. In this context the key aims of my research are detailed below. This is followed by my methodology, then the first of four core chapters, the excluded self a personal documentation and critique of accessibility in everyday life, follows my research aims.

Key Aims of My Research

- To document and analyse disabled people's experiences of living in a disabling society from their own perspectives:

- To use the experiences of other disabled people and disability theory to inform my understanding of my own disabled self:

- To employ my lived experience and that of other disabled people to understand and critique existing socio-political practices, perceptions, and understandings of disability and impairment.

- To highlight key ways in which austerity exacerbates the lived experience of impairment.

Chapter Three

Methodology

Introduction

The purpose of this chapter is to explain the key methods, methodologies and theories used in my research. I discuss using autoethnography as my primary method, which I situate within an Emancipatory Disability Research paradigm, informed by the Social Model of Disability. I outline the key principles of autoethnography and Emancipatory Disability Research and explain how they complement each other. I introduce and discuss the concept of psycho-emotional disablism as it underpins my theoretical understanding of the experience of disability. I describe and justify the use of my personal journal as the main 'data' for my research and give some examples of how I have analysed this through using autoethnographic methods.

My research is qualitative and is situated within the field of Disability Studies, which itself is informed by a range of other disciplines such as sociology, cultural studies and feminism. The key aims of my research reflect the key aims of Disability Studies as an academic field:

> Disability studies wants to unsettle tired stereotypes about 'people with disabilities'. It seeks to challenge our dominant assumptions about living with a disability. It situates the disability experience in the context of rights and exclusions. It aspires to retrieve dismissed voices and misrepresented experiences. It helps us understand the intricate relation between bodies and selves. It illuminates the social processes of identity formation. It aims to denaturalize disability. … Disability studies reimagines disability … questions our assumptions that disability is a flaw, lack, or excess. To do so, it defines disability broadly from a social rather than a medical perspective. Disability, it argues, is a cultural interpretation of human variation rather than an

> inherent inferiority, a pathology to cure, or an undesirable trait to eliminate. In other words, it finds disability's significance in interactions between bodies and their social and material environments. By probing the cultural meanings attributed to bodies that societies deem disabled … disability studies does vast critical, cultural work. (Garland-Thompson, 2005: 1557)

I try to enact this by seeking to unsettle stereotypes about disability, to challenge dominant cultural assumptions, to retrieve dismissed voices and misrepresented experiences and to reimagine disability based on my lived experience of disablism. The following section discusses Emancipatory Disability Research (EDR), the key research paradigm underpinning my work.

Emancipatory Disability Research (EDR)

EDR is really 'more a set of principles-fairly loosely defined rather than a set of rules for doing disability research' (Zarb, 1992: 127). The principles that form EDR were developed in a series of seminars that took place in 1991, entitled 'Researching Physical Disability' and funded by the Joseph Rowntree Foundation. These events brought together disabled and non-disabled researchers working in the disability field along with representatives of various research funding agencies and institutes to reflect on and discuss key issues for disability research. The initiative concluded with a national conference and a special issue of the journal *Disability, Handicap and Society*, later renamed *Disability and Society* (Barnes, 2003). The extent to which emancipatory research is able to liberate disabled people has been questioned (Mercer, 2002). However, Barnes (2001) argues that the political emancipation of disabled people is on-going and EDR provides disabled researchers with a platform to talk about their experiences and to theorise what the political emancipation of disabled people might look like.

For EDR, partisanship in research, or the forgoing of objectivity, is linked to its aim of facilitating the political struggles of disabled people (Mercer, 2002). Historically, partisanship in EDR is rooted in the experience of a group of disabled people who resided in a residential home and wished to live independently. These disabled people, led by Paul Hunt, were the subjects of a research study and the researchers refused to condemn how they were being treated, despite describing it as a form of 'social death' for the inmates (Miller and Gwynne, 1972: 8). Hunt commented that the researchers were 'definitely not on our side'. Instead, he claimed they played the role of 'detached' and supposedly 'unbiased' social scientists (Hunt, 1981: 39).

I strongly relate to this experience and have been deeply influenced by this approach. As a disabled person, my personal perspective in key life decisions has all too often been ignored completely or not taken seriously. This has particularly been the case in relation to decisions about health treatment, decisions relating to where I live, or during assessments for state support or funding. Furthermore, I do not think that the kind and degree of disadvantage and inequality experienced by me and many other disabled people can be solved or even mitigated by adopting a position of objectivity of this kind and remaining detached or neutral. I feel that to do so risks maintaining or worsening the disadvantage and inequality that many disabled people experience. I shall discuss the issue of forgoing objectivity further in a later section that draws together my primary research method of autoethnography and the principles of Emancipatory Disability Research (EDR).

The residents mentioned above also established the definition of disability that is commonly known today as the Social Model. Rejection of the individual (medical) model of disability and replacing it by a social model is a key aspect of EDR (Mercer, 2002: 233). The Social Model questions a way of thinking about, conceptualising, and framing disability, not medicine or the medical profession as a whole. It is recognised that disabled people require medical care as does anyone else (Barton, 1993). In addition, as Oliver (1996) acknowledges, a preference for the social model does not mean that individual interventions in the lives of disabled people, whether in the contexts of medicine, employment, rehabilitation, or education are of no use or are always counter-productive. However, it suggests that individual cures and interventions benefit one person, or those who can access them, whereas, for example, making environments more accessible would benefit many disabled people, and even non-disabled people too (Oliver, 2009: 46). I would add that individual medical understandings of disability offer little for those whose impairments, like mine, are incurable and therefore equal social access is essential. The individual medical model of disability is still the orthodox and dominant way disability is conceptualised in the UK and the task of challenging it and developing the social model has predominantly been undertaken by disabled people. As Cameron (2014) observes, problematic individual medicalised understandings of disability are:

> [M]aterialised in everyday practice through the myriad of behaviours, decisions and interactions taking place in the contexts in which they experience their lives. It is put into practice in hopes and expectations held, in thoughts unspoken and words spoken, in gestures and assumptions made, and through the processes by which services are planned and delivered. (Cameron, 2014: 99)

Those working within the context of EDR choose politically to reject the medical model precisely because it situates disability as a problem emanating from and within the individual, and disability and impairment are conflated. In contrast, the social model distinguishes disability and impairment. It defines the former as:

> [D]isadvantage or restriction of activity caused by contemporary social organisation which takes no or little account of people who have impairments and thus excludes them from the mainstream of social activities. (UPIAS, 1976, unnumbered)

In addition, the Disabled People International (DPI) definition of the social model defines disability as ‘the loss or limitation of opportunity to take part in the normal life of the community on an equal level with others due to physical and social barriers’ (DPI, 1982, cited in Oliver, 1996: 41). Within the same definition, impairment is defined as a ‘functional limitation within the individual caused by physical, mental or sensory impairment' (DPI, 1982, cited in Oliver, 1996: 41). Alongside this, the social model defines impairment thus: 'lacking all or part of a limb or having a defective limb, organ or mechanism of the body' (UPIAS, 1976, unnumbered). This original social model definition, which exclusively references people with physical impairments, was later expanded to acknowledge and include a broader range of impairments (DPI, 1982, cited in Oliver, 1996: 41). The social model is: 'an attempt to focus away from the functional limitations of individuals with an impairment onto problems caused by disabling environments, barriers and cultures' (Oliver, 2009: 45). As Barnes (2003) comments:

> The social model of disability represents nothing more complicated than a focus on the economic, environmental and cultural barriers encountered by people viewed by others as having some form of impairment. These include inaccessible education, information and communication systems, working environments, inadequate disability benefits, discriminatory health and social support services, inaccessible transport, houses and public buildings and amenities, and the devaluing of disabled people through negative images in the media—films, television and newspapers (Barnes, 2003: 9)

In response to criticism that the social model ignores or is unable to deal adequately with the realities of impairment (*see* Thomas, 1999), Oliver further argues that the model is about 'the collective experience of disablement' rather than a personal experience of impairment (Oliver, 2009: 48) Furthermore, Oliver (2009) recognises that whilst for some, 'disability may be a personal tragedy. the real misfortune is that our society continues to discriminate, exclude and oppress people with impairments' (Oliver, 2009: 47).

A further important principle in EDR is the reversal of the traditional researcher: researched hierarchy. This refers to where the researcher is considered to have greater importance and status than their research subjects, who are placed in a deferent position to the researcher, who controls the research and how any findings are represented. In a 1992 paper entitled 'Changing the Social Relations of

Research Production?' Mike Oliver analysed the problem some disabled people have with outsider, usually non-disabled, researchers researching disability and disabled people. For Oliver, reversing the traditional researcher/researched hierarchy, and challenging the social relations of research production are explicitly linked to the forgoing of objectivity in EDR. Referring back to those disabled residents who were the subject of research in a residential home, the key question that was posed was 'whose side are you on?' (Oliver 1992: 101). Therefore, it is possible to be non-disabled and undertake EDR, if the researcher has a commitment to the political struggles of disabled people and their concern with social justice. As Barnes (2003) observes:

> Emancipatory disability research is not about biology it is about commitment and researchers putting their knowledge and skills at the disposal of disabled people and their organisations; they do not necessarily have to have an impairment to do this. (Barnes, 2003: 8)

Oliver's analysis is concerned with the outsider researcher. An outsider researcher commonly has no lived experience of disability or impairment, is not disabled, or may not wish to reflect on their experience in a way that supports the political interests of disabled people in relation to equality. As a result, they may impose unwanted or unhelpful views of disability onto their 'subjects'. To address the production and reproduction of disability in medical or individual terms by 'outsider' researchers requires a consideration of 'the social relations of research production' (1992: 101). Oliver argues that researchers are typically characterised as specialist, skilled and legitimately powerful, while the researched are assumed to be passive and relatively ignorant. Experts lacking democratic control by disabled people, occupy an elite role in which they decide the subject, method of investigation and conclusion of research into disability. Stone and Priestley equate the role of this type of research expert with a rehabilitation professional who assumes they are best positioned to: 'define the self-concept, goals and inner motivations of disabled persons and determine their 'real' wishes and potential' (1996: 703). They suggest that such researchers implicitly assert that the knowledge and experience of disabled people does not count. Stone and Priestley argue that research produced by such ‘experts’ is constructed as if it is removed from the structures which produce disability, but it is implicated in their reproduction (Stone and Priestley 1996). Furthermore, Oliver (2009) raises a number of objections to most research into disabled people’s lives. Firstly, it does not adequately reflect the experience of disability from the perspective of disabled people themselves. Secondly, it fails to provide any useful information that could influence policy formation in a way that would improve disabled people’s lives. Thirdly, it fails to acknowledge the struggle of disabled people, or to recognise the political dimension of disability. As such, research is often irrelevant to the lives of disabled people.

The EDR paradigm underpins my research methodology because, as I am a disabled person writing about disability, it explicitly encourages disabled people to represent themselves, and to identify and discuss issues in relation to disability that are important to them. By virtue of its partisanship, EDR allows me to adopt a research position in support of my commitment to the pursuit of meaningful equality for disabled people. Furthermore, I feel the social model has an important part to play in the achievement of meaningful equality for disabled people. The next section outlines another concept and theoretical approach central to my methodological approach and to the development of EDR, psycho-emotional disablism.

Psycho-emotional Disablism (PED)

I draw on the concept of psycho-emotional disablism throughout my thesis in order to help me theorise the experience of living in a disablist society. Therefore, this section outlines the ideas underpinning this. Disabled feminist Carol Thomas established the concept of psycho-emotional disablism as a refinement of the social model as discussed in the previous section (Thomas 1999). She redefined disability in response to feminist criticism, including her own, that the social model neglected or ignored the personal experience of disablism by focusing on identifying and removing social barriers (Thomas 1999). The concept was further developed by Donna Reeve, also a disabled feminist, who applied it to a wide range of disabled people's lived experiences (Reeve 2012; 2014; 2006; 2006a; 2004). Referencing the work of other Disabled feminists such as (Morris 1992; 1996), Watermeyer and Swartz (2008: 600), suggested that 'for the social model to achieve its greatest benefits, both a political understanding and an appreciation of the emotional consequences of disablism are crucial'. Similarly, Reeve (2006) argued that a psychology of disability is much needed. Given the social tendency to associate disability with pathology it is important to state that this doesn't equate with a 'psychopathology of disability', which, as Reeve notes, has been done many times before (Reeve 2006). The concept psycho-emotional disablism provides disabled people with a way of naming and discussing how social responses to them detrimentally impact their psychological wellbeing. In Thomas' reconceptualisation of psycho-emotional disablism:

> Disability becomes a particular form of unequal social relationship which manifests itself through exclusionary and oppressive practices-disablism-at the interpersonal, organisational, cultural and social structural levels in particular social contexts. (1999: 40)

This definition of disability recognises the prejudice, discrimination, oppression and exclusion disabled people encounter. In this conception disability and disablism and are closely related, if not interchangeable. Importantly, this conception of disability 'recognises the relationship of ascendancy of the non-impaired over the impaired'. As Thomas observes, 'disability, like patriarchy, is a form of social oppression' (Thomas, 1999: 40). Reeve acknowledges that 'the experience of psycho-emotional disablism is not inevitable or fixed' (2004: 85) and 'not all disabled people experience this form of disability and it will be affected by factors such as intensity, time and place' (2006: 96). It is also affected by issues of social class and gender. As a disabled person with a permanent, 'chronic impairment', I found the concept of psycho-emotional disablism especially relevant to my experiences given the repetition and cumulative impact of disablism in my life. Whilst my research is informed by these key ideas in disability studies, I needed an appropriate research method to allow me to provide a detailed analysis and understanding of my experience of disablism. In using the lived experience of myself and other disabled people to theorise psycho-emotional disablism I am analysing the psychological and emotional impact of living in a disablist, neoliberal, austere society. The next section introduces and discusses my use of autoethnography to these ends.

Autoethnography

Autoethnography was developed as a research method following a crisis of representation within social research in the 1970s, in relation to how research subjects were being represented within the research process. This was not dissimilar to disability scholars' critiques of mainstream research about disability. Autoethnography is a feminist methodology (Ettorre, 2016). Autoethnographers questioned the practices of mainstream social research, such as the aim of seeking objective universal truths, particularly with regard to social relations and how researchers relate to those they research and their interpretations and representations of social structures (Jones *et al*. 2016; Adams, Holman-Jones and Ellis, 2015). Autoethnographers also questioned the possibility of making certain fixed knowledge claims about people, experiences, relationships, and cultures (Adams, *et al*., 2015). In addition, autoethnographers challenged the prohibition against stories and storytelling as ways of knowing and the bias in mainstream research against affect and emotion (Adams, et al., 2015). Furthermore, autoethnography highlights the value of local knowledge in research and how social identity impacts on how people research, read, interpret, write, and perform. As a method, autoethnography seeks to resist dominant colonialist and invasive ethnographic practices those such as entering and studying other people's cultures and then writing about them, disregarding member concerns about relational ethics, and the impact of the researcher's representation on the culture (Jones *et al* 2016; Adams, *et al*., 2015). In comparing autoethnography to autobiography Jones *et al*. (2016) comment that autoethnographic methods directly address, the silencing of certain people and stories:

> If an author experiences an epiphany, reflects on the nuances of that experience, writes to show how the aspects of experience illuminate more general cultural phenomena and/or to show how the experience works to diminish, silence, or deny certain people and stories, then the author writes autoethnographically. If an author writes to tell a story to illustrate a sad, joyful, or problematic experience but does not interrogate the nuances of this experience in light of general cultural phenomena and cultural practices, then the author writes autobiographically. (2016: 22)

Autoethnographers criticisms of traditional colonialist practice in research is similar to early disability scholars who critiqued 'outsider' research about disability and drew attention to the absence of disabled people's perspectives from research and the misrepresentation of their perspectives within research. Arguably, this type of colonialism was (and still is) common in research about disability and where disabled people are the focus of the research. As a research method, autoethnography prioritises a researcher's personal experience to describe and critique cultural beliefs, practices, and experiences (Jones *et al* 2016; Adams, *et al*., 2015).

Adams, *et al*., (2015) provide a literal definition which highlights its central purpose: 'the term autoethnography invokes the self (auto), culture (ethno), and writing (graphy). Therefore, when we do autoethnography, we study and write culture from the perspective of the self' (2015: 46). Chang highlights that, [autoethnography] 'is not about my autobiography *per se*, but about a research method that utilises the researcher's autobiographical data to analyse and interpret … cultural assumptions' (Chang, 2016: 9). Reed-Danahay (1997) articulates a practical and concise definition of autoethnography as a genre of writing and research that connects the personal to the cultural, placing the self within a social context. For the purposes of my research, this refers to my experience of living in a disablist culture and society including, but not limited to, attitudes to impairment and the imposition of austerity policy within a neoliberal, capitalist society. As a disabled person I frame myself, subject to what Dodd (2016) has referred to as 'disablist austerity' prejudicial to disabled people on both economic and cultural grounds. In respect of culture, he argues:

> Cultural representations of disabled people can affect the esteem in which disabled people are held as a group. This can play a role in the extent to which the public at large will accept cuts to benefits, support and public services for disabled people, and the extent to which disabled people experience discrimination and abuse. In addition, a feedback relationship can form between cultural subordination and economic disadvantage, as the absence of disabled people from community life can mean their presence is less able to combat negative cultural representation in the mass media. If negative cultural representations are less challenged by the prominence of disabled people, the esteem in which disabled people are held may fall, meaning they are put at a disadvantage in the pursuit of work, or considered unworthy of redistributive benefits. (2016: 156)

In 'Writing the Disabled Self', I am seeking to explore the way society responds to me as a disabled person. In 'writing back' through my thesis, I am critiquing a society that is disablist and disabling. I am writing at and about the intersection of self and society, where the individual and society meet. In a way I have used my experience to theorise the nature of a disablist society and try to understand and make sense of the self I have become in response to that society. I draw on my own subjective experience to provide a detailed understanding and conceptualisation of what it is like as a disabled person to live in the UK under neoliberal austerity policy. Producing accessible research which makes clear the deprivation and disadvantage many disabled people experience which is made worse by austerity is a central concern of my work. In autoethnographic terms, I am both the object and subject of my own research. I am the object because my lived, personal experience is the catalyst for my research, and the subject because I am analysing and commenting on my personal experience throughout my thesis. As a disabled person, doing disability research and writing about the daily experience of living with a long-term impairment, I have what is known in autoethnographic terms as an 'insider's view' (2015: 25). In my use of autoethnography I am trying to 'connect personal (insider) experience, insights, and knowledge to larger (relational, cultural, political) conversations, contexts and conventions' (2015: 25). Autoethnography acknowledges and values a researcher's relationships with others (Adams, *et al.*, 2015). Autoethnographers engage in reflexivity to name and explore the intersections between self and society, the particular and the general, the personal and the political (Adams, et al., 2015). In my thesis I am moving back and forth and continually connecting the personal with the social and *vice versa*. In addition, autoethnography shows people in the middle of figuring out what to do, how to live, and the meaning of their struggles and aims to balance intellectual and methodological rigour, emotion, and creativity in pursuit of social justice and to improve life (Adams, et al., 2015). This applies to my research in that many of the challenges I face are unresolved and I am concerned generally and specifically with social justice for people generally and disabled people specifically. The next section explores intersections and commonalities between my two central methodological approaches, EDR, and autoethnography.

Autoethnography as Emancipatory Disability Research

It should be apparent that the research principles of EDR and autoethnography as a research method intersect in a number of ways. EDR and autoethnography both reject a key principle of positivism that there is one ontological version of reality which we all share (Mercer, 2002; Jones *et al*., 2016). Linked to this is their shared forgoing of the requirement for research to be objective and detached. EDR and autoethnography are both grounded in lived and personal experience and see the personal as political (Thomas, 1999; Oliver, 2009; Jones, *et al*., 2016; Adams, *et al*., 2015). Forgoing objectivity allows me to attend to and address the politics of the various situations and contexts in which I find myself. This arguably makes for more honest and transparent research because I am stating my position up front, in preference to omitting it from my explanation of the research process as is common with much traditional research, which often hides behind the idea of ‘objectivity’ or ‘neutrality’. As Barnes (2003) observes:

> There are numerous debates about the question of objectivity within the social sciences and the sciences generally. The idea that ‘scientists’ of whatever persuasion, social or otherwise, can interpret data without reference to personal values or interests is one that has been promulgated by philosophers, scientists, and later politicians, since at least the enlightenment. The reality is that *all* information whatever its source and format can be interpreted in a variety of different ways and those charged with the responsibility of interpreting it are influenced by various forces, economic, political and cultural … Therefore, researchers must make their standpoint clear at the outset. This means stating clearly their ontological and epistemological positions and ensuring that the choice of research methodology and data collection strategies are logical, rigorous and open to scrutiny and commensurate with the goals of the sponsoring organisation and research participants. (Barnes, 2003: 10-12)

Bhavnani (1993) argues something similar in advocating a specific form of ‘feminist objectivity’ and asserting that knowledge is historically produced:

> Knowledge production is … an historical process. My argument is that feminist epistemologies, in the process of continuing challenges against positivism, have always placed questions and issues about the historical relationships between science and society at the centre of our work. Feminist theorising has always argued that there is a necessity for scientific work to examine its practices, procedures, and theories through the use of historical insights, for it is these insights that bring into focus the ways in which knowledge production is a set of social, political, economic, and ideological processes. (1993: 96)

Autoethnography and EDR also both value the self-representation of people who experience marginalisation. As a disabled researcher using EDR I can control the content, direction, and dissemination of my research. Barnes notes that the ability to represent yourself on your own terms and have the space to acknowledge, prioritise, and reflect on your lived experience as you perceive it is a key benefit of EDR (and, I would argue, autoethnography). This is a key part of the process in advocating for social change. Acknowledging a given predicament, disadvantage or injustice is the first and necessary step to changing it. In other words, you have to perceive a situation as in some way unjust or unfair before you can seek to change it. Therefore, as Barnes asserts, empowering disabled people to act on their own behalf Is an important aspect of EDR's stated need for social change:

> Empowerment is not something that can be given, it is something that people must do for themselves. The salient point here relates to ownership. Within an emancipatory framework it is organisations controlled and run by disabled people that devise and control the research agenda and, equally important, to whom and how the research findings should be disseminated. Advocates of this perspective recognise that research outcomes in themselves will not bring about meaningful political and social transformation, but that they must reinforce and help stimulate further the demand for change. (Barnes, 2003: 13)

As disabled scholar Mark Sherry affirms the historical denial of disabled people's perspectives is common:

> Disabled people have been spoken about, and spoken for, but rarely listened to. And much of the work of disability activists is designed to create a safe space where disabled people can name their experiences and change the society which oppresses them. (Sherry, 2006: 165)

EDR is a space in which disabled people get 'to define ourselves, name ourselves, speak for ourselves instead of being defined and spoken for by others' (Lorde, 2006: 43). Autoethnographic EDR gives me a framework within which to talk freely and openly about my experiences from my own perspective.

In a society that marginalises disabled people and denies our perspectives, the importance of having a place to speak about issues which affect our lives cannot be understated. This is what my use of autoethnographic EDR allows. In the context of disability autobiography Thomas G. Couser (2005) observes that:

> Disability autobiographers typically begin from a position of marginalization, belatedness, and preinscription. Long the objects of others' classification and examination, disabled people have only recently assumed the initiative in representing themselves; in disability autobiography particularly, disabled people counter their historical subjection by occupying the subject position. In approaching this literature, then, one should attend to the politics and ethics of representation, for the "representation" of disability in such narratives is a political as well as a mimetic act a matter of speaking for as well as speaking about. (2005: 605)

Couser's observation in the context of disability autobiography are equally applicable to disability autoethnography. In representing myself, I am attempting to counter the historical and current subjugation of myself as a disabled individual and disabled people as a social group. In my disability autoethnography I am speaking for disability and about disability. Bhavnani (1993) argues that inequalities are implicit within knowledge production and objectivity, in its adherence to positivism functions to silence certain perspectives and experiences:

> These arguments continue by suggesting that an important consequence of these histories is that racialised, gendered, and class-based inequalities are embedded into the creation of knowledge. What often occurs in the process of presenting feminist arguments for the historicization of knowledge is that the points about racisms, exclusion, and invisibility of women of colour become silenced. (1993: 96)

I would obviously add disability to her list of inequalities. In speaking for and about disability and giving preference to my own subjectivity and the perspectives of other disabled people, I am making disability inequality explicit. I am writing autoethnographically with a commitment to the political struggles of disabled people, and a strong awareness of the disadvantaged social position I occupy as a disabled woman. Based on my personal experience and with the knowledge that this is an experience that I share with other disabled people. Additionally, on the basis that the perspectives of disabled people are often ignored, marginalised or underrepresented, I have made a conscious effort to prioritise concepts developed by disabled people and their allies such as the social model and psycho-emotional disablism.

By its inherent partisanship my use of autoethnography as EDR makes manifest the unjust and unfair life experiences left hidden and unaddressed by traditional notions of objectivity. I do not subscribe to the view that objectivity is necessary for the production of 'good research' and feel that the omission of subjective experiences, including, personal pain, guilt, emotion, and so forth, leaves unaddressed the social inequality that many disabled people experience. As Ellis says in Jones, *et al*. (2015):

> I did not believe in the self-regulation guilt, pain, the denial of pleasure and the silencing of voice that was required to produce so-called proper academic subjectivities. Nor did I think that the worst sin I could commit as a researcher was to be too personal. I value the personal, and I wanted to include-even to feature it-in my work. (2015: 9)

In autoethnography the inclusion of the personal is made explicit in the methodological requirement to embrace vulnerability with purpose: 'authors make themselves vulnerable by exploring aspects of their experiences that may be particularly stigmatizing' (Holman-Jones, et al., 2016: 24). Barbara Jago's (2002) chronicle of her own depression is one example of this. At various points throughout my thesis, I embrace this idea of 'vulnerability with purpose' where I write about many practically and emotionally difficult situations and experiences. For example, the inaccessibility of many environments in my chapter on accessibility, the structural disablism I experience, and the cumulative emotional impact of these experiences in my chapter on psycho-emotional disablism. These experiences are emotionally and psychologically difficult to reflect on, they make me feel psychologically vulnerable because they make me aware that because of my impairment, and the way society responds to it, I am not free to go where I want, when I want.

The use of the personal in autoethnography has led some to criticise it for being narcissistic (Saltzman, 2002). In response to this I can only say with sincerity that the use of autoethnography has made the process of doing research more difficult, painful, and psychologically and emotionally challenging because of the issues I have been required to reflect on. In addition, writing honestly about my lived experience of impairment is a psychological and emotional risk because I may face criticism or psychological and verbal abuse. Indeed, autoethnographers consciously open themselves up to 'the possibility of being wounded or attacked' (Behar, 1998, cited in Adams *et al*., 2016). However, making myself 'vulnerable for a purpose' helps make the inequality I experience as a disabled person manifest and highlights the injustice I and many other disabled people experience whilst going about our daily lives. Miranda Fricker (2007) conceptualises the experience of many disabled people as a type of epistemic injustice. She identifies two classes. The first is testimonial injustice. This occurs when mainstream society holds an identity prejudice against a specific group and sees members of that group as having 'a deflated level of credibility' (2007: 158). The second type of epistemic injustice identified by Fricker is hermeneutical injustice. This is defined as 'having some significant area of one's social experience obscured from collective understanding owing to a structural prejudice in the collective hermeneutical resource' (2006: 100). It is my position that both these forms of epistemological injustice apply to many disabled people and form part of our experience of inequality. In the next section I discuss my application of autoethnography.

My Application of Autoethnography

My use of autoethnography means that throughout my research I occupy the dual position of researched and researcher. For some researchers, a key criticism of autoethnography is that it lacks the methodological rigour required of more 'objective' academic research (Holt, 2003). In response to this, Anderson (2006) posits an analytical form of autoethnography where the autoethnographer is expected to satisfy the following conditions:

> (1) is a complete member in the social world understudy; (2) engages reflexivity to analyse data on self; (3) is visibly and actively present in the text; (4) includes other informants in similar situations in data collection; and (5) is committed to theoretical analysis. (Anderson, 2006: 379)

I consider my work to be in keeping with the spirit and intention of Anderson's analytic autoethnography. According to Anderson's schema, I am a complete member in the social world under study as I am a disabled person studying disability. I am making a wholehearted attempt to engage reflexively and analyse the data on self, through analysing my journal writings. Because of this I am visibly and actively present in my journal and my thesis. In addition, by including the experience and perspectives of other disabled people and prioritising research by disabled people in my work, I address a common criticism of autoethnography, that 'the use of self is the only data source' (Holt, 2003: 19). I also meet Anderson's requirement to included other informants in similar situations in my thesis, if not in my data collection. I am also attempting to display my commitment to theoretical analysis throughout my thesis by utilising contemporary disability theories and concepts to inform and deepen my analysis.

According to Chang (2016), 'analysis and interpretation are intimately intertwined but not synonymous activities in qualitative research and writing' (p. 146). Further to this, she states that 'analysis and interpretation should be seen not in conflict with each other, but as a balancing act between fracturing and connecting, between zooming in and zooming out, between science and art' (p. 128). The process which Chang refers to as 'zooming in and zooming out' in autoethnography is comparably described by Adams, *et al*.:

> When we do autoethnography, we look inward-into our identities, thoughts, feelings and experiences-and outward, into our relationships, communities, and cultures. As researchers, we try to take readers/audiences through the same process, back and forth, inside and out. (2015: 46)

As Chang further writes:

> The zoom in approach refers to the microscopic analysis of data through which you pay attention to details, probe into small segments at a time, and keep a focus on one dataset at a time. This approach enables you to turn your attention to interesting details and their interconnectivity within and between your datasets. (2016: 129)

In my autoethnography, an example of Chang's concept of zooming in (analysis) is my exploration of my personal experience of inaccessible shops in chapter four. In this chapter, I shed light on my own exclusion from social spaces and highlight this specific aspect of social inequality and the adverse cumulative impact that it has on my daily life. The practical restriction it places on my life and the sense of psychological restriction and limitation it creates within me. In short, it highlights the human impact of inaccessibility. In documenting numerous occasions when spaces I visit are inaccessible to me, I aim to make others more aware of the cumulative effects of inaccessibility on myself and others, in the hope encouraging others to make more spaces such as shops accessible to disabled people.

In zooming in, I explore the personal impact of inaccessibility on myself as an individual. Whereas zooming out:

> Privileges you with a bird's eye view to the data, which will enable you to see how your own cases related to others, how your case is connected to its context, and how the past has left traces in the present. An ideal data analysis and interpretation process combines the zooming and zoom out approaches … interpretation tends to pull you away from details to hover over the entire data and the context. (Chang, 2016: 129)

In zooming out I connect my individual, personal experience to the individual, lived experience of other disabled people, and acknowledge that the inaccessibility of spaces is an issue for other disabled people too. At this point, individual experience becomes a matter of social concern, because it adversely affects the life of more than one person and is an issue many disabled people share. In my research zooming out also allows me to use my personal experience to explore to the broader issues such as the socio-economic position of disabled people as a group. This is most obviously addressed in my context chapter which looks at the impact of austerity policy on disabled people. The process of zooming out can also be identified in my psycho-emotional disablism chapter, where I explore the psychological and emotional impact of disablism on other disabled people. Whilst primarily drawing on my own subjectivity, I am also 'zooming out' in that I am including the testimony of other disabled people in my research because I recognise that disability is a collective shared experience. I do not wish to perpetuate the silencing of disabled people. I also made a conscious decision to give priority in my work to research and writing by disabled people who wish to live in a more equitable society. This includes but is not confined to, reports by disabled people's organisations. For example, Trailblazers, an organisation and charity operated by disabled people themselves whose work revolves around highlighting the concerns of disabled people in relation to a wide range of issues that affect our lives such as accessibility, employment and transport. I have also included work by disabled activist groups such as Disabled People against Cuts (DPAC) and Asylum, a magazine advocating for democratic psychiatry because their overt focus on pursuing social change is often omitted from official reports. I have also included testimonies from disabled people whom I identified in official research reports and informal sources such as social media posts. These testimonies specifically relate to accessibility, welfare provision, and the psychological and emotional impact of living in a neoliberal, austere and disablist society. The next section looks at the main data I draw on for my research, a journal I kept during the course of my studies, describing in detail what it is and how it came to be.

My Journal

As noted in my autobiographical commentary, I kept a journal while studying which provides the 'raw data' for my research. As Philippe Lejeune observes, in actively keeping a diary, I took a leap into the unknown. I had no way of knowing what would happen:

> The diarist always writes without knowing the end of his or her story, so he or she cannot write with certain knowledge of what will follow in the text. The very basis of the diary is not knowing the future. Writing a diary means agreeing to collaborate with the unknown … Diaries are usually studied as documents to be read in conjunction with other texts by their authors … They are rarely studied as texts in their own right (Lejeune, 2016: 338)

A comparable published example to my own diary is *Welcome to Biscuit Land a Year in the Life of Touretteshero* (2012). This text charts a year in the life of Jessica Thom, a British disabled woman and wheelchair user living in London with Tourette's. Thom documents aspects of her daily life and the varied responses and attitudes of people to her Tourette's, an impairment which involves involuntary verbal and physical tics. Whilst Thom does not directly name austerity in her work, she does make reference to the policy on occasion in relation to the NHS and, as below, the potential personal impact of the proposed changes to what was then Disability Living Allowance:

> A letter arrived this morning to say I've been awarded Disability Living Allowance. DLA is a benefit that helps cover the additional costs of having a 'disability'. I'll get a backdated payment from when I applied, and I've worked out that this pretty much matches what I have spent since

> then on things to limit the impact of the tics, like gloves and plastic cutlery. But it doesn’t come close to what I’ve spent on travel, on replacing things I’ve broken or on my friends’ expenses’ when they’ve helped me do something I couldn’t do on my own. DLA will mean that I can continue to get the things I need to keep me safe and improve the quality of my life. That’s if the government don’t get there first. (Thom, 2012: 70)

Although not written explicitly for ‘research’ and smaller in both length and timescale than my journal, it is clear from reading her account that our respective works share the intention to educate others about what it is like to live with an impairment and to be disabled in Britain. Despite the differing natures of our impairments, her experience often resonated with my own and points to a commonality of experience of disablism in modern Britain irrespective of which impairment(s). This is the case in relation to the hostility she experiences from strangers who do not understand or care that her tics are involuntary and cause her distress. An example is the train station staff member, who retorted: ‘I’m not giving you any fucking information’, when she asked for help on the tube (2012: 16). Similarly, I discuss the difficulties I encounter when using trains for example, in chapter four, where on numerous occasions I encountered unhelpful attitudes from staff. I stopped keeping my journal in December 2018 to focus on developing my analysis.

In autoethnographic terms my journal is the central ‘data’ of my study which I used to analyse and write my thesis (Chang, 2016). My journal is an example of a ‘personally produced text’, which, as Chang (2016) observes is: ‘particularly invaluable to … [autoethnographic] study because they preserve thoughts, emotions, and perspectives at the time of recording’ (2016: 107). The same can be said of my journal. Furthermore, she comments:

> Journal writing commonly engages in self-reflection and self-description. Similarly, diaries are used to record daily happenings; they tend to be more chronological and descriptive of the happenings. Both journals and diaries are usually written for the authors themselves, although

> some end up being published for broader audiences. These formats are valuable to self-narratives because the content often reveals less self-censored behaviour and thought. (2016: 36)

My journal features these characteristics, too. I engage in self-reflection, I record daily happenings, and my journal is chronological and descriptive of happenings. My journal also contains and reveals less self-censored behaviour and thought because it is a personal text, and I wrote about how I felt about various things that happened to me. One important point of distinction, raised by both Chang and Lejeune, is that usually journals are written for the author, but my journal was not just written for myself, as I was aware that many of my words and writings would be drawn upon in my thesis for the purpose of my research. Chang notes how:

> Some selected segments from raw data are likely to enter your final autoethnography, but not all bits and pieces of data appear in their entirety. When vignettes and excerpts from the data are adopted into the final text, their edges are trimmed and blended into the picture as whole so that they can tightly hang together within the overall structure of cultural analysis and interpretation of self. (2016: 126)

Certain writings from my journal are not included in my thesis because not everything written about in my journal was relevant to the social analysis I provide. I also omitted certain experiences from my thesis even though they were relevant to the focus of my study because I considered them too emotionally and psychologically painful to write about. An example of this is my Continuing Healthcare Assessment (Journal Entry, 2015: 140). It was such a traumatic event it is still giving me flashbacks. I also chose to exclude certain subjects from my thesis because I felt it was important to retain a degree of personal privacy and protect other people. For this reason, I have not, for example, made much reference to familial relationships in my thesis. It is perhaps a paradox of autoethnography that I am required to take considerable steps to preserve the confidentiality of organisations and individuals that feature in my research, yet I, as researcher and researched, am by the nature of the method not afforded the same protection. However, at least in the context of my research, I have some control over what information I reveal.

In producing my thesis chapters I wrote about issues that affected me most in the time period which I kept my journal. This is true for all my core chapters yet is particularly true for my ‘Assessed Disabled Self’, chapter five, which explores disabled people’s experiences of disability assessments. My decision-making process, in terms of my chapter focus, was also influenced by the availability of secondary material on a particular issue and the availability of testimony from disabled people themselves through a range of sources.

Conclusion

In this chapter I have explained the key methods, methodologies, and theories used in my research. I have discussed using autoethnography as my primary method, which I situated within an Emancipatory Disability Research paradigm, informed by the Social Model of Disability. I have outlined the key principles of autoethnography and Emancipatory Disability Research and explained how they complement each other. I have introduced and discussed the concept of psycho-emotional disablism as it underpins my theoretical understanding of the experience of disability. I have described and justified the use of my personal journal as constituting the main ‘data’ for my research and given some examples of how I have analysed this using autoethnographic methods. The next chapter is my first core chapter, The Excluded Self: A Personal Documentation and Critique of Accessibility in Everyday Life

Chapter Four

The Excluded Self: A Personal Documentation and Critique of Accessibility in Everyday Life

Introduction

In this chapter I apply Kitchin's concept of 'being out of place' and 'knowing one's place'(1998) to the lived experience of disabled people. I do so in order to show how we come to 'know our place' and know that we are 'out of place'. I argue that the inclusion of wheelchair users like myself is partial and conditional. I focus on specific areas based on my personal experience. From the perspective of my lived experience, I argue that because the Equality Act is founded on the principle of reasonable adjustments there is no imperative within the legislation to substantively to improve accessibility for disabled people. Additionally, based on my experience I assert that the persistent justification given of the cost for choosing not to provide access needs to be challenged. I am concerned that austerity serves to ratify cost as a legitimate and unquestioned justification for failing to provide access, and functions to nullify discussions of improved accessibility. Furthermore, my experience illustrates that the moral imperatives and policy aspirations of achieving full inclusion of disabled people within society are in reality consistently undermined by the practicalities and failures to ensure equitable accessibility: this has been my experience and is the unfortunate experience of - most if not all - disabled people in their everyday lives. In the next section I am going to feature examples from my journal (my lived experience) alongside the lived experiences of other disabled people. I shall begin by providing some important context to my experience.

My Lived Experience

In this section I plan to feature and discuss examples from my journal. My experience is contextualised and supported by the research of other disabled people. The situations I describe and discuss will be addressed in separate sections so as to make my chapter easier to follow. However, I wish to acknowledge here, that they do not occur in isolation. Indeed, depending on what I am doing, a number of such scenarios can happen on the same day. I can and do for example struggle to locate an accessible toilet and be left on a train in the same 24-hour period.

Because I am a disabled person and a wheelchair user almost everything I do has to be meticulously planned and researched, and requires additional effort not required of non-disabled people. I cannot go where I want when I want. I do not have substantive freedom of movement. The organisation and structure of the environment plays a pivotal role in these limitations. This is both a key illustration of my journal entries, my lived experience, and a central premise of this chapter. A similar thought is contained within the slogan of the Silver Jubilee committee on access in 1977 'can disabled people go where you go?' As disabled scholar Tony Heaton remarked:

> It could just as easily have been the slogan for the recent Diamond Jubilee in 2012, because there are still many subtle no-go areas … Access, or lack of it, is still the fundamental issue preventing disabled people from fully taking part in society in the UK, yet we are still-over 40 years after legislation began to be introduced to begin to address this-creating buildings and transport systems that perpetuate discrimination. (Heaton, cited in Cameron, 2014: 1)

Heaton's words provide an important supplement to my experience because he acknowledges that, despite the establishment of legislation, progress towards accessibility that makes substantive citizenship a viable possibility for many disabled people is very slow, and for me personally, painfully so. As a disabled person I am a partial citizen and my citizenship is highly conditional: lack of access is still a fundamental barrier to my and other disabled people's inclusion. Having provided an important context for my experience, I begin by discussing my experience of accessible toilet provision.

Accessible Toilet Provision

My own accessibility experiences of perhaps the most basic and universal human need, the need to use the toilet, are first discussed. At time of writing, my own access requirements in terms of toilet provision are basic. As a wheelchair user, I transfer myself on and off the toilet using my upper body. I am short, so I need a toilet that is not too high off the ground, and because of the way I transfer, has handrails on both sides of the toilet. Despite the basic nature of my current access needs, as this example from my journal serves to illustrate, in public places standard provision is sometimes non-existent:

> Last night I held my bladder for Tyler Bate. I went to a wrestling show and he was in the main event, it was worth it, but I don't enjoy doing it, due to the absence of needed facilities I either have to leave early or hold it in, so to speak. (Journal Entry, 2015: 196)

Repeatedly having to hold my bladder contents because of inconsistent accessible toilet provision has had a detrimental impact on my health. It is a key factor in my development of kidney stones as an adult. In situations where accessible provision is inadequate for me, I have allowed my Dad to assist me onto the toilet. For any a disabled adult woman, this is not a welcome scenario: it does little for my sense of self or self-confidence. However, given the health implications noted, and as I make clear in my journal entry (below), it is better than not going to the toilet at all:

> Yesterday was supposed to be a day off, I had tickets for Ring of Honor (sic), the news that my phone was dead ruined this, as did the fact I could not get on the show venue's accessible loo because it was very high, dad helped, I don't really enjoy this, but it's better than not weeing at all. (Journal Entry, 2015: 205)

In the UK, attempts have been made through the RADAR (Royal Association for 'Disability' and Rehabilitation) scheme to improve and standardise accessible toilet provision. It is a national key scheme, as part of which disabled people obtain a key, that opens the door to any ‘disabled’ toilet that is part of the scheme in the UK (Swann, 2005). To get your own key, you must provide proof of ‘disability’ and pay a small fee for the cost of the key. However, this is not a compulsory process because each location that both has a toilet and is part of the scheme also has their own key. Going through the process of obtaining a RADAR key makes the act of using a public ‘disabled’ toilet easier because you do not need to ask staff at a given location for a key: you can simply open the toilet yourself and use it. One stated aim of the scheme was to prevent ‘damage [to] and misuse of ‘disabled’ toilets’ (Direct Enquiries, 2007). Some disabled people consider the scheme to be segregated toilet provision and resent paying for a key (Imrie and Kumar, 1998). The RADAR scheme indeed offers segregated provision, while it does help to ensure that ‘disabled’ toilets are kept clean and used only by those who require them. The separate nature of the provision is in this instance useful, because the sex of the person helping me does not prevent me from using the facilities, as it does when toilet provision is segregated by gender. My Dad cannot come into a female toilet to help me. In her book, *Heroic Desire: Lesbian Identity and Cultural Space*, Munt (1998) referred to ‘disabled’ toilets as a ‘queer space’ where gender norms were not enforced (77). One trans participant in a study by Slater *et al*. (2018) acknowledges the positive value of an accessible toilet as a gender-neutral space: ‘I’ve got a RADAR key and that is like possibly the most useful thing as a trans person … being able to like go and into a gender-neutral toilet’ (960). It is psychologically reassuring to know that when he is with me my dad will help. One participant in Imrie and Kumar’s (1998) study ‘Focusing on ‘Disability’ and Access in the Built Environment’ acknowledges why some disabled people are reluctant to ask for practical help to go to the toilet:

> You can understand why some people would feel reticent about asking for help to go the toilet. I don’t enjoy having to ask someone to help me to go to the loo when ideally, it’s a normal bodily function which everyone has the right to use when and how they want. (1998: 365)

I can understand why disabled people are reluctant to ask for help of this kind and why some people might refuse to help, for example, when there are issues of physical intimacy. Experience has taught me not to ask for or to expect this kind of help, even in an emergency, where there is no accessible toilet I can use. I dread being in a situation like that in which the disabled person was left, in this extract from my journal:

> I went to a consultation meeting at a North West University, I heard a story which on its own displays the need for my research. A young disabled man went into hospital for an amputation, and was repeatedly forced to defecate and urinate in his own bed for want of a toilet. Not one of the nurses would help him to the toilet, this is the kind of story that keeps me awake at night and makes my blood run cold, how can they refuse to help a human so clearly in need of assistance? (Journal Entry, 2015: 6)

I fear being left in a similar situation to the disabled man I describe above, and this is part of the reason why I choose to transfer myself on and off the toilet when and where provision is adequate. Situations like the one above are a concrete illustration that practical help to go to the toilet is not something of which I nor any other disabled person can be assured. The reality of being left to hold your bladder or defecate or urinate on yourself is particularly unfair given that no one is always assured of accessible provision. The construction of accessible toilet facilities is a main area where accessibility has not kept pace with the imposition of increasingly restrictive health and safety policies and legislation. This makes situations such as the one described here more likely to occur. The above is not a ‘one off’ scenario (Pepper, 2017; Taylor, 2017). As are other disabled people, I am made responsible for and also suffer for that which is not my fault.

In the previous paragraph I cited the fact that I cannot be assured of practical help from others to go to the toilet as part of the reason I choose to transfer myself on and off the toilet when and where I can. A further important reason I will continue to do this is because if I do not or cannot then this unfairly limits where I can go and for how long I can stay there. The position I am placed in is usefully articulated by Kitchin and Law, in their 2001 study, ‘The Socio-spatial Construction of (In)accessible Public Toilets’:

> ‘Disabled’ toilet provision delimits the spatial behaviour of disabled people. In other words, disabled people often plan their daily spatial routines around the provision of toilets, avoiding locations where there is no provision, and consequently having a constrained, daily home range and constrained patterns of spatial behaviour. (2001: 295)

Inconsistent accessible toilet provision has impacts upon almost every aspect of my daily life. It influences every decision I make in terms of where I go and for how long I stay. I obviously cannot stay for long in a location that has no accessible toilet. I agree with Kitchin and Law (2001) when they assert that disabled people take responsibility, monitor themselves, and restrict their behaviour in response to restricted facilities. I do this myself and so do other disabled people, as their research illustrates. Furthermore, according to Kitchin and Law (2001), the result is that our constrained mobility becomes naturalised and is unseen by others. Based on my experience I also concur with this view: because I (and other disabled people) take responsibility for the limitation placed upon me by inconsistent accessible toilet provision, those same limitations do become invisible. The unjust nature of my predicament and other disabled people’s is hidden. The practical implications of inconsistent accessible toilet provision are acknowledged by one participant from Kitchin and Law’s study:

> Because when, as I say, you go outside your door if you’re going some place—if you’re going to a shopping centre, going to a pub, going to a hotel; if you are going to a cinema, or any type of entertainment, or if you’re going to a class in a school or college, you have to check to see if there is a toilet there. Otherwise, you can’t spend longer than three hours away from the house. (295: 2001)

The delimiting of disabled people's spatial behaviour based on accessible toilet provision, as observed by Kitchin and Law, has been conceptualised by Cooper *et al*. (2000) as 'the bladder's leash', because it restricts how long they are able to stay in a place, consequently constraining their participation (426). 'The bladder's leash' is additionally constraining for those disabled people who cannot use standard accessible toilets. There are over 250,000 disabled people in the UK for whom standard accessible toilets are inaccessible (Changing Places 'Home', 2018). These disabled people require a Changing Places toilet with necessary features, such as, space either side of the loo, a hoist, and an adult changing table (Changing Places 'Home', 2018). However, there are just 1161 Changing Places toilets in the UK (Changing Places 'Toilet Map', 2018). One respondent from the Muscular Dystrophy Campaign Trailblazers Short Changed report (2014) echos Cooper's concept of the bladder's leash in discussing what the absence of a Changing Places toilet means for them:

> I am unable to weight-bear at all, so need a changing table and hoist to be able to use the bathroom safely and with dignity. Otherwise I have to wait until I go home, which often means I have to cut short my trip out. (MDC 2014: 13)

The inconsistency of accessible provision is leading some disabled people to go to extreme measures such as wearing incontinence pads or having catheters fitted to enable them to get out and about and do the things they want to. In reference to a Guardian article on the subject by Dr Frances Ryan, the disabled journalist and reporter Mik Scarlet tweets about his own use of incontinence pads due to the absence of accessible provision:

> Yet again @DrFrancesRyan lifts the lid on a hidden part of Disability in 21st c UK. I have to admit I now wear pads when venturing on longish journeys because of lack of toilets despite not being incontinent. Society #disabled us again. (Scarlet, 2018)

I think the above is a clear-cut illustration of the inequality experienced by disabled people in respect of toilet provision. Needing to undergo surgery or to wear incontinence pads when not incontinent merely so that you can stay out in public and go where you want is an extreme occurrence. I think many non-disabled people would object to circumstances that meant the above situation was a reality for them, yet inconsistent accessible toilet provision makes this common practice for many disabled people.

In addition to the ways in which toilet access constrains social life for disabled people, with its associated psycho-emotional impacts, there is also a more subtle but powerful communication of social worth mediated by place. In 'Out of Place', 'Knowing One's Place': Space, power and the exclusion of disabled people’, Rob Kitchin (1998) wrote that ‘spaces are currently organised to keep disabled people `in their place’, and that spaces are social texts that convey to disabled people that they are `out of place’ (1998: 345). Inconsistent toilet provision is one obvious example of the veracity of Kitchin’s theorisation. The complete absence of accessible facilities sends the message to me and other disabled people that we are ‘out of place’, thus are not supposed to be in a particular space. In addition, the fact that one of my and other disabled people’s most basic needs is not considered in a given space is a means by which disabled people ‘know our place’. In social terms, it sends the message that our needs are not important and that as people we are inferior humans. I shall refer to Kitchin’s conception of ‘knowing one’s place’ and being ‘out of place’ as I discuss my experiences. His concept has relevance to many aspects of public space, not just toilet provision.

The inconsistency of toilet provision is a straightforward illustration of my own and other disabled people’s exclusion. It is one example of the partial and conditional nature of my citizenship as a disabled person. In the next subsection, my experience of shops and restaurants is examined.

Accessibility of Shops and Restaurants

I enjoy shopping and eating, and sometimes I enjoy eating out. These facts meant that I wrote about my experience of both in my journal and have more than enough material on which to draw for this section. The inaccessible nature of shops and restaurants is thus a common aspect of my lived experience. The inaccessibility of shops, the fact they have neither ramps nor level entrances, means that I end up having to carry out transactions in the street, as in the example below:

> I went to buy a Blu Ray after work and couldn't get in the shop, we had to do the transaction in the street, lots of people saw my dilemma and very few said anything. I mentioned to the assistant about getting a ramp. He was understanding but I'm not sure anything will get done, another day in paradise. (Journal Entry, 2015: 4)

On one occasion, I decided to visit a shop for an autograph signing without checking first that it was accessible. It was not: I had to have my picture taken outside the shop surrounded by other customers, who were also there for the signing:

> I went to an autograph session afterwards; this was a spontaneous decision. I met TNA Superstar, Mr Anderson, I don't think the photo will turn out well because, being surrounded by people, I was not relaxed and the shop wasn't wheelchair accessible, I felt on show. (Journal Entry, 2015: 24)

I have not been back to either of these shops since. I know that the one in my first example is still not wheelchair accessible (I wander past it after work). I have a suspicion that the shop in my second example also remains inaccessible to me and many other wheelchair users. The ubiquitous nature of lack of physical access causes me acute frustration and has an impact on how I experience my day. I am reluctant to spend my money in shops or with business that obviously think it is acceptable to serve me in the street or outside of their premises. As this example, from the Trailblazers Short Changed report (2014) illustrates, my experience is shared by other disabled people:

> I am often frustrated when one small step can stop me and my friends going into an establishment. A portable ramp doesn't cost much but can make a huge difference to my day out. If there is no access, I don't try and get someone's attention, I just go elsewhere as I don't think they deserve my hard earned-cash if they can't be bothered to invest in an accessible ramp or a piece of wood! (Trailblazer, London MDC, 2014: 6)

Lack of physical access is a direct example of how the environment excludes those disabled people who, as is my circumstance, cannot walk. As another participant from the Short-Changed report acknowledges how 'very small things can make a very big difference to people with mobility impairments. A small step can be hugely prohibitive' (MDC, 2014: 9). As with inconsistent accessible toilet provision, a lack of physical access restricts where I can go. Such a lack of physical access decreases the size of my and other disabled people's social world. It stops me going to places I would like to be: 'one of my best friends is having her art exhibition at an inaccessible vegetarian café. I cannot go' (Journal Entry, 2015: 208). I do not go to places I know are inaccessible to me, because if I cannot get in there is no point in making the effort. There are many shops I would like to enter that I cannot. I have lost count of the number of birthdays and social occasions I have missed because the restaurant or venue was not wheelchair accessible. My response is similar to that of another participant from the Short-Changed report:

> If I know that there is an area where most of the shops are inaccessible, I will avoid it. I often want to go to little boutique shops but I have to stick to the big department stores. (MDC, 2014: 2)

As with accessible toilet provision, the fact that disabled people account for lack of access, in this case by avoiding inaccessible shops and restaurants, means that the extent of inaccessibility to this kind of premises remains largely hidden. The owners fail to realise that they neglect to secure potential customers and the revenue that may come with them (Williams, 2017). There would be more examples in my own journal of shops and restaurants I cannot access but for the fact that I, as do other disabled people, avoid locations I know are inaccessible to me. However, accessibility does not end with being able to get in and out of a shop. The layout and design of a shop can be just as prohibitive:

> In my previous post I mentioned that I had upgraded my phone. Due to the height of the cabinets I was unable to even look at the phones available for upgrade. The shop itself would have been a rubbish working environment for someone like me. The counters were all at the wrong height and not adjustable, computers ditto. The environment was organised according to the requirements of non-disabled people, everything about the shop said don't apply here for a job if you're a wheelchair user or have any kind of mobility issue. (Journal Entry, 2015: 103)

As I make clear in the extract, as a wheelchair user, the organisation and design of the shop meant that this was not somewhere I could equitably shop for a phone alongside non-disabled shoppers. It was also not a place in which I could have worked for the same reasons. As a participant from the Short-Changed report observes: '[a] slightly lowered table can make a huge social difference' (MDC, 2014: 9). The organisation and design of shops and restaurants is a problem for other disabled people: the same report found that '[s]ixty percent of those surveyed said that the layout and design of shops/restaurants/cafés/supermarkets always or regularly affected their being able to get around once inside' (MDC, 2014: 5). In addition, more than two-thirds have been unable to access parts of an establishment owing to broken or faulty equipment (Trailblazers MDC, 2014). A similar incident happened to me when a main branch post office was relocated to a different building, and moved from the ground floor to the top floor. I was on the top floor buying Euros for an upcoming trip and the lift broke down. I had to be carried downstairs by two members of staff, my electric wheelchair following shortly afterwards by the same method:

> Got stuck on the top floor of WH Smiths today, the lift broke while I was upstairs in the post office getting Euro's for Brussels. I had to be carried downstairs by two members of staff, it took

> four to carry my wheelchair down after me. I missed my eye test and had to rearrange for later in the afternoon. I was spared the Evac chair as none of the staff felt confident using it, they had watched a video but never actually used the chair. The staff asked for my address and I was promised a letter of apology, but I would rather someone hadn't made the stupid decision to put a post office, an essential service, on the top floor of a shop. We used to have a post office which was in the town centre and on the ground floor, but it was closed down and moved to the branch of WH Smiths which I got stuck in. (Journal Entry, 2015: 87)

The above is a further illustration of how the accessibility requirements of disabled people are not a priority. My main branch post office, an essential service, was moved from a ground floor location in one building to a top floor location in another. Here scant consideration was given to the position a wheelchair user would be put in should the lift break down as it did on the day I visited. Returning to Kitchin's theorisation of 'being out of place' and 'knowing my place', the experience I have featured in this section on shops and restaurants illustrates, both how I come to know my place, and that I am out of place. An inaccessible shop sends the message to me and to other disabled people that we are out of place because we cannot enter. Being served in the street or outside a shop also reinforces the same message because it does not represent an equal shopping experience to that of non-disabled people: Nor does being unable to see which phone I want to buy in a shop, because of the design and layout of the premises. I come to know my place by the fact I cannot see the phones I might want to buy, so am compelled to ask for assistance or leave the shop without even being able to browse unobtrusively. I know I am out of place when my main branch post office is moved to the top floor of a building; the lift breaks down, and I have to be carried or Evacked downstairs by staff. I know my place when my safety and the safety of other disabled people is not prioritised, and I am trapped for some time on the top floor of a shop because equipment breaks down. I and other disabled people come to know our place in society because our access requirements in respect of shops and restaurants are very often not taken into account.

As with accessible toilet provision, my own and other disabled people's experiences of shops and restaurants I have explored here illustrate that our citizenship is partial and highly conditional. It is partial because there are many shops and restaurants disabled people cannot access. It is conditional because disabled people are required to tolerate situations such as being served outside a shop, or in the street, or being trapped on the top floor of a building because the lift broke down, and being carried downstairs. Commonly, the eating out and shopping experiences of disabled people are not equal to those of their non-disabled peers. The lived experience of disabled people featured here shows that shops and restaurants are further sites of exclusion to me and other disabled people. The next subsection discusses my experience of train usage.

Access to Trains

I have chosen to include a section on trains because of the personal frustration I experience when attempting to use them. The issues I and other wheelchair users encounter when traveling by train are deserving of attention and exploration. The issues I discuss here are to some degree an open secret; the research done in this area is predominantly by disabled people themselves. My own experience of rail travel is local and national, but, in part as a result of the experiences I describe here, I do not feel safe travelling nationally alone. I have a concessionary travel pass that allows me to travel for free within a defined geographical area. Outside this area I have to pay, as do non-disabled passengers. I do not drive although I do have a second-hand, privately purchased accessible car I use when I can get someone to drive me. When I use the local rail network, staff at my starting station must call my destination to make sure they know I am coming, and someone will be ready at the other end with a ramp so I can get off the train. Such a system has meant that I have missed multiple trains because staff at my destination station have failed to answer the phone. This is particularly frustrating since it extends my journey time: I have to sit and first watch all of the non-disabled passengers board the train then it pulls out of the station without me. This has happened so many times that I started to get off the train at a different station further from my home:

> The usual shenanigans with trains, my home station didn't answer the phone and I had to get off at another station which made my journey longer. On Saturday they couldn't find the ramp key and made no attempt to get me off the train, I had to press the alarm, the train doors had shut again, and the train was going to move off with me still on it. (Journal Entry, 2015: 192)

I have also experienced hostility from some staff members:

> Good day at work, rubbish train journey home, staff at my starting station rang my destination station and were promptly told that "all wheelchairs could fuck off". They eventually got through again, but after that I was dreading reaching the station and just to add to my stress our train was halted for several minutes at the station before my stop. (Journal Entry, 2015: 75)

The fact that staff at my starting station ring, get through and tell someone I am on the train does not guarantee that a staff member and a ramp will be present when I reach my destination. For understandings sake, I should say that I have privately christened one staff member Shit Van Winkle because of the amount of times he has left me stranded on trains and I have failed to make it home without incident when he is working:

> Eventually we reached my station and there was no sign of a staff member with a ramp, I was about to press the alarm when Shit van Winkle appeared, I should not be able to predict when he is working, but I can, and I have no confidence I will make it home without incident when he is working (Journal Entry 2015: 75).

But he's not the only one who has left me stranded … again:

> I am recovering from being stranded on a train again and having to press the alarm, no one came to get me off for 10 minutes, and no one apologised either. I was only removed from the train after my dad wandered into the booking office enquiring where his daughter was. Due to repeated poor experiences I will be departing at a different, slightly less local, station in the future. (Journal Entry, 2015: 157)

And again:

> I went for a burger afterwards and the quality of my day was only damaged by having to press the train alarm on the way home because staff seemed oblivious to my presence on the train and my fellow passengers did nothing to change this. (Journal Entry, 2015: 138)

Repeatedly being left on trains in the manner described has led me to self-exclude. I avoid using trains wherever possible, rather than having to deal with the anxiety of potentially being left on a train again. As *Trailblazers End of The Line* reports in 2009 and 2016 illustrate, being left on a train and waiting for a ramp that does not arrive, is a common experience for disabled commuters who require assistance:

> A couple of times there has been no one with the ramp to help me off the train at my destination platform, even though I had informed them at the other station and been assured that someone would have the ramps ready. Jagdeep Kaur Sehmbi, Birmingham. (MDC, 2009: 6)

As in my own experience, the fact that staff have prior knowledge of your arrival does not ensure that a staff member with a ramp will be there when you require them. The repeated experience of being left on trains has left me reluctant to use the rail network. Similarly to the disabled traveller below, I feel anxious when travelling by rail:

> If only there was a 'call button' on trains because the amount of times I've booked assisted travel and still ended up with no ramp and no help (especially at Victoria Station) – well, it's too many times to count. It makes me anxious if I'm sitting on the train worrying that no-one is

> coming to help me get off, especially at the end of the line when I know the train will turn around and we'll travel back the way we came! Chloe Timms, South East (MDC, 2016: 11)

There is an emergency alarm on some trains which, when pressed, allows you to communicate with the driver, but, as with pre-booking assistance, it is useful only if somebody actually responds, and is not a feature on all trains. Being left on trains in the manner I and other disabled people have described is another example of how disabled people come to 'know their place', because the situations I and others describe do not represent an equitable or decent response to the right and preference of disabled people to use trains as a method of transport. This is also another way in which disabled people learn they are 'out of place,' because we have been given retrospective access to a service that was not initially designed to be accessible to everyone. We are occupying a space no one planned for us to be in.

The way assistance is currently delivered, in practice, makes national spontaneous rail travel next to impossible for disabled people who require it. Although passengers are not legally obliged to pre-book assistance with 24 hours' notice, not doing so, means I can be refused if the staff member assisting decides it is not reasonably practicable to put me on the train. I have found that locally a degree of spontaneity is possible because of the understanding and informal cooperation of the majority of staff. The choice to travel spontaneously is not formally supported and recognised in policy. Some staff choose to apply and interpret policy inflexibly, which is problematic for disabled people who require assistance:

> I'm regularly refused the ramp for the train (Merseyrail) because I didn't book in advance. There is one member of staff who always reminds me that, 'People usually book in advance, you know?' I don't know who these 'people' are, but they're certainly none of my able-bodied friends. Alexandra Haines, North West (MDC, 2016: 11)

Even when there is a staff member waiting with a ramp, I am frequently made to wait until all of the non-disabled passengers have disembarked before the staff member will put the ramp in place and I can leave the train. The common and partial nature of this experience is acknowledged by disabled scholar Tony Heaton, who remarks that 'waiting in hope that a staff member with the portable ramp, will appear to get a wheelchair user off the train once all the ambulant travellers have alighted, is partial, rather than full, access' (Heaton, cited in Cameron, 2014: 2). Making me and other disabled people wait until last is a further means by which we come to 'know our place' and understand that we are socially inferior:

> I stood up for myself today, but I don't feel good about it. I got the train home from work and missed one again because staff couldn't get in contact with my home station. I was also made to wait till last to depart the train again (see previous entries for more details). (Journal Entry, 2015: 45)

Barnes (1991: 170) remarked that 'under the present system disabled travellers were denied the spontaneity of rail travel enjoyed by non-disabled passengers'. My research shows this is still the case. Again, Kitchin's theory of 'knowing one's place' and 'being out of place' can be easily identified, in that disabled people requiring assistance must carry out the additional labour of providing notice of their intention to travel, a step not required of non-disabled travellers. The fact that disabled people who require assistance cannot go where they want when they want by rail is a clear social indication that our preferences are a secondary concern, and a straightforward example of how disabled people come to 'know their place'. Getting on and off trains and the absence of spontaneity of travel are not the only ways in which disabled people come to know their place' and know that they are 'out of place' when it comes to train travel. The position and space provided for disabled people on trains are also a means by which disabled people come to both 'know their place' and know that they are 'out of place'. On some trains the wheelchair space is right next to the toilet:

> I mean, nothing says you’re welcome on board like 2 to 3 hours sat by a loo, having to tolerate the periodical flushing noise created by your fellow passengers (Journal Entry 2015: 64).

Whilst the location may have been decided for other reasons, such as the convenience of being near a toilet, an obvious social implication of this positioning is that disabled people are inferior, and their requirements are not important: non-disabled people have a choice where they sit, while disabled wheelchair users like me do not. As with the other areas explored in this chapter this is a common experience observed and disliked by other disabled people:

> Because I can only sit at one part of the train, the wheelchair space has a lot of very drunk people around it and I have nowhere to move to. We need more flexible wheelchair spaces – not beside toilets. Kiana Kalantar-Hormozi, Scotland (MDC, 2016: 11)

The limited space available to wheelchair users and other disabled people who require assistance on trains is not kept exclusively for those who require it. There are signs on trains to indicate that priority should be given to wheelchair users. However, often this policy is not enforced, and I can find myself in competition with a parent and a pram for a space that is supposed to be prioritised for wheelchair users. Many parents do not understand that they are supposed to give priority to wheelchair users and others simply refuse to vacate the space when asked. If I am alone, I do not ask people to move, out of concern for my own physical and psychological safety:

> If today has proved one thing it is that I would do a lot never to have to use trains again in my life. A member of the public stopped me getting on a train by having a chat about the state of society with the man who was supposed to put the ramp down for me, and by the time he did there was a pram in the wheelchair space. The pram’s owner didn’t move it from the wheelchair space. She moved it to one side a little, but there wasn’t enough room for my chair and I was stranded in the middle of train, making it difficult for other passengers to get off. I also had to endure having my chair used as a crutch by a very drunk man. To add to this tomfoolery, the

> passenger who delayed my getting on the train made a very unhelpful comment about the actions of the woman with the pram which could have been the catalyst for an argument I did not want to get drawn into, and nor did I possess the emotional energy at this point in my day, post work, to have. (Journal Entry, 2015: 146)

The fact that parents often place prams in the space allocated to wheelchair users is highlighted in *Trailblazers* transport reports in 2009 and 2016. It is a key concern for other wheelchair users who are often placed in the position of competing for space, and alongside my own experience, illustrates the capacity for conflict. In the example below, the wheelchair user asks the parent to move the pram, she is reluctant to move, and the staff member does not uphold the wheelchair user's right to and need for the space. Often staff are reluctant to ask parents and carers with prams to move, even though signs within the train clearly state that wheelchair users should be given priority. The wheelchair user in the example below was confident enough to ask the parent to vacate the space, but her request was not supported by the staff member which, in my experience, is a very common scenario:

> I got on a train and a mother with a pram was in the wheelchair space. I asked if she could move. She started to, but also said she didn't have anywhere else to move to. I pointed out that it was a wheelchair space, and she started shouting at me. She said I had an attitude problem, she was going to move but needed to know where she would move to, that I had no right to speak to her like that, that she was there first and where did I expect her to move to, there was no room. I said I didn't have an attitude problem. Then she started to talk over me, saying I shouldn't be speaking to her like that, who did I think I was, etc etc. In the end, the train attendant who had been at the side of the door from the second I got on the train, said it was fine. The mother could stay in the wheelchair space because her pram was too big to move anywhere else, and it would be no problem for me to sit in the doorway. She laughed it off saying, We won't let anyone fall on you! I was still knocked into as people got on, and my back was to the door. I'm

> not just being pedantic over the wheelchair space; my safety was at risk. She could have folded the pram up, and everyone could have been safe. But no, I was stuck in the doorway and the loud shouting woman got her way. I'm always expected to be fine being stuck in the doorway.
>
> Alexandra Haines, North West (MDC, 2016: 12)

Similar competition and conflict can occur on buses, as there is only one wheelchair space per bus, and parents and carers with prams often refuse to move from the space or fold up the pram. A disabled wheelchair user, Doug Paulley, took a bus company to court when he was refused access to a bus because a mother refused to move her pram from the wheelchair space. Mr Paulley won his case in the Supreme Court and the court concluded that bus drivers must do more to accommodate wheelchair users. However, the court stopped short of making this a legal duty, meaning that situations like this are likely to happen again on trains and buses alike (BBC Website, 2017).

The lived experience featured in this section on access to trains further illustrates that my and other disabled people's citizenship is partial and conditional. Disabled people like me are not afforded the freedom to go where they want when they want, and this is a clear example of our exclusion. Our access to trains is provided on the condition that we acquiesce to giving someone advance notice of our desire to travel and tolerate being left stranded on trains. It is also provided on the condition that we accept there is competition for space, and do not cause a fuss when the only space on the train provided for us is occupied by a pram or another passenger's luggage. The next section discusses my experience of ticketing and venue access.

Ticketing and Venue Access

I have included this section because it is a common theme of my journal, which notes that I have significant lived experience in this area. I like going to events. As the experiences in this section show, doing this as a wheelchair user is problematic for a number of reasons. Throughout this section I utilise the research of Attitude is Everything, a charity led by disabled people, who campaign to increase the accessibility of music venues and events. They look at both small-to medium-sized venues and large arenas, publishing State of Access reports in 2011, 2014, 2016, and 2018. In those reports they highlight and detail a comprehensive range of issues and experience in relation to event attendance. In the 2014 report, mystery disabled shoppers found the inequality of ticket booking systems compared to those of non-disabled patrons to be a key concern (Griffiths and Hilder, 2014: 7). The totals showed how 88 per cent felt discriminated against and 83 per cent were put off buying tickets (2014: 7). Given my own experience I find it difficult to disagree with this view. I have been booking tickets for and attending a range of events for more than 20 years. The repetition of poor experiences when it comes to the act of booking a ticket has made the process extremely stressful. A number of reasons for this are contained within my journal entry below:

> I am trying to buy tickets for NXT at two different U.K. venues, as a wheelchair user the booking process is rarely, if ever, straightforward. I rang one venue this morning, and was left with the distinct feeling that a cleaner who just happened to be in the booking office at the time had picked up my call. She did not seem to understand the venues booking policy, or that the event I was enquiring about was happening at that venue, (it is). She also told me I would have to 'prove my disability'; I have been visiting this venue for several years and I've never been asked to prove I am 'disabled', equally, at this venue, I've never been asked to call a dedicated line (not a process I'm a fan of), but today I was. As a previous booker I have received an email which is meant to allow me to book tickets tomorrow, (a day early), the person I spoke to had no

> knowledge of this, and I was not exactly filled with confidence. I will update tomorrow as to whether or not I am successful in my quest for tickets. (Journal Entry, 2015: 44)

The 2014 ‘Attitude is Everything’ report noted that some disabled people prefer to call an access line when trying to book the tickets they require. However, in my experience, having a separate, segregated line for access bookings, does not mean I receive a good or better service. I would perhaps be more inclined to tolerate the segregation if it did. Many venues now require those making access bookings to call a different number from non-disabled customers: it is particularly the case with larger arenas. This aspect of the process actually requires additional effort, because in many cases, the numbers I am required to call are not published on the general advertising sent out to encourage people to book. My experience has more in common with the respondents (below) in the 2014 report:

> Many venues still have a very limited number of wheelchair spaces compared to the total number of tickets available. I’ve experienced situations where the wheelchair spaces have sold out even though there are lots of ‘normal’ tickets still on sale - even at outdoor events. Very frustrating! (2014: 9)

As with transport, wheelchair users and those with mobility impairments are forced into competition for a limited number of accessible spaces. As a disabled person and wheelchair user, I often require the support of another person to attend a particular event. To obtain a personal assistant or carer ticket I must provide personal, medical information when booking tickets. Contrary to common perception, although there is no financial cost attached, because of the requirement to provide personal and medical information, such tickets are not free. The process of providing personal, medical information in what is a social context is not required of non-disabled people, many of whom would find it strange to have to provide such information, to attend, say, a music gig, but for many disabled people this has come to be an expected further and additional labour. As is highlighted in the 2014 Attitude is Everything report, DLA or PIP letters are the most commonly requested form of proof of entitlement to claim a PA ticket. The report importantly acknowledges that ‘not all disabled people claim this, and they might still require access to facilities and a Personal Assistant in order to receive an equal experience of a live music event’ (2014: 10). In the 2018 version of the same report, issues relating to ‘proof of disability’ are further elaborated upon:

> The concept of ‘proof of disability’ is a complicated and loaded one, that all too often ends up being reduced to whether or not someone is in receipt of particular benefits. There is also the lingering notion that people can be ‘registered disabled’, with businesses across the UK still asking for proof of this, despite it being a long defunct system that originated in the early 1970s and effectively ended with the arrival of the ‘Disability’ Discrimination Act 1995. (Adams, 2018: 16)

I am a member of five different venue access schemes, all of which require ‘proof of disability’ of the type described above, as well as additional information in order to claim a PA ticket. The venues that operate and administer these schemes justify repeated requests for information by suggesting that they are protecting their own profits and preventing abuse of the scheme. However, what often goes unacknowledged is the psychologically invasive nature of these requests for ‘proof of disability’ and the requirement to fill in forms just to attend a particular event. I am effectively being required to provide personal, medical information to attend a particular event or show. The administration of such schemes seems based upon the presumption of dishonesty on the part of the person requesting the ticket. This is in my view, a poor starting point for a policy designed to bring about a degree of equality for disabled people.

The act of booking tickets as a disabled person has a degree of commonality with benefits assessment in terms of having to satisfy someone else’s perception of what it means to be ‘disabled’, and the need to provide proof of entitlement. Some venues are requiring disabled people to name the PA they are bringing months in advance of a show, and asking the PA to sign a form to make them legally responsible in the event of a fire evacuation, a requirement that I consider both impractical and unfair. This was highlighted in the 2018 Attitude is Everything report, and I have chosen to include it here because I had an experience identical to that of the respondent below, as a result, I will not claim a PA ticket if I visit the venue again. I will pay for both tickets:

> For some venues you need to give the name of the person and carer when you book as this goes on the ticket and you have to take ID. This can be months before the concert, and sometimes you don’t know who the carer will be that far in advance. (2018: 14)

In an attempt to make the process of booking access tickets easier, Attitude is Everything have tried to establish a universally accepted access card, so that bookers do not have to provide personal information every time they buy a ticket. The scheme is growing in awareness and popularity. Members pay a fee and their different access requirements are represented on the card by a series of symbols. The value of the scheme for disabled people is encapsulated by a respondent from the 2016 Attitude Is Everything report:

> I really love having my Access Card which means that I don’t have to write an essay about my access requirements every time I go to a festival/venue. (Adams, 2016: 18)

The issues in relation to event attendance do not begin and end with ticket booking. As with shops, some event venues have no wheelchair access at all ‘I have once again been left upset because a venue I wanted to attend for wrestling is inaccessible to me’ (Journal Entry, 2015: 157). As with shops, there would be more entries like this in my journal but for the fact that I avoid venues I know are inaccessible to me, or venues where I know the access is poor. I am particularly appreciative when event organisers consider the quality of my experience, including ensuring that I have a good view:

> I went to the wrestling show I had tickets for. I'm glad I did. I had a good time and a great view of the action. … are a company trying to ensure that their disabled fans have a good time at shows and I appreciate this a great deal. (Journal Entry, 2015: 172)

Unfortunately, the extract below from my journal is a more common exemplification of my experience:

> My … weekend has been spoiled by the knowledge that I will, despite voicing my concerns, be spending the majority of it looking at the backs of people's heads, having paid £140 for the tickets. I have been to this venue before and was not warned about the seating change. I am supposed to attend for another two days, but I have no desire to spend my weekend in the aforementioned position. I am going today because I've paid for pictures, but I'm going to give Sunday a miss. The disappointment having looked forward to this for months is just too much, and I don't see any point in being there knowing I'm going to have a crap view, and knowing that the organisers don't care about whether I can see or not. (Journal Entry, 2015: 78)

The ability to view a show you have paid to see is a key concern for other disabled people whose experiences featured in the 2016 Attitude is Everything report:

> The fencing was at eye level if you were seated. As the area was on ground level, if anyone outside of the viewing area was standing up in front of it, your view was completely blocked. (Anon, cited in Adams, 2016: 25)

The report highlighted how 'in many cases viewing platforms or areas, whilst present, may be not fit for purpose due to their physical build and location, and/or poor staffing' (2016: 24). In addition, the 2018 version of the same report importantly acknowledges that 'there are venue and event organisers now being left behind as they continue to enact outdated and potentially discriminatory policies that impact the ability of Deaf and disabled people to access the paid-for services they provide' (2018: 14).

The experiences I have featured in this section on ticketing and venue access show how in this context disabled people are conditioned to both ‘know their place’ and understand that they are ‘out of place’. The requirement to provide personal, medical information as part of the booking process reminds disabled people that they are different and treats their desire to be social as an exception. The fact that disabled people are required to provide personal, medical information in what is in fact a social context is a further indication that they are socially inferior, because such additional effort is not expected of non-disabled patrons. In addition, the venue’s selection of the location of disabled people within a particular venue is a further indication of their socially inferior status, a means by which they come to ‘know their place’ and know that they are ‘out of place’, we are often positioned at a distance from what we have paid to see, and have little choice as to where we sit. The common total inaccessibility of venues illustrates that the desire of disabled people to attend social events is regarded as having little social importance. The message is sent that disabled people are inferior citizens. The fact disabled people like myself cannot enter a particular venue is a straightforward indication that we are ‘out of place’. Again, here, the nature of disabled people’s citizenship is partial and conditional; it is predicated on their willingness to provide medical information as a condition of being allowed to attend a social event, or to tolerate segregation and an inferior view of whatever or whomever they have paid to see, or - worse still - be faced with the fact that some venues are not accessible to them at all. The next section describes the key barriers to accessibility, based on my experience.

Barriers to Equal Access

One illustration of my personal experience and the lived experience of other disabled people is that the Equality Act is not substantively enforced. The act requires businesses, service providers, and public bodies to make reasonable adjustments (The Equality Act, 2010). It is not difficult to argue that a requested adjustment or accommodation is unreasonable and therefore avoid the requirement to provide access. As Brenda Puech from The Centre for Accessible Environments points out, the term 'reasonable adjustments' means that a service can be offered in a different way:

> All businesses since October 2004 have had a legal duty (the 'Disability' Discrimination Act 1995) to have made reasonable physical adjustments to make their businesses and business premises accessible to disabled customers. The law (it is now the Equality Act) says that changes have to be reasonable. So a small local business that has a large existing step into the shop may not have the space to put in a ramp, but they still have to provide the service to everyone who wants it. They may offer home delivery, or bring out the item to the customer. If they are a service, they can provide telephone or online service. The considerations of reasonableness include cost, practicability of making the change, and size of business. (Puech, cited in MDC, 2014: 8)

Therefore, in practice, having to carry out a transaction outside of a shop because the premises are inaccessible to myself and other disabled people is not necessarily a contravention of the law, because the business owner can argue that making a shop physically accessible to disabled people is an unreasonable adjustment. I was particularly disappointed when I discovered that a venue I wanted to visit for a wrestling show had no wheelchair access, nor plans to have any. They make the following statement on their website, in which they use a similar phrasing to that contained in the Act:

> We currently do not have access for non-ambulatory persons to The Dome due to the fact that we cannot reasonably adapt the premises. The site does not currently have a 'disabled' welfare facility. We do, however, welcome disabled customers who are ambulatory
> http://www.dometufnellpark.co.uk/ages-access/
> They even make a public statement about this on their website, the basic gist of which, is that people who cannot walk are not welcome.

> (Journal Entry, 2015: 157)

Inaccessible venues are common: the above is not an isolated occurrence. It may also not be illegal because the venue has argued that they cannot reasonably adapt the premises to make them accessible. The subjective nature of the phrase 'reasonable adjustments' means that there is little or no imperative within the Act to make a given venue, location or service accessible. While these justifications are allowed under the Act it is conceivable that many places and services will remain inaccessible to many disabled people.

Oliver (2009) summarises the predicament of disabled people in relation to accessibility. He compares the different social responses to disabled people like myself, who cannot walk, and people who do not have the innate ability to fly:

> After all, we do not punish non-flyers for not flying. In fact we do exactly the opposite. We spend billions of dollars, yen, Deutschmarks and pounds every year providing non-flyers with the most sophisticated mobility aids imaginable. They are called aeroplanes. An aeroplane is a mobility aid for non-flyers in exactly the same way as a wheelchair is a mobility aid for non-walkers … But that is not the end of it, we spend at least as much money to provide environments, usually called runaways and airports, to ensure that these mobility aids can operate without hindrance. Further, hundreds of thousands of people are employed worldwide, in helping non-flyers to overcome their particular mobility difficulties. And finally, in order to provide barrier free environments for non-flyers, we trample on the rights of others, ignoring their pleas not to have their homes bulldozed, their sleep disrupted, or their countryside disturbed. Non-walkers are treated in exactly the opposite way. Environments are often designed to exclude us, transport systems that claim to be public continue to deny us access when we protest we are told there is no money. We are also told that giving us access to such systems would adversely affect the rights of others; journeys would take longer and perhaps be more expensive for everyone … My

> point is essentially one concerning social justice; treat both groups equally, or at the very least, stop punishing non-walkers and nearly walkers for not walking (Oliver, 2009: 39-40).

One key point Oliver is making here in his use of the analogy is that disabled people are treated differently. Planes are built so that people without the ability to fly can in fact do so, while in contrast meeting the access needs of non-walkers is framed socially in terms of exceptional and unnecessary costs. The financial cost of providing access is persistently stated as a legitimate reason for not improving accessibility. In my experience the discourse of cost holds such symbolic power that it functions to nullify any discussion. The power of the financial cost as a justification for not improving accessibility needs to be challenged. To paraphrase Oliver's words, I am punished for being a non-walker and so are other nearly-and non-walkers. This punishment is inherent in an environment that repeatedly excludes. My punishment is exclusion. I am concerned that austerity as an ideology serves to further endorse the validity of the cost justification, leaving it unquestioned. I know from my experience that the costs of inaccessibility are more than financial: they are psychological, emotional, and human. As Napolitano (1995) acknowledges:

> Good inclusive design will send positive messages to disabled people, messages which tell them: `you are important'; `we want you here'; and `welcome'…. if the way that disabled people are expected to get into a building is round the back, past the bins and through the kitchens, what does that message communicate? How will it make a disabled person feel? (1995: 33)

Napolitano's words are a good example of how variable accessibility leaves me feeling. Poor accessibility is a factor in my experience of psycho-emotional disablism (PED), which is the focus of chapter five of this thesis.

Chapter Conclusion

In this chapter I applied Kitchin's (1998) concept of 'knowing one's place' and being 'out of place' to the lived experience of disabled people (including my own) so as to illustrate, using a range of examples, how the physical environment excludes disabled people like myself. I assert that currently the inclusion of disabled people like myself is partial and highly conditional. It is based on the willingness of disabled people to tolerate situations such as poor or non-existent toilet facilities or to ignore the fact that many shops, restaurants and venues are inaccessible to disabled people. I employed the lived experience of disabled people to show there is no absolute imperative within the Equality Act to improve accessibility. I assert that the power of cost as a justification for not providing access and as a means of nullifying further discussion in terms of improving accessibility needs to be challenged. I am concerned that austerity serves to legitimate and shore up this view.

Having used the lived experience of disabled people to show how the environment excludes us, the next chapter uses the lived experience of disabled people to discuss and explore how, under austerity, disability assessments are experienced by disabled people themselves, in the assessed disabled self.

Chapter Five

The Assessed Disabled Self

Introduction

The focus of this chapter is disabled people's experiences of the assessment process for Employment and Support Allowance (ESA), Disability Living Allowance (DLA), and Personal Independence (PIP). These are the main benefits currently available to disabled people like myself at the time of undertaking this study. It uses my personal experience as a catalyst for discussion. The chapter begins with background information for each benefit or allowance. It is divided into the following sections: 'declaring disability', in which I explore state definitions of 'disability' and the associated implications for claimants: 'disability', deficiency and 'decrepitification', in which I discuss the representations disabled people are required to make as part of the assessment process to have a chance of making a successful claim. I also define and develop my own concept of 'decrepitification': who's 'disabled' enough'? In which I discuss the importance of, and challenges associated with, being considered 'disabled enough' to be eligible for these benefits in the context of an increasingly narrow 'disability category'. In assessment, 'decrepitification' and the hierarchy of impairment, I discuss how the points-based nature of these assessments creates a flawed and superficial hierarchy of impairment that places disabled people in competition with each other and disadvantages specific impairment groups. The concluding sections look at the psychological impact of assessment, beginning with the impact of ineligibility and loss of other entitlements such as Motability vehicles and concluding with an exploration of psychological impact of reassessment and simultaneous assessment, as well as the part these assessment processes play in disabled people's experience of psycho-emotional disablism (PED).

Disability Living Allowance (DLA) and Personal Independence Payment (PIP)

DLA was established in 1992 by the then Conservative Government (Noble *et al.*, 1997; Burchardt, 1999). I have been in receipt of DLA since childhood. The stated aims of DLA and its replacement PIP are to help with the extra costs of a ‘disability’ or ‘long-term health condition’ (Gov.co.uk/pip; Burchardt, 1999; Machin, 2017). It is not means tested or contribution based (Robinson, 2019) and therefore can be claimed whether in employment or not (Gray, 2014). Assessment for DLA took the form of a self-assessment, responding to questions about ‘your disability’ or ‘medical condition’ and medical evidence from your own G.P. (Machin, 2017). In contrast, the assessment for PIP requires most claimants to attend a medical and undergo assessment by a medical professional who has not met them before and may have little or no knowledge of their ‘condition’ and or ‘disability’. As with, DLA, claimants are required to provide medical evidence as part of the assessment process. DLA and PIP are points-based assessments (Gray, 2014). Points are awarded on the basis of a claimant’s inability to perform a series of daily tasks such as going to toilet, preparing a meal or getting dressed. The more you are unable to do, the higher you score, and the greater the likelihood you will be awarded DLA or PIP.

DLA has two key components: a mobility component, and a care component. The mobility component for those who need help getting around had a higher and a lower rate. The care component had lower, middle, and higher rates for those who need help with personal care. PIP retains the mobility component of its predecessor, but the care component is now covered within the category of daily living and is awarded as is mobility, at either standard or enhanced rates (Gray, 2014). The abolition of the middle-rate care component from PIP resulted in fewer disabled and ill people being eligible for PIP than were for DLA: the subsequent loss of income was a concern for many disabled people (Campbell, 2012; Machin, 2017). A further key difference between DLA and PIP is that the distance a person can walk to be eligible for PIP has been reduced from 50 metres to 20 metres making the eligibility requirement for the mobility component of PIP harder to satisfy (Alldridge, 2019; Roulstone, 2015). In addition, PIP regulations downplay such important factors as the pain and fatigue a person may experience when carrying out an activity (Roulstone, 2015).

PIP was brought in by the Coalition Conservative-Liberal Democrat Government and the legislation to introduce it is part of the 2012 Welfare Reform Act (Machin, 2017). The process of transitioning claimants from DLA to PIP began in April 2013 for new claimants (Machin, 2017). As an existing claimant of DLA, my transition to PIP did not begin until April 2018 and my DLA was stopped in May of the same year. The introduction of PIP and the transfer of existing DLA claimants was part of the Conservative Government's plan to reduce spending on welfare by 11 billion pounds as part of its austerity measures (Wood, 2012). The next section provides background information for ESA.

Employment and Support Allowance (ESA)

The stated aims of ESA are to provide financial support to 'sick and disabled' people who are unable to work, or to provide personalised help to those who can (gov.uk/employment-support-allowance). ESA replaced Incapacity Benefit in 2008 and was introduced under the then Labour Government. It continued under the Conservative Liberal Democrat Coalition Government (Grover and Piggott, 2007; Grover and Piggott, 2013). As are DLA and PIP, ESA is a points-based assessment. Points are awarded based on an individual claimant's inability to perform or complete certain rudimentary daily tasks, such as going to the toilet or walking. Also, similarly to PIP, benefit awards are predicated on scoring highly enough to qualify. There are two types of ESA: Contribution Based, which applies to those successful ESA claimants who have made enough National Insurance contributions (NI) to qualify, and Income Related, which is means tested. This means it involves a financial assessment of an individual claimant's income and is awarded to successful ESA claimants who have made insufficient NI contributions (Puttick, 2007).

Everyone who makes a claim for ESA must fill out an ESA50 work capability assessment (WCA) and most claimants undergo a medical assessment. The WCA is used to determine whether a claimant has limited capability for work. There are three key outcomes. A claimant who is found to have no limited capability for work, or in other words is deemed fit for work, is directed to claim Job Seekers' Allowance (JSA). They must attend the Job Centre and prove that they are actively looking for work as a condition of retaining their JSA. Claimants who are found to have limited capability for work are placed in the Work-related Activity Group (WRAG) and are expected to engage in work related activity as a condition of being granted their ESA, similarly to those in receipt of JSA (Grover and Piggott, 2010). Not doing so can result in monies being stopped or withheld. The remaining claimants, those considered to have the most limited capability for work, are placed in the support group and not expected to engage in work-related activity or look for work as a condition of receiving their ESA. As was PIP, ESA was subject to cuts as part of the Conservative Government's plan to reduce spending on welfare as part of its austerity measures. The section that follows discusses 'declaring disability' as a necessary aspect of the assessment process.

Declaring Disability

'Declaring disability' is a compulsory requirement of the assessment process for Disability Living Allowance, Employment and Support Allowance, and Personal Independence Payment. The definition of 'disability' as stated within the 2010 Equality Act (previously the 1995 'Disability' Discrimination Act), forms the basis for this declaration in the context of these assessments. It is embedded within these assessment processes and is included in the paperwork every claimant receives at the outset of their application. Within this definition 'disability' is defined as follows:

> (1) A person (P) has a 'disability' if—(a) P has a physical or mental impairment, and (b) the impairment has a substantial and long-term adverse effect on P's ability to carry out normal day-to-day activities. (The Equality Act, 2010)

The opportunity to receive any state or governmental support is predicated on my public acceptance of the above definition of myself as a disabled person, since choosing not to agree with this definition of 'disability' means I would have no opportunity to access state support (Prowse, 2009). I recognise that there are a range of reasons why people either refuse outright or are reluctant to claim state benefits, such as not considering themselves 'disabled enough' to be entitled to state support, or the social stigma and shame associated with being a recipient of state assistance (Garthwaite, 2014; Hannam-Swain, 2017). However, I contend that 'declaring disability' is problematic whatever definition the claimant is expected to ascribe to, and regardless of whether an impairment is long-term or acquired later in life. My rationale for this is based on my understanding that for many people the word 'disability' has wholly negative connotations, and because of those connotations it is a label and a social category many people do not want to have applied to them: this forms part of the reason many people are put off claiming benefits (Prowse, 2009). Although I satisfy this definition given the nature of my impairment, from the very beginning of the claim process I am compelled to agree with a definition and way of understanding 'disability' that I find problematic and with which I disagree. I find it problematic because it defines 'disability' as a problem within the individual. It makes scant acknowledgement of the role social or structural factors play in creating and sustaining disability (Grover and Piggott, 2007; Grover and Piggott, 2010). As Lewthwaite (2014) asserts '[t]he "fact" of 'disability' is conceived strictly as a matter of medical expertise, rather than social ascription' (2014: 1162). As Harlan Hahn has argued, 'fundamentally disability is defined by public policy. In other words, disability is whatever policy says it is' (Hahn, cited in Oliver and Barnes, 1998: 36). If this is the case, then in the context of assessments for DLA, PIP, and ESA, state and governmental understandings of disability draw little or no distinction between disability and impairment: they therefore fail to recognise the role of social factors in the experience of disability and are individual and medical in character. This is because they conceptualise ‘disability’ as being located solely within the individual and as matter of bodily failure and deficiency. The understanding of ‘disability’ as individual medical, bodily failure, and deficiency is embedded within the entirety of the assessment process. This has a range of implications for myself and other claimants, and this is the focus of the next section, ‘disability’, deficiency and ‘decrepitification’.

Disability, Deficiency and Decrepitification

I concluded the previous section with the contention that state understandings of ‘disability’ as individual, medical bodily failure and deficiency is embedded within the entirety of the assessment process. This means that assessments for DLA, PIP, and ESA are deficit based and thus neglect a social understanding of disability (Grover and Piggott, 2007; Lewthwaite, 2014; Watts, 2018). In the background sections of this chapter, I noted that all three benefit assessments are points-based. The deficit nature of these assessments creates a relationship between inability or deficiency and eligibility. In other words, the more unable you are, the more points you score and the more likely you are to be found eligible for the benefit. This correlation, which is inherent to these assessment processes, puts pressure on disabled people to represent ourselves in solely negative terms, as being unable and deficient, to have any chance of making a successful claim. I reflected upon the deficit-based nature of DLA, PIP, and ESA, the requirement to represent yourself negatively in my journal:

> This morning I received a letter saying my DLA will stop … and advising me how to claim PIP. This news has spoiled my Saturday. It means another deficit-based form and the possibility of being called in for a medical assessment, all of which could result in me being found ineligible

> and being left with very little to live on. I have to ring on Monday and request a form which I have absolutely no desire to complete. I had been given an indefinite award of DLA as a child, which until now no one has questioned, and my condition/impairment has only gotten worse in the intervening years. At no point has anyone offered me anymore money or support to account for this fact and now I could lose that which I have been for so long considered entitled to … In terms of the content and direction of the questions it is worse and longer than an ESA Work Capability Assessment. It wants, for example, to know in detail how I go to the toilet, including whether or not I can wipe my own backside, a question which irrespective of context I consider a massive invasion of privacy. I mean, try asking a non-disabled person that and see what response you get. Yet I, by virtue of the process, am expected to respond to this question, and many others in a similar vein, rationally, and not feel as if I want to punch the nearest human in the face. Just for the record there are 37 pages of this Oliver Twist based malarkey to navigate with no guarantee of success, such as maintaining my current award level. What makes the above more distressing is I was just starting to feel ok again, after learning that a disabled friend had died in awful circumstances, and I'm now feeling shit again because I have to go through this. I am never going to be one of those people that goes around naively thinking everything's going to be alright, although, I suppose it makes a nice song lyric (Journal Entry, 2015: 194)

The deficit-based nature of assessments is a commonly noted theme amongst disabled people who have been through the process. See for example the experience of 'Nicola' in Akers' (2016) research 'How Does It Feel to Be Assessed?':

> Everybody just deals with it, you just carry on around and nobody makes a fuss. So that's how I've looked at it. I've always looked on the positive side, I can't do that, but I can do that. Whereas just filling this form, I just found horrendous. It made me face what I couldn't do … But

> as I say, it made me, look at what I couldn't do and have to write it down. It was so much. No I can't do this, no I can't do that, well yes I can do that but have to do it this way or I have to alter the way I do it in my house, because my house has everything planned how I need it … But what…when I came to fill in this new form... I mean it's so invasive...so…really makes you look into what you can do and what you can't do. (2016: 12)

The type and character of the representation disabled people are required to make as part of the assessment process is concisely encapsulated by Stephen Unwin, the parent of a disabled child, in the following Tweet. I contend that in the context of the assessment process his assertion is equally applicable to disabled adults:

> Those of us with disabled children know that the only way to secure the support they need is by emphasizing how useless they are in every respect. Which rips your heart out because you know how much they can do. And how much they mean not just to their families, but the world. (Unwin, 2019)

The necessity to make certain representations as part of the assessment process, to tell the worst story about ourselves and represent ourselves as wholly useless and deficient, compels us to engage in what Watts (2018), writing as part of a guide intended to help her fellow mental health professionals assist patients with their benefit claims, refers to as doublespeak:

> Filling in forms in the way the DWP [Department of Work and Pensions] requires, and providing useful letters of support, often means focusing on what is difficult and writing in a far more pathologising 'medical model' manner than you might normally. It must be deficits based, with diagnosis used as shorthand. If you are critically minded, speak with claimants first about the need to adopt what Recovery in the Bin administrators calls 'doublespeak', i.e. writing in a way

> that you disagree with because that is the best way to serve the interests of the claimant. Ask permission to do so. I have always found claimants understand, are relieved and say yes to this. (Watts, 2018: 6)

As part of the assessment process I must engage in ‘doublespeak’ and write in a way that I disagree with because that is the best way to serve my interests. The requirement to engage in doublespeak as part of the assessment process is one aspect of a concept I am naming ‘decrepitification’, which alongside doublespeak requires disabled people to make deficit-based self-representations, to represent ourselves as ‘useless in every respect’ (Unwin, 2018), then support and confirm this story with medical evidence. I wish to acknowledge that while engaging in ’decrepitification’ may increase a claimant’s chances of being found eligible, doing so does not guarantee a successful claim. The process may also present those with ‘fluctuating medical conditions’ with a representational dilemma, in relation to describing their ‘disability’ on a ‘good day’ or a ‘bad day’. I suggest that their chances of being found eligible are increased by representing their ‘disability’ as experienced on a ‘bad day’, but this may leave some open to the accusation of exaggerating or ‘faking’ their ‘disability’. Furthermore, the process of ‘decrepitification’ when being assessed for ESA is additionally complex because the benefit is linked to a claimant’s employment status. In completing the ESA50 Work Capability Assessment (WCA) as part of the assessment process I must represent myself as unfit for work even though I do not consider myself as being unfit for work, but being found ‘fit for work’ does not mean I will obtain employment: it does mean I would be without the financial support ESA provides. This is a good example of doublespeak as an aspect of ‘decrepitification’: I am responding in a way with which I fundamentally disagree so as best to serve my own interests:

> I have had what I consider to be a small but significant victory today, for approximately the second time in three months I have survived trial by ESA. The success of my form filling skills was confirmed by the fact my money was there to collect this morning and I did not get called for the medical assessment I’ve heard so many lovely things about. I think this means I am good

> at pathologising my own body for the purpose of my own financial survival. (Journal Entry, 2015: 20)

> Today started with me having to rationally contemplate whether my behaviour annoys other people, I said no. I am too psychologically and emotionally exhausted to be bothered having this debate. I also think it is a diabolical question to ask of any human being, even those who would answer yes. For the uninitiated I have been sent another ESA50 to fill out, they have made it even harder to satisfy this year, I am currently in the support group and that is where I want to stay for now. (Journal Entry, 2015: 201)

As I said earlier, I do not consider myself unfit for work, but as a disabled person, as do other disabled people I face considerable barriers to employment (Muscular Dystrophy Campaign, 2010; WHO, 2011; EHRC, 2017). It is harder to get and keep a job when you are disabled and therefore my earning power is reduced. This is a situation which the ESA assessment process leaves unacknowledged. For most of my adult life, despite considerable effort on my part, I have been unable to source regular financially viable employment. I claim ESA and PIP as a result of the issues I have had sourcing this type of employment. For myself, ESA and PIP function as an income replacement and without them I would have very little to live on and be at considerable risk of poverty. As Grover and Piggott (2010) comment, in their paper 'From Incapacity Benefit to Employment and Support Allowance: social sorting, sickness and impairment, and social security':

> The structure of ESA suggests the threat of falling into poverty is still viewed by the state as a crucial element in getting people to engage with paid work and activities thought to be helpful in getting them into work. (2010: 275)

I wish to challenge the view that the threat of poverty, as indicated through policy and highlighted by Grover and Piggott, motivates people to find work. The threat of poverty is one key aspect of what makes the assessment process so stressful. It does little to help my chances of finding employment.

Others researching and writing about the impact of austerity noted that PIP contains the same threat of poverty and I consider the threat of poverty to be an inherent aspect of both ESA and PIP assessment processes (Wood and Grant, 2010; Mendoza, 2015; O'Hara, 2015).

Providing medical evidence to support the representation of the 'self' you make is an important part of the process of 'decrepitification' required for assessment: the medical character of state and government understandings of 'disability' dictate that these assessments are based on need (Popplewell, 2013). As Grover and Piggott observe in respect of ESA, these needs are distinctly medical. This is also the case with PIP (Machin *et al.*, 2018) and it is based on the same understanding of 'disability':

> The WCA is clearly a statement that income maintenance policy for people who are sick and/or who have impairments should be framed by medical considerations only, rather than broader socio-economic considerations. (2010: 269)

One reason I find basing assessment on medical need problematic is because the inequality I experience and the social and economic context I live in as a disabled person, the issues I face in relation to employment, for example, are hidden or subsumed within discourses of medical need. In addition, it has been argued that ESA and PIP serve to perpetuate the inequality they hide (Grover and Piggott, 2010; Burgess, 2014). It is an inequality that, if state understandings in relation to 'disability' are taken as an indicator, the government has little substantive desire to tackle. Despite being assessed for ESA multiple times under austerity, I have managed to remain in the support group: this means I am not required to engage in work related activity as a condition of my ESA. My experience really resonates with that of Christopher, a disabled man who has autism, a learning disability, and a speech impediment. Christopher was interviewed for Ryan (2019). About Christopher, Ryan recounts:

> [He] has been struggling to find work for the past 20 years. 'It drives you around the wall. Year after year', he says wearily. 'You're forced to worry about the future every day'. Christopher

> speaks to me from his parents' house in Cornwall. At his age he wants to move out to a place of his own ('I feel like a failure', he tells me) but he knows he's stuck until he's got a secure wage coming in. Since he left school in the 1990s, he struggled to keep hold of jobs. He finds it hard to 'fit in' with colleagues when they don't understand autism, while employers judge him as less capable once they hear his stutter. Contract work is sporadic: a spell as a postman lasted eight months and a bed raiser fitter only a month. For the last year, he's worked as a cleaner at a plastics factory 2 miles down the road: a contract for 12 hours a week at minimum wage. He earns £181 every fortnight or just about enough to keep his car running to look for the work. (Ryan, 2019: 56)

Whilst I do not have the same impairments as Christopher, I have encountered similar issues. I have been looking for employment for the best part of 15 years. I have experienced discrimination and come across employers who have considered me less capable because of my physical impairment. When I have found work it has been *ad hoc*, temporary, and often for the minimum wage. My placement in the support group, thus not having to engage in work-related activity, gave me time to look for the part-time, zero hours contract job I currently have. My employment is allowed under ESA and conducted under permitted work rules (less than 16 hours a week). Ironically, research by Burgess (2014) found that those placed in the support group were more likely to find work than those expected to engage in work-related activity (Burgess, 2014). In their paper 'From Incapacity Benefit to Employment and Support Allowance: Social sorting, sickness and impairment, and social security', Grover and Piggott (2010) provide a useful summation of the employment context in which I and other disabled people find themselves:

> The problem for people who are sick and/or who have impairments is that policies, such as the ESA, operate within existing employment structures. This means that people who are sick and/or who have impairments will be expected to compete for work alongside people who are well and who do not have impairments with little account being taken of how working patterns

> and environments contribute to their exclusion. Indeed, the process of claiming ESA appeals to the need for more ‘personalised’ approaches to ‘supporting’ people into paid work, are aimed at making people who are sick and/or who have impairments conform to the working patterns of able-bodied people. They will do little to improve the position of people who are sick and/or who have impairments who, because of meritocratic notions that frame concerns with economic and social advancement, systemically disadvantage people who are sick and/or who have impairments. (2010: 273-274)

As Grover and Piggott observe, ESA operates within existing employment structures and does little to address the barriers to employment faced by disabled people. Importantly, Grover and Piggott acknowledge that in practice personalised approaches and supporting people in the context of ESA equates to little more than expecting disabled people to adapt to existing employment structures, fit into existing working environments, and keep pace with non-disabled people. The nature and degree of my impairment makes this difficult, if not impossible, for me and many other disabled people. I will always need adaptions and adjustments to my working environment and conditions. There is a myriad of locations I am excluded from working within due to the inaccessibility of working environments. I consider it unethical to expect disabled people to keep pace with non-disabled people in the workplace and to use arguments about reduced productivity as justification for not employing a disabled person. On the relatively few occasions I have been employed attempting to keep up with non-disabled colleagues has often left me exhausted and has sometimes exacerbated my impairment. If experience has taught me anything, it is the importance of working at my own pace. Whereas attempting to keep up in this way to some extent demands substantial workplace adjustments or the individual’s ‘disability’ being relatively minimal, the navigation of disability benefits assessments can demand that individuals demonstrate they are ‘sufficiently disabled’. In the next section, issues in relation to being considered ‘disabled enough’ in the context of assessment to be eligible for ESA and PIP are discussed.

Who's Disabled Enough?

Prior to being transferred to PIP, despite having more than one 'medically verifiable impairment', I was concerned that in the context of assessment I would not be considered 'disabled enough' and therefore be found ineligible and thus lose my entitlement to PIP. Stories like the one I reflect upon in the journal entry (below) were a common occurrence in news reports following the cuts to welfare, and did nothing to reassure me:

> My mood has dipped very low over the past 24 hours, I feel very down. My mood has not been helped by my seeing on my TV a woman with Alzheimer's, I will say that again, a woman with Alzheimer's, has had her benefits stopped and is having to go to a tribunal in the hope of getting them back. It was also made clear in the report that she is not a one-off case. I have not yet been moved onto PIP, I'm still on DLA, but this is just one reason why I dread the future and why I have learnt to fear that whatever I say during any assessment process will be used against me. (Journal Entry, 2015: 161)

In a society where a woman with Alzheimer's disease (a significant and 'deteriorating condition', and a terminal illness) is not considered 'disabled enough' to qualify for PIP, I too could have been considered not 'disabled enough' or not 'disabled' at all and not qualify for PIP. Not being considered 'disabled enough' for the administrative purposes of assessment was a concern for other disabled people. In the context of assessment for Disabled Students Allowance (DSA), a grant intended to support disabled people who wish to study in Further or Higher Education, Hannan-Swain (2017), a disabled woman and wheelchair user like me, voices her own feelings in respect of being consider 'disabled enough' to qualify for support:

> After years of trying to be as non-disabled as my body would allow, here I will be expected to talk openly and fully about all of the things that I cannot do and to embrace my 'true' disabled self in full, or fail to meet the increasingly narrow definition of 'disabled enough' to get the help that I need. (2017: 4)

As Roulstone (2015) observes part of the government's justification for cuts to welfare was that too many people were wrongly considered disabled and that disability benefits were too easy to obtain:

> Major changes to welfare benefits, most notably the out-of-work disability benefit Employment and Support Allowance (ESA) and now the extra costs benefit PIP, have been premised on the governmental idea that too many have wrongly entered the 'disability category'. The idea has become pervasive in policy terms that it is too easy to enter and stay in receipt of disability benefits. (2015: 677)

In this journal entry prior to my PIP assessment, I reflected further on the potential for me and other disabled people to be found ineligible or not 'disabled enough':

> I've not slept properly in days. I have a PIP assessment on Friday and I want Friday to be over. So far in the various phone calls I have made to DWP I have been treated poorly. They sent me an assessment appointment for 8:30 am in the morning, which was unsuitable for me or my advocate. I had to ring and rearrange and was told I can only change it once. I'm not even allowed to change it due to illness and if I don't go they stop my money. In no way am I being treated equitably, the promises made in the booklet I received with my initial appointment are already meaningless and I've not even been assessed yet. There is no flexibility in the process what so ever, bearing in mind it is 'sick' and disabled people, some of whom are terminally ill, that are the subject of this process and you have a recipe for disaster … As I've said before in

> this journal being assessed has rarely been beneficial to my life, and on this occasion, I can be left financially destitute if the assessor chooses to find me ineligible. I am even considering composing the appeal letter in advance, that is how pre-determined, how unfair, this assessment process feels. I feel as if I am being called in for assessment so that every response I have provided on the form can be questioned, undermined and torn apart, the result being the removal of vital financial support. (Journal Entry, 2015: 198)

The same concern applies every time I am assessed for ESA. My concern at being found non-disabled in the context of assessment was not without an evidentiary basis. As Scott (2014) argues, approximately half of the cuts (4.87 billion pounds) to disabled people's living standards are being achieved through moving disabled people off incapacity benefit (ESA) and onto Job Seekers' Allowance. 'They are being redefined as nondisabled even though there has been no change to their impairment or condition' (Scott, cited in Cameron, 2014: 157). The net effect of such cuts and the associated narrowing of the 'disability category' is that people with a wide range of impairments and 'verifiable medical conditions' who would by any reasonable standard be considered disabled and/or sick and unfit for work, were assessed, reclassified as non-disabled and found fit for work. As Mendoza (2015) discusses, a number of these people were so ill that they died despite being categorised by the state as fit for work:

> Stories such as 'Linda Wootton, 49, who was on 10 medications a day after a double lung and heart transplant. She was weak and suffered regular bouts of blackouts. She was put through the Atos work capability assessment and, as she lay in a hospital bed dying, she received confirmation she was 'fit to work'' or 'Brian McArdle, 57, had been left paralysed down one side, blind in one eye, unable to speak properly and barely able to eat and dress himself after a stroke on Boxing Day 2011. Despite this, he was deemed fit to work by Atos. He died of a heart attack the day after his benefit payment was stopped' or 'Colin Traynor, 29, suffered from epilepsy. He was deemed fit for work by Atos and forced to enter a lengthy, bureaucratic

> process to appeal the decision-during which his benefits would be frozen. He did not live to see the result of his appeal 5 weeks after his death, the family received the news that his appeal had been successful. (2015: 66)

Assessments for ESA and PIP have been numerously described as 'inhumane' (Saffer *et al.*, 2018) Declaring ill, dying, and dead people 'fit for work' or not 'disabled enough' to qualify for PIP is a clear indication of the malevolent character of these assessments and the policy that underpins them. In the next section I return my focus to how the assessment process treats the living and discuss the assessment process and the hierarchy of impairment.

Assessment, Decrepitification and The Hierarchy of Impairment

The points-based nature of the assessment process, the relationship between inability and eligibility, creates what I consider to be a flawed and superficial hierarchy of impairment (Reeve, 2006a). This places disabled people with a range of impairments in competition with each other (Saffer *et al.*, 2018) to engage in the required 'decrepitification' and to present the most decrepit representation of 'self' possible in the hope of being considered disabled enough to be found eligible for DLA/PIP or ESA. As someone whose primary impairment is physical, tangible, and 'medically verifiable' (actually, I have more than one), if you asked me to stand and walk I cannot, I would fall over. Research indicates that I am near the top of this hierarchy in that I am more likely to be considered eligible for ESA and PIP (Gray, 2014; Pybus *et al.*, 2018). The binary character of the assessment process presents particular challenges for those disabled people with fluctuations in their conditions. Often, limitations in the questions posed mean that the assessment does not contain the level of specificity and flexibility required and claimants find it difficult to be found eligible. This factor, alongside the shame associated with claiming benefits, prevents many people from making a claim (Price *et al.*, 2019).

For a number of reasons, I have been depressed for most of my adult life: I could have made claims for ESA and PIP based on my mental health. However, I felt that I had a better chance of being considered eligible for ESA and PIP if I claimed primarily on the basis of my physical impairment. Mental health problems and psychological impairments are perceived by some to be more subjective and open to easier and greater refutation than is a 'physical medical condition' such as Cerebral Palsy. As others, including disabled people themselves, have asserted, assessment processes for ESA and PIP place at a disadvantage 'people with mental health problems' or psychological impairments: those with such types of problems or impairments are less likely to be considered eligible for ESA or PIP (Messere and Stenger, 2007; Gray, 2014; The Spartacus Network, 2015; Pike, 2018; Pybus *et al.*, 2018). The brute objectification of individuals, and the distinctions and divisions drawn between disabled people in the course of such assessment processes, undoubtedly has broader consequences beyond the ascertainment of eligibility. In the next sections I discuss the psychological impact of assessment, beginning with ineligibility for ESA and PIP and the loss of other entitlements.

The Psychological Impact of Assessment

Ineligibility for ESA and PIP and Loss of Other Entitlements

In the section 'disability', deficiency and 'decrepitification' I commented that the potential loss of income if you are found ineligible and the associated threat of poverty was one aspect that made the assessment process stressful as it is. However, being found ineligible for ESA or PIP does not just mean the loss of vital income. Eligibility for ESA and PIP includes other entitlements. For example, those in receipt of Income-Related ESA do not have to pay for prescriptions. DLA/PIP comes with more entitlements and is known as a 'passport' benefit (Kennedy, 2011; Gray, 2014; Alldridge, 2019). It is nationally accepted as ‘proof of disability’ and as such provides access to a range of other benefits, services and concessions. In my case, my DLA/PIP enables me to obtain concessionary travel on national public transport, *via* a Disabled Person’s Railcard: free travel on local public transport with a travel pass: a blue parking badge which allows me to access available disabled parking spaces, and any car I am a passenger in to park on double yellow lines, and Personal Assistant tickets, so that someone can accompany me to a range of events and provide any help I need. PA’s do not incur a charge. More crucially, being in receipt of the higher rate mobility component of DLA or the enhanced- rate mobility component of PIP entitles claimants to access the Motability scheme. The scheme is run by an independent charity funded by the state and leases cars to disabled people (Henry, 2014; Power, 2016). Some of these cars have bespoke adaptions so that the individual disabled person is able to drive that car: a proportion of their DLA or PIP is taken to lease the car. As had been forecast (*see* Harris, 2014), in the transition from DLA to PIP many disabled people who received the higher rate mobility component of DLA and had leased cars under the scheme were reassessed and found no longer to be entitled to the enhanced mobility component of PIP. According to Wood (2012) a third of recipients are losing their Disability Living Allowance through PIP reassessments. According to Motability 2015:

> 3000 out of 8000 of their customers who have so far been reassessed have lost their eligibility for the scheme and have therefore had to give up their vehicles. (Motability 2015, cited in Power, 2016: 280)

In addition, as of 2017, figures from Motability show that over 50,000 disabled people had their vehicles removed (Vale, 2017). Research by Power (2016) found that disabled people consider the car to be a space of ‘autonomy’, ‘refuge’, and ‘protection from crime’ (Power, 281; 282). For myself, even though I do not drive, having access to a car provides me with freedom of movement, as it does for other disabled people. I do not have a car through Motability: I have a second-hand, privately purchased wheelchair-accessible vehicle. A central reason why I choose not to get a car through the Motability scheme is that the user does not own the car: at a given point someone who has never met you and has no concern over how this impacts your quality of life can decide you are no longer eligible for, then remove, your transport. I understand that for some disabled people Motability is the only way of getting access to a car. However, I did not and do not consider it is wise to give a stranger such a high degree of power and control over your access to a car or whether you can go out or not. If I did not have access to a car, it would be very life-limiting and restrictive. I need to know I can go where I want when I want. I know from experience that not being able to go where I want when I want is not just practically limiting, but is psychologically limiting too: being without a vehicle increases my social isolation, and adversely affects my mental health, and exacerbates my feelings of depression. The removal of vehicles as a result of PIP reassessments has left some disabled people suicidal (BBC News, 2017). Thus, the loss or reduction of ESA and DLA or PIP can have a knock-on effect and make it difficult or impossible to access other forms of support, benefits or concessions. Such measures have an impact on other aspects of a disabled person's life. Being reassessed and found ineligible for the enhanced mobility rate of PIP and having a vehicle taken away has an adverse impact on the mental health and wellbeing of disabled people by removal of their autonomy, freedom of movement and increasing their social isolation. In the next and final section, I discuss the psychological impact of reassessment and simultaneous assessment and how the assessment process forms part of my experience of psycho-emotional disablism (PED).

Reassessment and Simultaneous Assessment

The experience of undergoing one assessment on its own is distressing enough, but for many disabled people assessments are not 'one-off' occurrences. During the just over four-year time span in which I kept my journal I was assessed once for DSA, three times for ESA, once for PIP, once for an NHS wheelchair, and once for Continuing Healthcare. The continual assessment process required adds to the cumulative stress experienced. I remarked in the ‘disability’, deficiency and ‘decrepitification’ section of this chapter that the threat of poverty embedded within the assessment process is only one of the aspects that make it stressful. The levels are enough as a singular occurrence. One reason why reassessment is additionally stressful is because it repeats and continues to offer the threat of poverty. As the claimant, I have little control over the process; based solely on the opinion of a stranger, a large proportion of my income can be taken away overnight. For myself and for others, each reassessment is accompanied by fear and anxiety. It is like being forced to play Russian roulette with your way of life and standard of living because the threat of poverty and other limitations is repeated. In addition, I argued in the section assessment, ‘decrepification’ and the hierarchy of impairment that the assessment process disadvantages those who make a claim on mental health grounds. However, I would also argue that the assessment process itself can adversely impact the mental health of all claimants. I assert that having repeatedly to engage in ‘decrepitification’ as part of the reassessment process and pathologise my own body over and over again, alongside the repeated threat of poverty, forms part of the reason why it is acutely distressing, and detrimentally impacts on my mental health. The requirement repeatedly to reflect on my own bodily deterioration is mentally harmful. It is as if a wound is perpetually reopened:

> I filled in the PIP form yesterday, it hurt me physically and psychologically, repeatedly considering my own predicament in the way required by the form causes me acute distress and is humiliating. I also can’t write for long periods without pain. I voted in the local elections today, being switched to PIP is intimately related to the fact I voted Labour. I have bought myself some new PS4 games as a treat and to help lift my mood (it’s better than eating cake or sitting around compounding my own sense of despair). (Journal Entry, 2015: 196)

Other disabled people have similarly acknowledged the impact of repeated assessment on their mental health and psychological state. For example, Pike (2018) has described the impact of repeated assessments:

> Living in fear of brown envelopes, feeling paranoid and caught in an endless cycle of assessments makes life unbearable and I am in a constant state of fear and high alert. I can never relax and it is no wonder I have become so detached, as my body has shut down and nothing feels real. I feel like I am dead, my life over, and there is no prospect of ever getting better. (2018: 9)

I relate very strongly to this experience, in particular the perception of assessments as an 'endless cycle'. That is exactly what it feels like. I am also in a constant state of fear and high alert because at any time I can be reassessed and found ineligible for ESA or PIP. The impact of the cycle of assessment in respect of ESA is a key finding of disabled people's campaign group The Spartacus Network Report (2015):

> [N]o matter how ill and weak, you have to constantly battle-revolving door process, no security, just WCA, claim ended, appeal, win… WCA… And now we have the mandatory review… (The Spartacus Network, 2015: 17)

The prospect of reassessment is never actually removed, so for me the associated anxiety remains constant. It is difficult to feel any sense of security and I struggle to plan for the future:

> I had a letter to say that I do not have to be assessed for ESA again, having filled in the form, again. The letter also said I will not be reassessed again for ESA unless I report a change in my 'condition' (not bloody likely). This has come as a relief, but I don't know what it actually means

> in practice, or how long I will be left alone for, because they are changing the name of ESA to Universal Credit and reassessing everyone again and making people reapply. I am hoping, at least, for a peaceful winter/Christmas, but you never really know, and this is part of what makes it so distressing. I could get another letter tomorrow telling me I have to apply for Universal Credit and have to do everything all over again, it really does drive you to the point of despair. I didn't start out like this it developed. (Journal Entry, 2015: 206)

I have also experienced for myself what, Pike (2018), refers to as the 'double whammy' of concurrent assessment, in my case the arrival of PIP and ESA forms:

> At the same time I was sent my PIP form I also received the 'double whammy' of the Work Capacity Assessment (WCA). This means two lengthy forms of a similar nature to fill in all at once. This is totally overwhelming and affects your mental and physical wellbeing, creating unimaginable levels of stress and torment. You get four weeks to fill in both - except that the four weeks starts from the date of the letter with the form (which takes over a week to reach you). Plus you have to allow a week to send it back, which gives you a little under two weeks to complete each form. (2018: 9)

I returned home early from a very unsuccessful and particularly stressful trip to France to find a Work Capability Assessment waiting for me and I was still awaiting the outcome of my PIP assessment:

> Just to top it off I got home to find an ESA assessment form waiting for me, I may be forced to go through another assessment and I am still awaiting the results of the PIP one. I am on the verge of breaking, in a psychological sense I can take no more and physically my entire body is aching, I also have a very sore throat. (Journal Entry, 2015: 199)

Moreover, reassessment is particularly distressing for people like me with long-term impairments or 'chronic illness', because these only get worse with time. The issue of reassessing disabled people with 'incurable conditions' was a further central finding of the Spartacus Report (2015):

> The worst thing about ESA/WCAs is the ongoing stress of assessment. I have been diagnosed with a 'long-term chronic health condition' with no cure, and which is made worse by stressful situations yet have to be assessed every year or two and despite filling the form the same way every single time, the response can be totally different (The Spartacus Network 2015: 17; 18).

Despite the fact that I have an 'incurable medical condition' that only gets worse over time, the amount of money I receive has not increased to reflect this. Following my transfer to PIP I retained the same amount of money I was on under DLA; this is actually a cut because the amount awarded has not kept pace with the rate of inflation. As noted above, each reassessment can yield a different response. I have come to resent the repeated questioning and checking whether I am still impaired, particularly as I am living with a 'primary medical condition' for which there is no cure and to which medical negligence was a contributory factor. Disabled people have argued for an end to reassessments for ESA and PIP for those like me with long-term 'incurable conditions' and impairments (Grover, 2017; Atik, 2020). The impact on my mental health can be clearly seen in the following extract:

> My worries are being heightened because of being forced to transfer to PIP. I had an anxiety attack last night and woke up in a cold sweat. The frequency and speed with which people completely ignore my wishes, preferences, desires and rights is a continual and unabating source of terror to me … Being forced to fill in the PIP form, and having my right to the same amount of money I've been considered eligible for for more than 20 years questioned has once again made me painfully conscious of the extent of my own unhappiness. The last two days

> have been horrible, I had a nightmare last night and I'm not sleeping very well. My anxiety levels are high. I'm posting the PIP form tomorrow. I'm going to send it signed for because I don't want it to go missing and have vital money stopped, and believe me they would, they have done this before now for a lot less and because of organisational incompetence. (Journal Entry, 2015: 195- 196)

I am not alone in asserting that the assessment process for ESA and PIP has a detrimental impact on my mental health as it does on the mental health of other disabled claimants. Burgess (2014) conducted research with disabled people who had undergone ESA assessments. One of his central findings is that: 'The WCA is abusive. It causes harm and damages health, especially mental health' (2014: 4). Respondents from the second independent PIP review by Gray (2017) also asserted that the PIP assessment has a detrimental impact on health generally, and on mental health specifically:

> Had to wait 12 months for an appeal date. The affect the whole process had on my mental health was a dramatic worsening of it. It is a horrible system to navigate when you are so weak mentally. (2017: 25)

> Very stressful and impacts adversely on existing health conditions, this is especially a problem for people who suffer mental health conditions who are more at risk/vulnerable to stress factors. (Health Care Professional, 2017: 30).

Research by Machin *et al*. (2018) concurs with the view of the healthcare professional in the above extract in finding that the PIP assessment process 'led to increased anxiety and uncertainty' in those like myself with existing mental health problems such as depression. Repeated assessments and reassessment exacerbate my feelings of depression. In addition, as acknowledged by Reeve, benefit assessments also form part of my and other disabled people's experience of psycho-emotional disablism (PED) (Reeve, 2006a). This is because, to paraphrase Thomas's (1999) definition of disability, and as the experience featured in this chapter serves to illustrate, the assessment process represents a particular type of 'unequal relationship between people' that 'undermines my psycho-emotional well-being' (Thomas, 1999: 40; 60). My experience of psycho-emotional disablism (PED) is the focus of the next chapter. I apply Garfinkel's concept of degradation ceremonies to show how assessment processes for ESA and PIP function as degradation ceremonies.

Chapter Six

The Psycho-emotional Disabled Self

Introduction

This chapter looks at disabled people's experiences of psycho-emotional disablism, using my lived experience as a catalyst for discussion and exploration. It is important to note that the experience of psycho-emotional disablism existed before the most recent political imposition of austerity in the UK, thus I wish to acknowledge that some of my examples predate the defined time period. Unarguably however, the imposition of austerity, ongoing since 2010, has exacerbated and intensified the experience of psycho-emotional disablism for disabled people, to which I have made reference at relevant points throughout the chapter. I begin by looking at the psycho-emotional effects of structural or indirect disablism. This is followed by a section that defines the key concepts, principles, and terms of successful degradation ceremonies, as developed by Garfinkel (1956). Using Goffman's work on the subject of stigma for a deeper understanding, I apply Garfinkel's work to the stigmatised identity of disability and then to the specific context of disability assessments. Following this I feature the section the psycho-emotional consequences of negotiating disability visibility, in which I use Leder's concept of the 'dys-appearing' body to explore some of the different implications of having a visible or invisible impairment and occupying public spaces. I conclude the chapter by looking at one of the more extreme examples of direct psycho-emotional disablism with the section disability hate crime violence and hostility.

Structural or Indirect Psycho-emotional Disablism

The idea of structural or indirect psycho-emotional disablism highlights the psychological and emotional impact of situations that disabled people regularly encounter, such as being faced with an inaccessible building or being denied information in accessible formats (Reeve cited in Cameron 2014). This type of disablism can also occur when reasonable adjustments designed to comply with ‘disability’ discrimination legislation are ‘undignified or humiliating to use’ (Reeve, cited in Cameron, 2014: 124). An example is a disabled person’s being forced to access a building through a back entrance (Reeve, cited in Cameron, 2014). Similarly, wheelchair spaces on trains are often sited exactly next to the toilets, and we have to endure the steady stream of passengers barging past us to use them - not to mention the noise of the flush and the smells of others’ excrement and urine. My accessibility chapter, chapter four features many examples of structural disablism: the current section focuses predominantly on how these experiences can translate emotionally for disabled people and analyses their psychological impact. In her chapter ‘Towards a psychology of disability: The emotional effects of living in a disabling society’. Reeve (2006) features the experiences of Robert, a wheelchair user, who, as he cannot open doors, describes what happens when he goes shopping:

> A lot of people see you want to go in, and they just walk past you. Or you ask them to hold the door and they just go straight on into the premises. You know, you just [pauses] how can I put? it? Just feel like you’re not wanted. They just look, everybody just looks down [their] nose at you. (Reeve, 2006: 97)

Given that I am a wheelchair user, I have had many experiences similar to Robert’s when shopping. I commonly find myself having to be served in the street, as in the example below, because a shop I would like to enter has a step or steps and is therefore inaccessible to me:

> I went to buy a Blu Ray after work and couldn’t get in the shop, we had to do the transaction in the street, lots of people saw my dilemma and very few said anything. I mentioned to the assistant about getting a ramp. He was understanding but I’m not sure anything will get done, another day in paradise. (Journal Entry, 2015: 4)

Robert talked about the emotional and psychological impact of these situations:

> You say, oh sorry for doing this, or, sorry for doing that. By the time you get home you think, why should I say sorry? But it upsets you that much-what do you do? You come home, you pop your pills, whatever you got to take, and then you go and have a lie down for an hour and it's still there, you know. (Reeve, 2006: 97)

I relate strongly to the description Robert provides. There is a psycho-emotional complexity in appreciating and wanting to appear grateful for the help strangers offer, yet also a feeling of anger and frustration at being placed in the position of having to ask for help because of society's failure to provide access. Robert recognised that a degree of performance is required in order to obtain the help he needs as a result of the shops inaccessibility:

> You've always got to put that false smile on, say, oh thank you very much. Can you please pass me that? Can you do this please? Can you do that? Oh excuse me, can you move out of the way? (Reeve, 2006: 98)

It is evident from the above that Robert feels he has to perform the role of grateful disabled person needing assistance to overcome the physical barriers both to and within the shop (a structural dimension of disability) and to deal with the reactions of others who appear to look down on him or ignore him (a psycho-emotional dimension of disability). This is a role I have been placed in often and shows some of the psycho-emotional effects of structural barriers. These exacerbate the experience of disablism because the inaccessible shop forces disabled people to ask for help, placing us in a psychologically and emotionally vulnerable position. It risks people's refusing or ignoring our requests for help, which can leave disabled people feeling unwanted or worthless (Reeve, 2006). In addition, his being a disabled male may make it more difficult for Robert to request help from strangers than it would be for me, a disabled woman, because of cultural representations of masculinity (strength and independence) versus disability (weakness and dependence) (Robertson, 2004). This is one way in which the psycho-emotional dimensions of disability can be intersected by gender (Reeve, 2006). The notion of performance in everyday life is also broadly shared in the experience of particular social processes and circumstances, such as the rituals and symbolism recurrent in the degradation ceremonies referred to elsewhere (see associated sections for further exploration). It is also important to note that situations such as the above can occur multiple times in the course of a day; therefore there is a cumulative impact, itself exhausting because of the repetition of emotional and psychological vulnerability. Moreover, it often requires the suppression of anger at experiencing so much structural disablism in lacking having the same freedom to shop as non-disabled people.

These kinds of experiences influence my day-to-day decisions about my life. For example, sometimes I do not have the energy or psychological resolve to manage these situations. One outcome is that I decide to stay indoors when I could in fact go outside. This is sometimes necessary for self-preservation, an act of recuperation and rest because of the amount of structural disablism and its psychological impact upon me. Therefore, the experience of structural disablism contributes to disabled people’s exclusion both practically, in respect of physical barriers, and psycho-emotionally. A considerable amount of energy is required to anticipate how I can deal with any physical barriers in order for me to manage situations like those described above. The psychological impact of structural disablism can be just as exclusionary as the physical barrier and equally as difficult mentally to overcome. The knowledge that I will encounter structural disablism and its cumulative impact can be just as disabling as any physical barrier that I may encounter and can lead to self-exclusion. Sometimes I do not want to go out, because I know there is a strong chance I will encounter some form of structural disablism: one way or another, I will have to contend with or account for it. I do not always have the emotional or psychological energy to do this.

A further example of how structural disablism contributes to experiences of psycho-emotional disablism is in relation to public transport. Many examples of this, specifically in relation to trains, were given in chapter four. I have so frequently been left on or denied access to many trains that using them now causes me a high degree of anxiety, frustration, and distress. The apathetic response I receive from some staff members sends me the message that I do not matter. Consequently, the repetition of incidents of this type has a detrimental impact on my self-confidence and sense of self-worth. These experiences mean that I now use trains only when I have no alternative. If I have this kind of psychological response, it seems likely that other disabled people will, too. My experiences of train travel are shared with other disabled people and, as this example from a fellow wheelchair user helps to illustrate, so is my psycho-emotional response:

> Ever wondered what it feels like to be trapped on a train, unable to get off? Here is a video from my point of view, as it happened to me *again* just now … It makes me feel that my time as a disabled person is less valued and less important than everyone else's … Having my independence taken from me – having to rely on staff assistance and having that assistance fail – is demoralising and makes me feel powerless and small. (Law and Scully, 2020, unpaged)

My broader concerns based on the experiences featured in this section are that environments which feature structural disablism will continue to be created and recreated. There exists thus the potential for the kind of psycho-emotional disablism described here to be repeated for other disabled people.

Degradation Ceremonies, Key Concepts, Terms and Principles

In 1956, in his paper ‘Conditions of Successful Degradation Ceremonies’, Garfinkel developed the concept of Status Degradation Ceremonies, defined as: ‘Any communicative work between persons, whereby the public identity of an actor is transformed into something looked on as lower in the local scheme of social types' (1956: 420). Garfinkel offers a court trial as an obvious example of the degradation ceremony or a context where the person's status may be lowered. Based on his description, though, I would suggest that a person's status can be lowered in a wide range of public settings and contexts and in a varied number of ways. Given that successful degradation ceremonies involve the reduction or implied inferiority of a person's public identity, these social processes require a stigma to be created in respect of a person's selfhood or particular perceived identity characteristic or behaviour. For the degradation to be successful, the resultant public identity or associated characteristic must be socially perceived as undesirable by others. In Erving Goffman's 1963 work *Stigma, Notes on the Management of Spoiled Identity*, he defines the term in relation to damaged identity, and his work provides a practical basis for greater understanding of the concept:

> The Greeks, who were apparently strong on visual aids, originated the term stigma to refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier. Signs were cut or burnt into the body and advertised that the bearer was a slave, a criminal or a traitor - a blemished person, ritually polluted, to be avoided, especially in public places … Today the term is widely used in something like the original literal sense, but is applied more to the disgrace itself than to the bodily evidence of it. (Goffman, 1990: 11)

In relation to this Goffman discussed aspects of social identity suggesting that society establishes means of categorising people and a set of attributes felt to be ordinary and natural for members of each category. He also affirmed that social settings help to establish who should be seen in them (Goffman, 1990). Usefully, Goffman distinguished between a person's actual identity on the one hand who they are and who they perceive themselves to be, and on the other their virtual identity, which is who others perceive or judge them to be based on how they represent themselves or what can be observed about them and interpreted from their bodily appearance:

> [W]hile the stranger is present before us, evidence can arise of his possessing an attribute that makes him different from others in the category of persons available for him to be, and other less desirable kind-in the extreme, a person who is quite thoroughly bad, or dangerous, or weak. He is thus reduced in our minds from a whole and unusual person to a tainted, discounted one. Such an attribute is a stigma, especially when its discrediting effect is very extensive; sometimes it is also called a feeling, a shortcoming handicap. It constitutes a special discrepancy between virtual and actual identity. (Goffman 1990:12-13)

Goffman conceptualised ‘disability’ as one example of the stigma to which he referred. His work is replete with examples from the experience of ‘disabled’ people who, in the language of the time, he referred to as ‘cripples’, ‘disabled’, or ‘handicapped’. In Goffman’s terms, I am the possessor of a stigma, an undesirable difference. In public settings ‘disability’, as an observable perceivable aspect of my identity, serves to stand for the entirety of my identity; it is a primary aspect of my virtual identity, comprised of other people’s perceptions of me, how others represent me in public, and how I represent myself in public. Furthermore, ‘disability’ as a perceivable identity characteristic is a means by which I am commonly socially objectified. The term ‘objectification’ refers to being treated as an object (OED Online, 2021). ‘Disability’ as a public identity is the categorisation through which I am most commonly publicly degraded and my status is lowered. In common with ‘disability’ as a public identity, Garfinkel argued that successful degradation ceremonies make ‘other’ the denounced person and turn them into a ‘social object’ (Garfinkel, 1956: 420). Goffman noted that the experience of stigma is context specific:

> The term stigma, then, will be used to refer to an attribute that is deeply discrediting, but it should be seen that a language of relationships, not attributes, is really needed. An attribute

> that stigmatises one type of possessor can confirm the unusualness of another, and therefore is neither creditable nor discreditable as a thing in itself. (Goffman, 1990: 13)

Whilst being impaired is a practical disadvantage, there is nothing inherently wrong in itself with being publicly identified as disabled. The attributes and characteristic others ascribe to you based on their perceptions, attitudes and understandings of disability can, however, make the practical disadvantages of impairment more difficult in a range of public situations and contexts. In my case it has played a part in my complete exclusion from many public spaces such as shops, nightclubs, and cafes and a highly conditional, partial inclusion in others such as education. It has severely reduced my career opportunities. Alongside Goffman's theorisation of virtual and real identities, the context-specific nature of stigma implies a kind of performance of public identity. Some of my own experience bears this out because there are situations when my own sense of stigma reduces or becomes irrelevant. Examples of more comfortable spells include when I am with other disabled people, with friends who know me well or when I am alone.

As does stigma, Garfinkel theorised that successful degradation ceremonies involved a degree of performance in referring to the degraded, those who had their status lowered or were the intended target of such ceremonies as 'actors' (1956: 420). Goffman further distinguished between stigmatised people whose identity was discredited and those who, he said, by virtue of their stigma were discreditable. Given that disability is an identified type of stigma, and remembering Goffman's concept of virtual identity, I am someone who is straightforwardly and publicly perceived by others as 'disabled'. In Goffman's terms I am in the discredited category because my impairment is immediately visible. The category of discreditable by virtue of their stigma applies to those for whom the source of their stigma cannot be immediately observed or is hidden or concealable. In his work Goffman frequently refers to former mental patients as an exemplification of one identity that qualifies as discreditable (Goffman, 1990).

Next, I shall discuss and explain the remaining key principles of degradation ceremonies in relation to 'disability' as a stigmatised public identity. Throughout his explanation of the concept, Garfinkel refers as the 'denouncer' to the person(s) who lower the status of the person(s) subjected to the ceremony therefore, it is necessary for me to explain how I understand the term. In this context, I understand the term denouncer or to denounce to mean to degrade, discredit, undermine or reduce the social status of an individual. Garfinkel states that moral indignation is a necessary condition of status degradation ceremonies (1956). I interpret moral indignation, in Garfinkel's context, to mean a sense of injustice or unfairness. This is one method of denouncement, an example of which in relation to the stigmatised identity of 'disability' is when people assume that on the basis of that identity, I get access to a range of resources to which they do not, or when policies put in place in an attempt to provide a degree of equity are referred to as 'special' or 'preferential' treatment. Such definitions completely lack an understanding of the fact that I face disadvantage in the first place. I have never fully understood the hostility and aversion that seems to me to be intimately related to the public identity of 'disability'. Garfinkel further theorises that any denouncer must be considered as acting in a public, official capacity, and with the consent or assumed consent of the public, and be perceived as upholding shared and commonly understood values:

> The denouncer must so identify himself [*sic*] to the witnesses that during the denunciation they regard him not as a private but as a publicly known person. He must not portray himself as acting according to his personal, unique experiences. He must rather be regarded as acting in his capacity as a public figure, drawing upon communally entertained and verified experience. The denouncer must make the dignity of the … supra-personal values of the tribe salient and accessible to view, and his denunciation must be delivered in their name. The denouncer must arrange to be invested with the right to speak in the name of these ultimate values … The denouncer must get himself so defined by the witnesses that they locate him as a supporter of these values. (1956: 423)

Throughout my life I have been denounced by a range of people acting in a number of official capacities on the basis of ‘disability’ as a stigmatised public identity. This includes but is not limited to, teachers, lecturers, nurses, taxi drivers, shop assistants, and strangers on the street. Those who have denounced or attempted to denounce me often act as if they are protecting an often undefined, transient public interest. Commonly, other people have been present during these events and have not always intervened. it is also not uncommon for others present to join in with the process of denouncing me. Garfinkel also proposed that for a degradation ceremony to be successful the denouncer(s) must distance themselves from the denounced, position them as an outsider and represent them as strange. He comments:

> Not only must the denouncer fix his distance from the person being denounced, but the witnesses must be made to experience their distance from him [*sic*] also … The denounced person must be ritually separated from a place in the legitimate order, i.e., he must be defined as standing at a place opposed to it. He must be placed "outside," he must be made "strange". (1956: 423)

Based on ‘disability’ as a stigmatised public identity, people acting in a number of public roles have distanced themselves from me often by the nature of their roles, or how they have interpreted their roles or attitudes to ‘disability’ that they have either projected on to me or directly verbally expressed to me. The understanding that I am, in social terms, an outsider as described in the stigmatised public identity of ‘disability’, is by now well established in my mind due in part to the ‘chronic’, long-term nature of my impairment, the fact I have been disabled since birth. As referenced in the Introduction to this thesis, I began my education in a segregated school, and I have been wholly excluded from a range of social settings on the basis of ‘disability’ as stigmatised public identity. In addition, my exclusion on the basis of that Identity and my understanding that I am an outsider are contemporaneous and on-going. The knowledge and feeling that I am an outsider according to the stigmatised public identity of ‘disability’, will probably never leave me, whatever I do with my life. I will never feel socially accepted. To varying degrees, I shall always feel that I am on the outside looking in. Repeated and long-term experience of degradation given the stigmatised public identity has provided me with a strong understanding that in social terms I am anomalous and I am strange. The stigmatised public identity of ‘disability’ is a contributory factor to the inequality I experience and is why I feel my citizenship is excessively conditional and partial. Goffman referred to those whose social identity was stigma free as ‘the normals’:

> The attitude we normals have towards a person with a stigma, and the actions we take in regard to him, are well known, since these responses are what benevolent social action is designed to soften and ameliorate. By definition, of course, we believe the 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. We construct a stigma theory, and ideology to explain his inferiority and account for the danger he represents, sometimes rationalising an animosity based on other differences, such as those of social class. (Goffman, 1990:15-16)

Despite the passage of time, I feel that Goffman’s comments in relation to the impact of stigma are still broadly accurate, in that stigma, in terms of the public identity of ‘disability’, does play a part in reducing my life chances. I recognise that unfair treatment on the grounds of stigma can be difficult to prove, but I strongly believe stigma has played a part in my exclusion from public spaces, denial of and prolonged wait for medical treatment, and unequal access to education and employment. Stigma, as defined in this section, is a tangible aspect of my lived experience.

Having discussed degradation ceremonies in respect of disability and defined key terms and principles, I next propose that disability assessments are a contemporary example of a successful degradation ceremony as conceptualised by Garfinkel.

Disability Assessments as Degradation Ceremonies: The Psycho-emotional Effects

I see the disability assessment process as a contemporary example of a status degradation ceremony because my social status is lowered within and by the assessment process. Garfinkel's definition identifies the basic inequality of degradation ceremonies. The assessment process provides a basis for the experience of psycho-emotional disablism because, as was discussed in chapter three, methodology, in social model terms disability is a social relationship between people. It refers directly to restrictions of activity on impaired people and, in doing so, highlights an unequal social relationship between impaired and non-impaired people. In social model terms disability refers to 'the relationship of ascendancy of the non-impaired over the impaired … Disability is a form of social oppression' (Thomas, 1999:40). I see the disability assessment processes as an example of this. I do not consider applying for disability benefit to be a choice I make freely. It is a decision into which I feel forced by my existing socio-economic position, the knowledge that I am poor. Without the financial support benefits provide I would have almost no stable income. Psycho-emotionally, my distress and anger are compounded by the fact I have no choice but to engage in the process. The previous section of this chapter discussed how being made to feel distance, strangeness and like an outsider was a key principle of degradation ceremonies in relation to 'disability' identity. These characteristics are also induced throughout the assessment process. One way in which they are created between me, a claimant, and the DWP is demonstrated in the letters sent out to claimants: these are official, formal, and often threatening in tone. Many articulate in written form the threat of poverty that is inherent in the assessment process; they clearly set out the circumstances in which support can be removed and the conditions upon which that support is premised. As discussed in the previous chapter, chapter five, the complexity and conditional nature of state support is made abundantly clear to any claimant. I received such an example as part of the transfer from Disability Living Allowance to Personal Independence Payment:

> This morning I received a letter saying my DLA will stop on 14th May and advising me how to claim PIP. This news has spoiled my Saturday. It means another deficit-based form and the possibility of being called in for a medical assessment, all of which could result in me being found ineligible and being left with very little to live on. (Journal Entry, 2015: 194)

It is not usual for a human to be threatened in this way and live under the pressure of being subjected to very many conditions during the course of their daily life. Arguably, being addressed in such a way is itself a mark of strangeness and can induce similar feelings in any claimant. This is also one way in which the DWP distances itself from society and induces a sense of strangeness and outsider status in claimants, because many people claim benefits and anyone who does is likely to receive one of these letters. The fact that a large number of people receive such letters does not make them any less strange, or reduce the potential for some people to feel like an outsider or distanced from the DWP as an organisation. There are few other contexts in which it would be acceptable to threaten people in such a manner as the tone and language of DWP's organisational communications. The social impact of this communication is increased because other people, relatives and family members of claimants are made more aware of the organisational and governmental response to those who claim benefits *via* such letters. It is not just the letters sent to claimants that induce the feelings of distance, outsider status, and strangeness. The requirement within the assessment process to make private information public, information that would normally be kept private becomes a matter of public record and subject to public scrutiny. The necessity of 'decrepitification', as outlined in the previous chapter, while those administering the process retain their anonymity and privacy, and the threat of poverty, combine to have the effect of placing me at a distance, making me feel strange and positioning me as an outsider.

In the previous section of this chapter, I acknowledged that Garfinkel's conception of successful degradation ceremonies turns those involved into a 'social object' (Garfinkel, 1956: 420). I would argue that in common with the stigmatised identity of 'disability', the assessment process does 'other' me and turn me into a social object. Being a person in receipt of welfare makes me a member of a social category that some people judge, speak ill of, or seek to avoid. Being in receipt of state benefits is an additional layer of stigma that diminishes a claimant's social status. Remembering Goffman's concept of discredited and discreditable outlined in the previous section, alongside the stigmatised public identity of 'disability' which discredits me, the fact of my being in receipt of state benefits also makes me socially and publicly discreditable, due to the associated stigma. Furthermore, for any status degradation ceremony to be successful both the individual, in this case, the benefit claimant or person being assessed, and society as a whole must be aware that being a member of a particular social category has negative associations or can be a source of shame. Research by Garthwaite (2014) illustrates that the stigma associated with claiming benefits functions to deter others from claiming support they may need or may be entitled to 'leading to under-claiming and amplified financial strain and hardship' (2014: 782). The idea that being in receipt of state support is stigmatising is proliferated socially through statements made by politicians, word-of-mouth, and newspaper and media coverage of benefit claimants. As Jensen and Tyler (2015) have documented, since 2010 the British elites (including politicians, journalists, and television producers) have engaged in an intensive programme of welfare stigma production, reanimating longer histories and figures of the undeserving poor, for them to justify austerity. This is one way in which shame may be induced in those who claim state support or apply for state assistance, resonating with Garfinkel's exposition of moral indignation as a necessary condition of status degradation ceremonies (1956). I interpret moral indignation in Garfinkel's terms, to mean a sense of injustice or unfairness, typically associated with a sense of opprobrium directed at the perceived transgressors of the accepted social order. This can make for some complex, and often contradictory, positioning of public views of just and fair entitlements, perhaps never more so than in relation to the perceived fairness of state welfare regimes.

One result of moral indignation can be seen in the lack of public sympathy for those who claim and need state support, which can be influenced by inflammatory headlines that represent some claimants as cheating the system or living a lavish lifestyle (Harrison, 2015; Chapman, 2016). This can produce an understandable public anger and increase hostility towards those receiving state support. It may also leave the perception that the system is unjust or unfair to those who are in paid employment or do not claim benefits. Politically, such representations provide a context for welfare reform and the reduction of state support. Furthermore, the need for state benefits is thought of, and represented by some, as an individual moral failure and this is commonly encapsulated in the term 'welfare dependency' where often little or no acknowledgement is made of the difficulties disabled people face in seeking employment and the conditions they face when employed (Grover and Piggott, 2010; Tyler and Slater, 2018). In the light of such perceptions, the potential for the perceived reduction in the status of benefits claimants is obvious. As a benefits claimant, the existence and proliferation of such perceptions can induce anger, distress, and fear. I feel angry because such perceptions do not reflect the reality of living a life on benefits. I find it distressing to know that some people are most willing to think this of myself and others. I avoid talking openly about the assessment process, and what it's like to live on state support, because I am fearful of psychological or physical abuse.

In the previous section I have outlined another necessary component of degradation ceremonies in relation to the stigmatised identity of 'disability' and as identified by Garfinkel. The assumption is that the denouncer must be seen as acting on behalf of the public, in a public capacity, invested with public consent in that role, and must be seen to uphold and represent universal values. The assessor is a public figure who acts on behalf of the government, the Department of Work and Pensions, and society at large. The values represented by the assessor at the time of the assessment serve to stand for what is reasonable, civilised, and decent in terms of social expectations. The assessor is given power to act on behalf of the aforementioned groups by virtue of the functions of a democratic society. Symbolically, assessors are perceived to be acting in the public interest and protecting the interests of taxpayers and ordinary citizens. The assessor is also perceived to be a supporter of the decent values they are there to uphold. Acting on behalf of the government, assessors are required to determine entitlement to benefits, in making this determination they are also required to implement the central publicly stated aim of austerity and make cuts and savings (Scott, cited in Cameron, 2014). In the context of assessment of each individual, this has meant that existing claimants have had vital money removed from them and new claimants have been denied money they need. Garfinkel argues that performance is a further principle of successful degradation ceremonies (1956). In defining the concept of status degradation ceremonies, he refers to those degraded as ‘actors’ (1956: 420). The threat of poverty that is for many an inherent aspect of the assessment process ensures that I am compliant, play along, and engage with the assessment process. As one claimant in a study by Garthwaite (2014) commented:

> They send a letter to say I’ve passed or I haven’t passed, if it’s passed then all well and good but if its failed . . . they don’t realize how stressful it is, just waiting and waiting for a sword of Damocles hanging over you. They don’t realize how it eats away at you and how people worry . . . they don’t give a shit as far as I’m concerned. (Garthwaite, 2014: 788)

Psycho-emotionally the threat of poverty induces feelings of intense anger at being put in this position in the first place, arguably, my status is lowered by having to appeal to a stranger for money alone. I also feel anxiety, fear and distress because I can be left destitute if I fail the assessment. As public figures, working in and for the name of society, the government and DWP assessors are afforded organisational protection from the impact and consequences of their decisions. They are not held personally accountable for their actions. As public figures, they are removed from the adverse impact of their decisions. Issuing a threat of poverty places them in a position of power, whether they perceive themselves to be or not. Psycho-emotionally this also makes me feel angry because my assessor, acting in a legitimate capacity, could have removed my support without facing any personal consequences. Furthermore, psycho-emotionally the knowledge that assessors can indeed do this makes me fearful, making the unequal nature of the relationship - which the assessment process is - obvious to all involved. My psycho-emotional response is heightened by the knowledge that other people are having similar or worse experiences to mine and have had support removed or denied (*see* Mills, 2018). It is distressing to be aware of the consequences of the decisions for some disabled people. As Pike (2018) asserts:

> Many people are dying each year, directly related to benefit cuts and sanctions. Most of these cases are not picked up on or reported in the media. Coroners courts do not rule that [these] deaths were a direct result of these welfare reforms, even when there is a clear-cut case where someone has been pushed over the edge as the result of an adverse welfare benefits decision. The DWP say there are 'complex reasons' why someone would end their life. Just like there are 'complex reasons' people 'choose' to use foodbanks. (2018: 8)

In addition, the fear of poverty these situations induce does not diminish because the financial support produced by even a 'successful' outcome is conditional; the prospect of reassessment is continual. Even though my 'condition' is 'chronic', 'incurable', and will most likely get worse as I age, I am not exempt from these degradation ceremonies. As Pike 2018 commented:

> People who had been granted a life-time Disability Living Allowance and provided thorough and detailed medical evidence are now having to be completely re-assessed. This entails jumping through hoops of fire to re-prove what you had already proved before. (Pike, 2018: 8)

The situation forces me to confront the deteriorating state of my health, and rubbing it in my face serves to increase the emotional distress I experience. My entitlement to benefits has been questioned more times under austerity than at any other time in my life. At every stage of the assessment process, including within in the literature that accompanies the forms people receive, promises are made about fairness and fair treatment of claimants. I struggle to see how a process that a goal has of making cuts and savings at its centre can ever be fair; my experience leads me to the conclusion that such promises are not substantively meant (Scott, cited in Cameron, 2014).

I consider the process of 'decrepitification' required as part of the assessment process for a claimant to have a chance of success to be an example of performance as identified by Garfinkel. I consider it a performance because there are few other contexts, (the only other one I can think of is charity), in which I would be required consciously to represent myself as so useless and deficient to obtain or retain financial support. Charities sometimes represent disabled people as useless, desperate, and pitiable figures; emphasising our poverty and vulnerability as opposed to representing us as humans with rights, strengths, and talents (Thompson, 2013). Such images play a part in sustaining those charities that use them and are designed to appeal to a non-disabled audience. I feel angered by the way I am compelled to represent myself for the purpose of assessment. My status is lowered, it is degrading, and it makes me feel inferior. My anger is intensified by the knowledge that the decrepit representation I am compelled to provide functions to reinforce and support socio-cultural perceptions of benefit claimants as 'useless', 'burdensome' or a 'drain' on society. These views are shown alongside wider representations of disabled people as inferior, other, and worthy of pity rather than solidarity. Furthermore, such perceptions function to justify a general socio-political response to that same group. I feel mistrust, suspicion and anger towards a government and a society that treats me in the ways described, the many who regard the assessment process in its current form as legitimate and neither speak against nor object to it.

As referred to in the section where I defined the key concepts and principles of degradation ceremonies, Garfinkel uses a courtroom as an example of a setting for a status degradation ceremony. Ironically, the assessment process can feel like a trial because, as part of the decision-making process, assessors must judge the validity of disabled people's claims and there is an interrogatory aspect to the proceedings. The pressure to make cuts and savings under austerity can leave claimants feeling as if they are criminals, accused, disbelieved, and regarded with suspicion (Burgess *et al.*, 2014). In addition, the 'decrepitification' required can place you in the position of reinforcing the perception that you are faking or overstating your 'disability' while in the act of trying to retain or access the support you need. In the current system there appears to be an inherent assumption of dishonesty on the part of claimants embedded within the assessment process. Additionally, the conditional nature of benefit entitlement means that the feeling of being scrutinised or surveilled is ever present. The experience of Pike is a clear illustration of how the process makes the applicant feel: 'I became very paranoid and felt the DWP were watching me at all times (which is what they want you to think.) I felt I could trust no one. Thoughts spiralled out of control in my head' (2018: 8). I still retain such feelings long after being assessed. Reassessment replicates and compounds these feelings, repeatedly bringing them to the surface.

In looking for work on Garfinkel's concept of degradation ceremonies I did Internet searches using the terms 'degradation ceremonies', 'Garfinkel', 'disability assessments as degradation ceremonies', and 'welfare assessments as degradation ceremonies'. The most relevant example I found was a paper by Harry Murray (2000), 'Deniable Degradation: The finger imaging of welfare recipients'. Murray asked homeless respondents at a soup kitchen in Munroe County, USA how they felt about having to undergo fingerprint imaging (the taking of a digital fingerprint, justified on the basis of reducing welfare fraud) as a condition of receiving welfare payments. In his research, Murray references Garfinkel's concept of degradation ceremonies and proposes deniable degradation as a counterpoint to Garfinkel's conceptualisation. He argues that fingerprint imaging in the context of welfare provision is an example of deniable degradation, which, he says ‘involves the use of procedures that can be legitimated in instrumental terms, but that also evoke cultural symbols of humiliation and degradation’ (Murray, 2000: 30). Such procedures may function to degrade, which may indeed be the intention, but the fact they are degrading to some can easily be publicly denied by those who implement them. Although Murray’s work is relevant to my own, in that we both draw on Garfinkel’s concept and both our works share the context of welfare, unlike Murray, I am not arguing that the assessment process is an example of deniable degradation. In applying Garfinkel’s concept, I am arguing that the assessment process is an example of a successful degradation ceremony. Having said that, Murray’s concept of deniable degradation could also usefully be practically applied to the assessment process as I and other disabled people experience it. This is because much of what happens to claimants as part of the assessment process is degrading but can be easily publicly justified. Furthermore, both Murray’s work and my own illustrate that Garfinkel’s concept can be even more widely applied.

In this section, I have argued that benefit assessments under austerity are a contemporary form of status degradation ceremony as conceptualised by Garfinkel (1956). I applied Garfinkel’s concept to the assessment process and used it to explore, describe and explain the psycho-emotional disablism I and others experience as a result of the assessment process.

The Psycho-emotional Consequences of Negotiating Disability Visibility

This section focuses upon the seen and the un-seen, what can be observed by looking and what cannot and on objectification. It centres upon the often unwanted and unhelpful perceptions and attitudes that people express then looks at some of the different public implications of these for people with either visible and/or invisible impairments. I understand ‘objectification’ to mean being treated as an object (OED Online, 2021). In this context, I relate it to unwanted staring or observations that can be dehumanising. In her chapter entitled ‘Psycho-emotional disablism: the missing link?’ Reeve (2012) uses Leder’s theorisation of the ‘dys-appearing’ body (Leder, 1990), to illustrate some of the complexities that arise from having an invisible impairment. For Reeve, it is Leder’s discussion of social dys-appearance, and intercorporeal interactions, which I understand to be interactions between the body and the social world, that are of most interest here. She states that: ’Acknowledgement is made of the ways that dys-appearance is linked to aesthetic judgements which in turn are located in particular times and places’ (2012: 83). In Leder’s conception, bodily awareness is absent for the majority of the time for non-disabled people, but at times of dys-appearance, whether due to illness or as a result of a changing body during puberty, the body returns to the foreground of awareness at the same time as being experienced as away or apart from the self (1990: 82). Furthermore:

> Bodily awareness is absent most of the time (it disappears) and it is only when one experiences pain or stumbles, for example, that the body is suddenly brought to the foreground. The dys part comes from the Greek for ‘bad’, ‘hard’ or ‘ill’ as in ‘dysfunctional’, in Latin dys can mean instead to pull ‘away, apart, asunder.’ (Leder, 1990: 87)

I understand Leder’s concept of dys-appearance to mean making dysfunction both obvious, apparent and observable. Applying this concept in my experience, as someone whose impairment is visible and observable. I am repeatedly made aware of my body and how others perceive it. My physical dysfunction is always apparent or observable. This is psychologically challenging and contributes to my experience of psycho-emotional disablism. The vast majority of these encounters are detrimental to my sense of self in that I am repeatedly reminded that I am a wheelchair user; ‘disabled’, and in social terms this is predominantly thought of as a negative characteristic with multiple negative associations and meanings. Strangers consciously or unconsciously often take the opportunity to remind me of the various negative ways in which they perceive ‘disability’ and, by extension, ‘disabled people'. The following examples from my Journal illustrate what is important here is not the intention of the looker, but how such encounters leave me feeling:

> I was gawped at yesterday, for longer than is socially acceptable. I wanted to inquire as to why he was gawping, but I was already feeling emotionally raw. So in an act of self-preservation, I turned my face away, he just stood there, silently, close to the car, looking, as if he'd paid general admission and was entitled to. I had to drive past him to go into the gym, he was still looking as I did so. There could of course have been a legitimate explanation for his excessive looking, perhaps training for an upcoming staring contest? A relative or friend in need of accessible transportation? Who knows? In that moment, I am a butterfly preserved in wax. (Journal Entry, 2015: 72)

> Held open a lift door today for a lady on a walking frame, she taps me on the shoulder more than once and offers, "I'm glad I'm not in one of those", gesturing towards my chair, and eventually naming it. (Journal Entry, 2015: 93).

My body is not afforded the opportunity to disappear. To use Leder's concept, I wish my dys-appearance was not obvious and observable. Repeated occurrences of this type of direct psycho-emotional disablism have played a part in making me almost always self-conscious when out in public. In addition, the stress caused by encounters such as those described above is compounded by not knowing when they are going to happen next. I can be just going about my day and strangers can look at me for a little bit too long which can change my own perception of my day. It undermines my psychological and emotional well-being to know that people notice me in these ways and, as in the above examples, feel it is okay to do and say such things out loud and in my presence. To know that the sight of me serves as a catalyst for such reactions has a detrimental impact on my sense of self, on my self-confidence, and often lowers my mood, even though I make a concerted effort to ignore it. In addition, the ‘chronic’ nature of my impairment means that incidents like these have become a normal aspect of my daily life, which I will most likely have to endure for the rest of my life. Such encounters have a cumulative long-term impact that, over time, has worn me down, reduced my tolerance for such occurrences, and reduced my ability to deal with them amicably. In the past I have described experiences of this kind as like being a celebrity without the income.

There are different psycho-emotional challenges for those with invisible impairments. This is illustrated by the example of Lucy, who has an invisible impairment yet feels compelled to exaggerate her limp when out in public so as to prevent people’s challenging her right to park in a disabled bay:

> I limp worse when I get out the car than I do normally [laughs] just to show people that I have got a ‘disability’, I can park in the bay. That’s deliberate. It’s probably subconscious now, but in the beginning [after the accident] it was deliberate. Because my husband’s noticed it – because he says, ‘What’s the matter with you today?’ And I say, ‘Nothing’. ‘Oh, alright then’. And then I forget and start walking then, once I’ve passed the bay, and people look [laughs]. (Reeve, 2012: 87)

In effect, Lucy is displaying her dys-function and making her impairment visible in the hope of avoiding confrontations with strangers which according to Thomas (1999: 55) leads to ‘negative psycho-emotional aspects of concealment’. The emotional cost of having to make your impairment obvious and publicly identify as ‘disabled’ is the impact on your sense of self, related to having to identify as ‘disabled’ given the number of negative associations with ‘disability’ as a social identity. In addition, in dys-appearing, those with invisible impairments are placed in the position of having to sacrifice their privacy in an effort to avoid confrontation or hostility. As with structural disablism, gender may intersect here with the psycho-emotional dimensions of disability: it is possible that women with invisible impairments are more concerned about being confronted than are men. Social perceptions may be that some women are perhaps less likely to talk back, or the fear of violence may also play a part in making disabled women with invisible impairments accentuate their impairments when occupying public spaces. As Reeve notes, similar situations can occur when people with invisible impairments attempt to use facilities such as accessible toilets reserved for the use of disabled people because they 'do not match the stereotypical image of someone who is elderly and/or a wheelchair user' (2012: 86). Arguably, political and media rhetoric propagated under austerity is leading to increased hostility and confrontation in public, as those with invisible impairments are not perceived by some members of the public to be 'genuinely disabled' (Briant, *et al*., 2013; Briant, *et al*., 2011). Such rhetoric encourages people to be suspicious, question and confront those with invisible impairments (Carrington, 2020).

There are additional implications for those with invisible impairments who keep their impairment private. As Lingsom (2008) comments, people with invisible impairments occupy a highly vulnerable position because they are continually managing whether to conceal or disclose information about their impairment. If someone can pass as non-disabled or 'normal' then they will be expected by others to conform to conventional norms of behaviour and stamina – which can be particularly difficult if an invisible impairment is fatigue related. However, one benefit of the concealment of impairment is that it reduces the likelihood of the experiences of direct-psycho-emotional disablism since the individual is less likely to be perceived by members of the public as being disabled (Kanuha, 1999). However, some within the Disability Movement have been critical of those who choose to pass as non-disabled, interpreting their doing this as a rejection of a disability identity. According to Morris (1991) passing may 'defend an individual against the commonality of our oppression but it is dangerous in that it denies our very identity' (37). Whilst I acknowledge that not everyone who can pass as non-disabled is making a conscious choice to do so, there are many occasions on which I wish I could conceal my own impairment or pass as non-disabled. Based on my experience of oppression I understand that being able to pass as non-disabled might in some circumstances at least allow those with invisible impairments to avoid overt discrimination.

In this section I have explored some of the different and complex implications of having a visible or invisible impairment and occupying public spaces; through applying Leder's concept of the dys-appearing body I have discussed some of the psycho-emotional effects for those with visible and invisible impairments. The next section explores perhaps the most extreme types of psycho-emotional disablism that often derives from observation and perception: disability hate crime, violence, and hostility.

Disability Hate Crime, Violence, and Hostility

'Disability' hate crime is an example of direct-psycho-emotional disablism because 'it emerges from the relationship that a disabled person has with other people or themselves' (Reeve, 2014: 123). It is an extreme articulation of the prejudice, discrimination, and marginalisation that disabled people face daily. 'Disability' hate crime is a relatively new crime in law, and has only been recognised as such since 2003 (Mencap, 2013). Disability Hate Crime is defined in law as:

> Any criminal offence which is perceived, by the victim or any other person, to be motivated by a hostility or prejudice based on a person's 'disability' or 'perceived disability'. (College of Policing, 2014: 4)

By this definition, I experienced 'disability' hate crime twice during the period in which I kept my Journal. The first occasion was an instance of verbal abuse while I was out shopping:

> A guy in CEX with the old it’s alright, don't move because you're in a wheelchair. He didn't ask me to move or say excuse me, I was unaware of his presence till he ranted at me. The price I pay for shopping alone I suppose. (Journal Entry, 2015: 41)

The perpetrator directly mentioned my impairment and therefore I consider this incident to be a ‘disability’-motivated hate crime. I also consider this occurrence an example of ‘disability’ hate speech, because it was a verbal attack and my wheelchair, a marker of my impairment was directly referenced. The conceptualisation of ‘disability’ hate speech is complex and in its relative infancy and therefore lacks a common, shared definition (Sherry *et al*., 2020). However, as is the more general category of ‘disability’ hate crime, it is indeed a crime. My understanding of ‘disability’ hate speech is that it is discriminatory speech predicated on ‘disability’. (Sherry *et al*., 2020: 6) state that ‘disability’ hate speech of the kind I experienced ‘occurs along a continuum of disablist practices, from the micro - to the macro - level-and for many disabled people, micro-level hate speech is so common that it is often not even recognised as hate speech’. This resonates with my experience, as I have been verbally abused and devalued as a person multiple times based upon my impairment and the social identity of ‘disability’.

Referencing the work of (Briant *et al*., 2013) Sherry suggests that the state may itself be responsible for the production and circulation of various forms of hate speech. ‘UK policies of austerity have been framed around the notion of disabled people as scroungers unworthy of state support-basically treating them as folk devils’ (Sherry *et al.,* 2020: 7). Alongside this, ‘the UN Committee on the Rights of ‘Persons with Disabilities’ (2016) reported that inciting criticism towards disabled people in this way had fuelled an increase in ‘disability’ hate crimes (CRPD, 2016; Healy, 2020). The visible nature of my impairment played a principal role in why I was targeted: as a lone disabled female, my gender may have also played a part. I did not report this incident to the police because there were no other witnesses. Given that my concerns are commonly not taken seriously when I report poor treatment or discrimination on the basis of my impairment, I thought it would be difficult to have this incident recognised as a ‘disability’ hate crime.

The second incident was physical:

> Last night I was punched in the head by a drunk ginger man who kept shouting at me to “touch him”. It happened opposite Central Station and he was wearing a denim jacket. Up until that point I had what could accurately be described as a good day. (Journal Entry, 2015: 177)

Whilst this example is less obviously a ‘disability’ hate crime, as he did not directly reference my impairment, yet bearing the definition given above of what in law constitutes a crime of this type, I believe my impairment was a key factor in why I was attacked. Although I do appreciate that women are frequently sexually harassed, and that my gender played a part in this attack, I find it hard to believe this man would have approached a non-disabled person in the same way. In his drunken condition, my wheelchair was a source of fascination to him. At the urging of friends, I reported this incident to the police. The police officer assigned was reluctant to investigate what happened and look for CCTV footage, as it was his day off the next day, (I still have the email stating this). The incident was recorded as the less serious crime of common assault, as opposed to a crime motivated by a specific form of prejudice and based on a characteristic protected under the law (The Equality Act, 2010). The only follow-up I received, was when a Police Community Support Officer posted a leaflet through my letterbox on the subject of victim support, giving numbers I could ring. Most of these were outside my geographical area, as a result of which I was not eligible for their support. I did not want a leaflet: I wanted the person who attacked me to be held accountable, and for others around me to recognise that what happened to me was wrong. My experience of the police’s responses is similar to Ruby’s, recounted by Healy (2020) in her paper”It spreads like a creeping disease”: experiences of victims of disability hate crimes in austerity Britain’:

> Ruby describes being given the impression of ‘let’s not press charges if we can help it’. In this way, her experiences are minimalised by the police response, and she is left feeling that she is making a big deal out of nothing. (Healy, 2020: 190)

Healy notes in her study that many other participants spoke of comparable police’s responses (Healy, 2020). Similarly, a study by Manji (2017) found that respondents doubted the police’s ability to respond and as a result saw little point in contacting authorities. For my own part, the apathetic Police response I received means that I will think very carefully before reporting a crime of this type if it happens again. The police’s response to my report has also made it very difficult for me to regard them as an institution and a service that is indeed there to support disabled people who experience a crime, whether or not that crime is considered a ‘disability’ hate crime.

In addition to the very real distress experienced around the assault, I see the policing response as compounding my experience of psycho-emotional disablism because it resulted in me feeling that crimes against disabled people are not taken seriously, that disabled people do not matter and are not worth supporting, because what happened to me was not investigated. Based on the response I received I felt that those involved did not care about me or that I was harmed by this incident. Healy observed that many of her participants had experienced ‘disability’ hate crime in locations that they previously considered safe spaces for them, such as the supermarket or their G.P.’s surgery (Healy, 2020). This was also the case for me. Both of the ‘disability’ hate crimes I have featured in this section took place in locations and spaces with which I am familiar: the first in a shop I had visited a number of times before, and the second on a route I knew as it formed part of my journey home from work. Hall and Bates (2019) argue that this may engender anxiety and fear of returning to those locations. Supporting this view, and following the hate crimes that happened to me, I did not visit the shop where I was verbally abused for more than a year afterwards, and for many months after being punched in the head I would not travel to and from work alone or go out in the evening without ensuring that someone was there to pick me up and accompany me home. I socialised less. My already small social network was further reduced, as was my own sense of freedom and psychological security. I felt, and still live with, the impact of increased anxiety and fear when attempting to go anywhere alone. These incidents had a particularly detrimental impact on my self-confidence.

Reeve (2014: 123) remarks that family members can be 'unwitting agents' of direct psycho-emotional disablism. Unfortunately, this was the case with a relative after I had told them of the incident where I was punched in the head. Their reaction left me feeling blamed, as if the attack was my fault, and compounded the level of fear I felt:

> I'm still feeling angry at my relative for the way they responded to the fact I was assaulted. They blamed me and tried to increase the level of fear I felt so I wouldn't leave the house again. I don't know what I expected, their poor response wasn't exactly out of character, but I still feel angry. (Journal Entry, 2015: 180)

The experience of psycho-emotional disablism is distressing enough when initiated by strangers; I would further argue that the distress is compounded when relatives are the perpetrators and fail to be supportive. To a degree, I expect more support from those close to me than from someone I do not know. Sin (2013) observes that some disabled people report being encouraged by carers, family members, and society to ignore and/or accept negative behaviour towards them. As Healy (2020), (Richardson *et al.*, 2016) and Blee (2007), argue repeated exposure to this kind of response can result in disabled people feeling that they are expected to live with certain forms of victimisation. The experience of disabled people is comparable to that of the social response to the sexual harassment of women, which is often denied or not taken seriously. These everyday experiences which disabled people, women, and other oppressed groups are expected simply to tolerate can be seen as the 'normalisation' of hate crime. This leads to victims feeling there is nothing that can be done. I am not suggesting that being punched in the head is a 'normal' experience for me, but the apathetic response of others from a range of perspectives to the hostility, verbal abuse, and psychological violence I experience on the basis of 'disability' is commonplace and has become widely accepted as normalised and is therefore often unchallenged.

Many of the disabled respondents in Healy's research (2020) had experienced hate crime multiple times, including verbal and physical abuse. Based on the social responses received and mentioned, I would be reluctant to employ my energy in reporting any such occurrence. These experiences play a part in the under-reporting of disability hate crime. For example, in the year 2015 to 2016 there were just 941 prosecutions for disability hate crime, with 707 resulting in a conviction (*The Independent*, 2016). The number of prosecutions contrasts sharply with the picture of 'disability' hate crimes presented by the most recent crime survey for England and Wales covering the years 2013 to 2016, in which there were 45,000 reported incidents of 'disability' hate crime and 130,000 personal crimes committed on 'people with disabilities' (ONS, 2017). Disability is a protected characteristic under the Equality Act (The Equality Act, 2010) as a particular aspect of identity including race, gender, and sexuality. Therefore, legislation exists for the recognition of hate crimes as being based on particular and specific forms of associated prejudice. However, as the experiences documented in this section illustrate this is not substantively enforced. Research by Fetzer and Pezzella (2019) found more severe violence and greater psychological trauma experienced by those who are targeted because of a specific characteristic of their identity: 'bias crime victims'. In his paper 'Psycho-emotional disablism: a differentiated process' Hanish (2014) recounts the findings of his Norwegian study into disabled and non-disabled school children's experiences of violence. His key findings showed:

> [S]trong and disturbing associations with impairment. These become even more disturbing if we restrict our focus to severe violence and bullying on a weekly or daily basis. Among both

> boys and girls, the disabled respondents are approximately twice as likely as are the non-disabled to experience severe violence, and approximately three times as likely to be bullied at least once a week. (2014: 222)

Hanish found that students with an impairment were more likely to experience violence than were their non-impaired peers. In a comprehensive literature review Hughes *et al.*, support this finding in demonstrating that violence against disabled people is more prevalent than violence against non-disabled people (2012). Hanish also found that this experience of psycho-emotional disablism is compounded by class (Hanish, 2014). Petersilia (2001) found similarly in respect of 'people with learning disabilities' in acknowledging that the relationship between 'disability' and poverty increased the likelihood of being a victim of crime. Ultimately, the experience of 'disability' hate crime, as an example of direct psycho-emotional disablism, has a significant psychological and physical impact on disabled people. This can result in engaging less often with society, restricting our own movements, and sometimes not leaving the home (Healy, 2020; Manji, 2017). In addition, as are the other experiences of psycho-emotional disablism I explore in this chapter, and perhaps more than the others, 'disability' hate crimes undermine disabled people's 'ontological security' (Thomas, 2007: 72). Ontological security refers to the security people feel in their own existence, psychological safety, and in their very right to be. Arguably, the enmeshment of moral degradation and stigma with many aspects of everyday life for disabled people, including experiences of austerity policies and navigating the benefits system presents another realm of ontological insecurity. This is further compounded by an ever-present threat of violence and hatred, which operates to distress, exclude, and de-value individuals in contemporary society. I feel that in the knowledge gained from disabled people's individual and collective experience of psycho-emotional disablism there are solutions to the inequality we experience. In the next chapter, I explore strategies in which I and other disabled people engage to mitigate and resist the impacts of disablism, including the experience of psycho-emotional disablism and disablist austerity.

Chapter Seven

Caring for the Disabled Self: Mitigating the Impact of Disablism

Introduction

In this chapter I discuss and define self-care in the context of a neoliberal, austere, and disablist society. I highlight the caution with which I approach the concept of self-care because it maps well onto the ideas and principles of neoliberalism and has been used as a vessel for their progression. However, despite the fact that I find the concept practically and conceptually problematic, I also consider self-care, as I understand and define it here, to be a necessity in terms of my own self-preservation and survival as a disabled person within a society that is neoliberal and disablist in character. I look in detail at two activities, employment, and gaming. These might not commonly be seen as examples of self-care. I look at the ways in which these activities function as such for me, to mitigate the impact of disablism.

Self-Care, Neoliberalism and Disablism

My own definition of self-care is any activity that maintains or improves my wellbeing. Andre Spicer notes that self-care is a 'remarkably flexible term' which can include any activity, from getting enough sleep, eating well, or learning to say 'no' to others requests' (Spicer, 2019, unpaged). In a paper 'American Nightmare Neoliberalism, Neoconservatism and De-Democratization', Brown (2005: 694) offers a different conception through defining self-care as a person's 'ability to provide for their own needs and service their own ambitions'. I approach the concept of self-care with caution because of its flexibility and individual focus, which means that it maps well onto some of the principles and aims of neoliberalism. As such it has been used as a vessel to progress unhelpful neoliberal ideas and principles because of its association with self-care and personal, individual, responsibility. Writing in the context of employee repair and recovery from the impact of paid work, Kinnamon (2016: 192) asserts that 'for some critics, capitalism's instrumentalization of personal responsibility becomes grounds for a paranoid reflex against care of the self, if not the staging of a total refusal to take oneself as object of one's attention.' Ward (2015) adds:

> Caring for ourselves forms part of our species activity, but how we think about and do this, like all other aspects of care, are political as well as personal matters. Over recent years the concept of 'self-care' has been mobilized by policy makers and governments in the deepening of neoliberal objectives to dismantle public welfare resources and shift responsibility for care onto individual citizens … As a concept, self-care is a valuable ideological tool not only because it appeals to common sense notions of individual empowerment and greater choice and control, but more significantly because it fits neoliberal economic imperatives to place responsibilities for health and welfare firmly with individual citizens. (Ward 2015: 45-46)

Furthermore, Brown (2005) argues that self-care functions in support of neoliberalism because its apparent focus on individual, personal responsibility to provide for the self-legitimises inequality. Ward explains this thought in stating that:

> By constructing care as an individual responsibility of the self, the normative policy framework that has emerged furthers existing inequalities by obscuring the collective responsibility of the state to provide adequately for its citizens … the argument emanating from feminist ethics of care are ever more urgent and important. The effects of the[neoliberal] shock doctrine are not only discursive shifts in framing care as an individual responsibility but the creation of greater inequalities and social injustice impacting the most on those already marginalised and vulnerable to market forces and who continue to shoulder most responsibility for care. (Ward 2015: 46; 55)

Similarly, Spicer (2019) urges caution in respect of the practical conceptualisation of self-care:

> While self-care may work for individuals, it doesn't come without dangers. This once radical idea is being stripped of its politics to make it more palatable to a mass market. As this happens, the central insights associated with self-care may well get lost. This could mean self-care becomes just another brand of self-help. Self-care could also be seen as cheap replacement for social care. Already many governments around the world are starting to focus their resources on promoting self-care in the medical world. This is fine if it is a complement to professional care. But when it becomes a substitute, we probably should be worried. (Spicer, 2019, unpaged)

These critiques articulate some of my own concerns in relation to the concept of self-care and the socio-political direction it is being used to push people in. As someone who is disabled and lives with 'chronic illness', my health, medical, and social care needs already go unacknowledged and unmet. I know from experience that self-care is not a replacement for skilled health or social care, and it should not be considered such; nor should self-care as a concept be used to absolve governments of their responsibility towards, and for, the care of their citizenry. Yet, at the same time, the neoliberal, disablist nature of society makes some form of self-care a necessity for me as a disabled person. In *A Burst of Light and Other Essays*, Audre Lorde wrote that: 'Physically. Psychologically. (sic) Caring for myself is not self-indulgence, it is self-preservation, and that is an act of political warfare' (Lorde, 2017: 129). As someone who spends a significant proportion of my time reclining on my couch, I struggle to conceive of myself as engaged in an act of political warfare; however, I do consider self-care, as I understand it, to be central to my self-preservation and survival, as Lorde espoused. In addition, self-care need not automatically be interpreted as universally supporting neoliberalism and aligned to its goals and aims. As did Ward earlier, I would argue that self-care and the meaning and framing of care becomes even more important in the context of neoliberal inequality. In referencing Foucault's work on care of the self, Kinnamon (2016) argues for an alternative interpretation of self-care that does not position it solely as a concept that aligns with and supports neoliberalism or functions only to support the demands of capitalism. Kinnamon (2016) allows for the possibility that attention to and repair of the self may be ‘a portal into pleasure, collective enjoyment, and political change’ (2016: 194). In other words, self-care may at times function in support of neoliberalism and or capitalism, but this need not be its only interpretation or function and other possibilities should be explored and theorised. In the sections that follow, I explore two key activities that might not straightforwardly be considered as examples of self-care, yet for me serve as such and help to mitigate the impact of disablism, I begin with employment.

Self-care and Mitigation of Disablism: Employment

I wish to acknowledge that employment is not commonly considered an example of self-care, and critics challenge the idea that work can function as a form of self-care under neoliberalism. For example, they emphasise productivity for profit as the central aim of the workplace and the idea that working contributes to ill health or even death (Stansfield *et al*., 2011; Takala *et al*., 2014; Slorach, 2016). Therefore, work, in this context, is not perhaps the most obvious example of self-care or mitigator of disablism during the time in which I kept my Journal.

However, at a basic level, employment provided a contrast to, outlet for, and alternative to study and to the associated stressors of being a researcher and producing research. The most obvious way in which work helped mitigate the impact of disablism is financial, through the extra cash it provided through the provision of a wage. This allowed me to pay for things I needed and wanted, and since I had extra money, this allowed me better to care for myself. I was able to buy clothes without buttons or fastenings, so I could go to the loo while at work. I bought a heated blanket to use while at home to keep me warm thus reduce the pain and discomfort I experience from the spasms in my legs which are commonly associated with Cerebral Palsy.

My employment was mitigative in the sense that it provided me with personal affirmation and a deep sense of satisfaction and fulfilment. This is difficult to convey in written form. Obtaining employment feels like a massive personal achievement even though my employment was part-time and conducted under zero hours conditions. It also helped mitigate my experience of disablism because my presence in the workplace provided a counter-narrative to a common and pernicious political discourse under austerity that disabled people are unproductive, do not contribute to their communities, and are therefore considered by some as inferior: a situation that contributes to increased levels of hostility towards disabled people (Burch, 2018). Additional personal mitigation is provided by the context in which my employment was gained. As discussed at various points throughout this thesis, being impaired makes it more difficult for many disabled people to get a job. I obtained employment in a context in which people had told my parents when I was a child that I would never work and should not be allowed to try. I obtained employment having gone four years between paid work and, as is common to other disabled people, having experienced a raft of employment related discrimination (Muscular Dystrophy Campaign, 2010). At the time I applied for the job I eventually got in April 2014, I had experienced so much discrimination and rejection that the process of finding a job was having a particularly adverse effect on my mental health, to the extent that I was seriously considering giving up my employment search altogether.

Employment also helped me to mitigate the impact of disablism by boosting my confidence and improving my sense of self, giving me both a public identity and a role that went beyond that of (just) being a disabled person. I was an employee, a team member, and a colleague. I was given responsibilities and learned new skills, and the organisation that employed me openly displayed belief in me and allowed me to make mistakes. In contrast to my previous experiences of employment, this was much appreciated and refreshing. Moreover, the physical, conscious act of working relieved some of the pressure and social negativity that comes with being perceived as disabled in a public space. My presence in the workplace sent out the positive message that disabled people can work if given the opportunity, irrespective of whether others were open to this message. In addition, I hoped my presence would encourage other disabled people to apply for a job with the organisation and thus I allowed myself to be photographed as part of an advertisement campaign in an effort to attract a greater number of disabled candidates.

As a disabled woman active in a public space, allowing myself to be photographed felt mitigative in a broader sense, in a society that routinely air-brushes out the views of disabled people, provides us with limited public narratives, and often functions to deny our very existence by, for example, not providing access. The discrimination and exclusion I face as a disabled woman is meted out both on the basis of my gender and my impairment. As Morris (1992) comments:

> Women are excluded from this public sphere, ghettoised into the private world of the family, our standpoint is excluded from cultural representations. When I became disabled I also realised that the public world does not take individual, particular, physical needs into account… People whose physical characteristics mean that they require help of some kind … have no place in the public world… Women have thus been excluded from a full share in the making of what becomes treated as our culture. When I became disabled I realised that, although disability is part of the human experience, it does not appear within the different forms that culture takes- except in terms defined by the non-disabled. A lack of disability is treated as both the positive and the universal experience. (Morris, 1992: 158)

I found it psychologically valuable from a self-care perspective to be practically engaged in the support of an issue I am passionate about, such as the employment of disabled people. In the context of a society that is increasingly hostile towards disabled people, and routinely discriminates against us, it is important that organisations publicise the fact they are committed to the employment of disabled people in the broader context of equality. To find an organisation actually willing to employ me, to consider me skilled, teach me further skills, and to pay me a wage, irrespective of my impairment, helped to mitigate the impact of disablism: it had a restorative affect. To a degree, I felt as if it atoned for my previous experiences of rejection and discrimination in employment. Furthermore, work also functioned as a form of self-care in the sense that something I wanted to happen that is, finding a paid job, actually did happen. Part of what made my job enjoyable was that the position I occupied was not directly related to 'disability' or impairment, either my own or someone else's. This provided important psychological respite in a daily life either where I am giving my perspective on the basis that I am impaired or in which my impairment is a recurring topic of discussion.

I received a number of supportive comments from customers who were surprised and encouraged to see a disabled person working in a public-facing role. This I found particularly heartening because in my experience people with visible impairments are not a common sight in many workplaces. When I have worked, I have on occasions felt like an anomaly. In my teens and early 20s I used actively to look for disabled people working in places I visited. I recall my excitement when out shopping one day I spotted a wheelchair user working at the cinema, meeting and greeting guests. Happily, I was not the only visibly disabled employee in my own workplace, and this knowledge helped me to relax and settle in. My colleagues were very supportive of my presence in the workplace. They bent over backwards to make me feel welcome and to let me know that they were supportive of my desire to work. I did not ask for many reasonable adjustments, but when I did, my requests were taken seriously. For example, my start times were flexible to allow for the fact that I needed support to get to work. The response of those I worked with helped to mitigate the impact of disablism at a psychological level, in the sense that nobody responded to me with hostility or attempted actively to make things more difficult, which are common factors in other contexts. I did not have to argue for any reasonable adjustments I needed.

A further way in which employment helped me to mitigate the impact of disablism is by providing me with a social network. Work gave me, as it does for non-disabled people, the opportunity to make friends and do things with others outside of work. This is important because, according to the 2017 Equality and Human Rights Commission Report ‘Being Disabled in Britain’, the employment rate for disabled people is below 50% compared to just below 80% for non-disabled people (EHRC, 2017). This limits the opportunities for disabled people to make friends and develop social networks through employment. My workplace made sure that I was included in the majority of social gatherings by choosing accessible venues and making a genuine effort to be inclusive, which I appreciated because the inaccessible nature of society means I am often excluded from events I would like to attend. I particularly enjoyed the festive period and went to the work Christmas dinner every year:

> I’m doing Secret Santa at work, I have spent the afternoon realising how hard it is to find a gift I don’t mind giving to another human being for a £5 or less, and I can confirm it is very hard. Many of the potential gifts I liked were either out of stock or slightly over budget. I would have gladly exceeded said budget for my chosen giftee, but we have been asked not to, and so I’m sticking to the spirit of the thing. We are due to exchange gifts at the work Christmas dinner which I am very much looking forward to … Tonight is the [work] Christmas Dinner and I’m really looking forward to it, it will probably be the best dinner I have over the festive season, I am having Bath chop, turkey with all the trimmings and winter fruit meringue. (Journal Entry, 2015: 81;83)

Work Christmas dinner was one highlight of my year, I enjoyed both the food and the social aspect, and I had new experiences such as eating meringue for the first time:

> Work Christmas dinner was immense, I enjoyed all three courses and it was a pleasure to be in such engaging company. I had pigs cheek for starter, turkey for main and tried meringue for the first time for pudding. (Journal Entry, 2015: 83)

The efforts made by staff and colleagues at my workplace to be inclusive in terms of my attendance at staff events helped me to mitigate the impact of disablism in that they did not perpetuate my common exclusion from social occasions. As a result, I felt connected to both the organisation and the people I worked with. The link between social connection and self-care is highlighted by Ward (2015), who states:

> Our capacity to be taken care of ourselves is predicated on our connectedness to others. Self-care can only be fully expressed through recognising not only one's own needs for care, but also, crucially, that these will be met in relation to others. (Ward 2015: 55)

For once, instead of being on the outside looking in, I felt that I was on the inside looking out. Moreover, feeling like part of a group lessened the sense of alienation I often feel from other people as a result of common and repeated social exclusion; this also helped to reduce my sense of isolation. The social aspect of work aided the mitigation of disablism in that it helped me see society as a less hostile place and provided a counterweight to some of the hostility I had experienced as a disabled person living under austerity. The social network my employment provided helped me to mitigate the impact of disablism further by providing me with greater psychological resolve. For the reasons noted, occasions such as this improved my sense of well-being and were an important aspect of my self-care during austerity.

As an Arts Council England funded organisation, my workplace was required as part of its remit and funding conditions to be inclusive and work with people from a diverse range of backgrounds in a substantive way (Arts Council England Strategy, 2020). Many of those we worked with are recognised as members of marginalised and disadvantaged social groups, some of whom were detrimentally impacted by austerity. This included: disabled people, mental health service users, refugees, and fostered children. From a self-care perspective, whilst work might for others be a source of oppression (*see* Stansfield *et al*., 2011; Takala *et al*., 2014; Slorach, 2016). and not function a self-care, mine did for me because of the values my workplace supports and progresses. It felt good to be in a position to work in accordance with my own values, such as being kind to others and demonstrating a degree of equality within my role and broader organisational remit. I particularly appreciated being in a position to help refugees in a small way by working for an organisation that allowed the stories of refugees to be told in their own words and by providing free and subsidised entry to shows. In her book *Revolting Subjects,* Imogen Tyler highlighted the cruel state response to refugees who, upon reaching the UK, are reclassified as asylum seekers, a category that, unlike that of refugees, comes with few rights and legal protections (Tyler, 2013). As Tyler observes:

> At the heart of Britain’s rapidly expanding asylum and immigration industry and estate is a transnational traffic in bodies. This is an industry fuelled by the import and export of human misery. If we understand the injury, violence, rage and desperation in which this industry trades and profits as a distinctly neoliberal form of state crafting, what kind of psycho-social map of contemporary Britain would this produce? The picture of the state which emerges is, … a deeply melancholic map of Britain. This melancholy is inevitable as the abject the asylum industry trades in are largely invisible and nameless (and are thus unmournable). However, if melancholy is a trauma or loss that is not sanctioning through public mourning, it is incorporated all the more integrally in the body of the nation, in the form of internalised scars and wounds. (Tyler, 2013: 75)

In working within an organisation that worked with so many marginalised and disadvantaged people, I was part of a team attempting to mitigate the impact of austerity and neoliberal capitalism through its work. It helped others affected from backgrounds and circumstances comparable to and yet different from my own. The next section explores the ways in which gaming acted as a form of self-care for me and helped me to mitigate the impact of disablism.

Self-Care and Mitigation of Disablism: Gaming

I am often reticent to talk about being a gamer because gaming is viewed by some as a detrimental, negative activity and has a poor public image. For example, computer games are often criticised for their portrayals and representations of violence, or for their associations with addiction (Carnagey, 2004; Anderson *et al*., 2010; Griffiths *et al.,* 2012). Gaming as a form of entertainment, as is employment, can be seen as functioning to support the principles of neoliberalism. For example, gaming can be addictive for some and it generates profits, both from the sales of consoles and games, and also from techniques and approaches which aim to cure gaming addiction (Griffiths and Meredith, 2009). It has been observed that a classic trait of neoliberalism is to sell us things and then sell us cures or solutions for the problems those things create (Courtwright, cited in Illing, 2020). I also recognise that cost can be a barrier to gaming for both non-disabled and disabled people. Despite its being an accessible activity for many disabled people, gaming is not yet as accessible as it could be for those with impairments. However, efforts are being made by companies and charities in both the U.S. such as AbleGamers and Special-Effect in the U.K. to change this through the production of adaptive controllers and increased accessibility features built into games (AbleGamers, 2018; SpecialEffect, 2020). Whilst this has the potential to increase profits by capturing more of the ‘purple pound’, the term used to describe the spending potential of disabled people, it also makes gaming a more accessible and inclusive medium (Williams, 2017). As someone whose impairment affects their motor skills, there are some games I cannot play, such as Guitar Hero, because I do not have the dexterity to play a guitar, a requirement of the game:

> I bought some PS4 games today, Argos had a sale. I bought Guitar Hero, which I am physically incapable of playing, Street Fighter, which I already have a digital copy of but I’m old school and like physical copies of games and it was only £9.99. I also got Puyo Puyo Tetris, bought online, which arrived today and Everybody’s Golf which I forgot I pre ordered and this arrived in the post this morning. Guitar Hero will be traded in by Monday. (Journal Entry 2015: 163)

I do not enjoy playing violent video games and I am not a fan of the war or horror genres that are a common aspect of gaming for many. I consider the society I live in violent enough and do not go in search of violence in the context of gaming. I consider myself a casual gamer and for me, in the context of self-care and mitigation of disablism, gaming is much more about enjoyment. Despite the negative public image often attributed to video games and gaming, I am choosing to write about my enjoyment of them in my thesis in part because I feel there is a lack of space given in research to activities which disabled people enjoy. In my experience, many of the things disabled people talk about are not connected to their pleasures or to activities we enjoy. I think it is important in a society were disability and impairment are the focus of so much negativity that alternative narratives, such as those highlighting disabled people's enjoyment, are acknowledged and developed. There is an element of nostalgia in my enjoyment of gaming because I have gamed since I was young:

> Recovering from my gym exploits on Saturday, relaxed last night and took my PS4 to bed, played Lego Marvel Avengers, I was Captain America and then Iron Man. I've not gamed in weeks because I haven't had the time, and a lot of the new releases haven't really grabbed me, I'm not a fan of war or horror genre games, so my console has been gathering dust. I have been a casual gamer since I was young, we got an Atari for Christmas one year when Atari was the thing to have, as a kid I particularly loved Sonic, Mario, and Duck Hunt on the NES. (Journal Entry, 2015: 99)

Wulf *et al*. (2020) define nostalgia as:

> Remembering meaningful events in their earlier life, people sometimes become affected by a mixture of positive and negative affect entangled with a certain longing for the past. On the one hand, they experience a sense of happiness remembering these events. On the other hand, they are aware of the fact that this is past and will never happen in the same way again. (Wulf *et al*., 2020: 84)

For me, playing games provides a link between my childhood and adulthood which is comforting because it has been a familiar and reassuring presence throughout my life (Wulf *et al*., 2020). One way in which gaming helps to mitigate the impact of disablism is by providing a sense of stability and in turn improves my psychological well-being. Gaming is the way through which I can recall happier times and also create new happy memories. Modern consoles such as the Playstation 4 (PS4) and Microsoft X-Box allow gamers like me to play games that they played as children and thus relive gaming experiences or return to old favourites (Suominen, 2012). For example, I bought a Super Nintendo classic mini so that I could play some of the games I used to play when I was younger:

> After months of waiting, my mini classic Super Nintendo arrived, this is a retro games console, (I owned one as a kid), with 21 pre-loaded games on it, which were released on the original console in the 90's. I'm going to play it in bed if the various leads are long enough. (Journal Entry, 2015: 172)

As is nostalgia, gaming can also be a social activity. I have fond memories of gaming with my sister when we were younger, in particular, playing the original Zelda and Mario Bros games. We both still enjoy gaming as adults and it and helps us to remain bonded (Wulf *et al*.,2020):

> Brothers a tale of two sons arrived yesterday it is a really good game, you have to control two characters at once and use each half of your brain to do different things … The visuals are also stunning, which adds to the playing experience the only point I would make is the game cannot be played as a two player, initially it was purchased with me and my sister in mind, as we enjoy playing together… So far I have befriended an ogre, escaped a rabid dog, and made a sheep run in a waterwheel. (Journal Entry, 2015: 48)

Ryff and Singer (2006) argue that one benefit of nostalgia is that it encourages positive relationships with others. In addition to gaming with my sister, I sometimes game on-line with others from around the world, I play games such as ‘Mario Kart 8’ and ‘Tetris 99’, which are modern versions of classics. My experience supports Ryff’s and Singer’s assertion that nostalgia, in the context of gaming, encourages positive relationships. When I game with my sister or online I experience a sense of inclusion with and connection to others, an experience that runs counter to, and helps to mitigate, my many experiences of disablist exclusion. I feel included when I game with others, and I experience a degree of equality while gaming that is absent from other areas of my daily life.

As alluded to earlier, gaming is an accessible activity for me. When I game, my impairment is largely irrelevant: when I play on-line I do so anonymously, so no one can see me and judge me based on my physical appearance, as many people do in my daily life. Thus, it is a time when I am relieved of the pressure of having to explain or account for my impairment, a common aspect of my experience. The anonymity and invisibility that gaming affords helps me to cope better psychologically with the impact of disablism and this is linked to another key reason I game. Gaming helps me to relax, switch off and recharge. It functions as a form of escapism. When I game, I forget about things that have happened to me. As Myers notes, in reference to the role-playing game Final Fantasy XIV’, gaming can provide players with self-care in the form of ‘escape’, ‘relief’ and ‘renewal’ (2019: 178). Contrary to a common misconception, gaming is not necessarily simplistic or mind-numbing. As Calleja observes, part of the escapism gaming provides derives from the pattern-seeking, problem-solving and decision-making involved (Calleja, 2010). Gaming engages my intellect and these processes are integral to my enjoyment. In reference to the game ‘Everquest’, Taylor (2006) argues that games allow players to set and pursue their own goals, as well as providing a broad degree of complex systems and tasks with which to engage. I particularly enjoy playing the Lego series of games, because in these games you play though the plot of a number of popular books and movies such as the *Harry Potter* series, *Star Wars* and *Jurassic World*:

> I’ve just bought the new Lego Jurassic World game which I’m currently playing my way through. It is by the way, awesome, you can play as Richard Attenborough, enough said! (Journal Entry, 2015: 23)

These games are recreated in detail and beautifully rendered in Lego. I enjoy completing levels based on well-known narratives, collecting studs to unlock rewards like extra characters with different abilities that allow players to progress within the game and to undertake many of the available side quests which are a feature of the series. The variety and diversity of ways in which I can interact and engage with the medium is part of why gaming is a form of self-care. As Calleja (2010) observes, games are ‘the opposite of seriousness and work’ (2010: 335). This contrast, and the fact that gaming is not considered to be a serious activity or a form of work, forms part of the reason why I enjoy gaming so much. In a society where much of my time is accounted for and taken up with ‘serious work’, time spent doing things that do not matter or are not considered serious, like gaming, is important because it helps to relieve stress and pressure. Moreover, there are few, if any, consequences for mistakes made while gaming. The fictional nature of games provides a safe space for release, relief, and relaxation.

I have already highlighted the social aspect of gaming and how gaming with others functions as a form of self-care, helping to mitigate the impact of disablism. In addition, alongside playing with others, I also enjoy playing alone. In gaming terms, I am what is referred to as a solo gamer (Thornham, 2008). Gaming is not just ‘me time’: it is my time. Solo gaming gives me the opportunity to refuse people’s demands and deny people access to me (Myers, 2019). I enjoy the solitude and peace that solo gaming allows me. I am in control of what I do, what I play and for how long I play. Juul (2010) contends that the ability of a game to be interrupted is crucial to its ability to be flexibly integrated into the daily rhythms of a diverse audience with unpredictable schedules (Juul, 2010). Whilst historically this was not the case, the majority of contemporary games allow players to save games at a certain stage and return to them as and when they wish. In the context of a disablist society, where I feel increasingly restricted due in large part to the way society responds to people with impairments, the value of gaming as ‘my time’ should not be understated. Gaming helps me to mitigate disablism because, unlike other aspects of my life, I am in control of it. Gaming is one of an ever-decreasing list of activities that no one has tried or been able to stop me doing. This is in part explained by the fact that gaming for me, as for many, is a domestic activity taking place in the private space of my home (Thornham, 2008). Where I play is just as important as are the other factors discussed here in relation to mitigation of disablism and self-care. I am naturally more comfortable and physically and psychologically relaxed at home, and I often game in bed:

> I took my PS4 to bed last night and played Everybody’s Golf and Scrabble, such a rebel, but it was lovely … Tonight I’m having Chinese, playing Mario 3D World and watching Eurovision, I’m looking forward to a few quiet days, feeling knackered. (Journal Entry, 2015: 176; 12)

At home I can give greater priority to my own needs and preferences, in bed I can stretch out and my pain levels are reduced. My anxiety levels are also often reduced on account of the fact I am at home and do not have to engage with disabling structures and relationships. The relaxation gaming at home engenders helps me to recuperate, heal, and relax. In addition, when I game, I get to adopt roles or take part in in activities that I do not get the chance to occupy or undertake in daily life, such as owning and operating my own theme park as in the case of ‘Rollercoaster Tycoon’ or playing golf as in the case of ‘Everybody’s Golf’. I also get to experience what it is like to participate, and even win, which is not a common experience for me. Gray *et al*. (2005) have coined the concept of ‘juice’ or ‘juiciness’ to describe a type of gaming interface that provides positive feedback through excessive visual spectacle when an in-game goal is achieved, a level completed, or a reward earned:

> “Juice” was our wet little term for constant and bountiful user feedback. A juicy game element will bounce and wiggle and squirt and make a little noise when you touch it. A juicy game feels alive and responds to everything you do – tons of cascading action and response for minimal

> user input. It makes the player feel powerful and in control of the world, and it coaches them through the rules of the game by constantly letting them know on a per-interaction basis how they are doing. (Gray *et al*., 2005, unpaged)

As Juul (2010) asserts, juiciness also enhances the experience of feeling competent, clever, or otherwise powerful when playing a game. Similarly, I enjoy the challenge of seeing how far I can progress. Completing levels in games like ‘Super Mario World’ provides me with a sense of achievement:

> I started my morning the way all Sundays should begin, with a gaming session. My current game of choice is Mario 3D World and I have managed to conquer the first castle and make it to world 2. (Journal Entry, 2015: 12)

I get a lot of confidence from testing my own abilities against a game, particularly in a disablist society that frequently represents disability and disabled people as inferior and deficient. Gaming is one activity that reminds me I am capable and thus builds my confidence. In helping me to feel capable and confident, gaming enables me to think differently about myself and provides a counter-point to the negative attitudes to disability to which I am daily exposed, and which have increased under austerity. In addition, when I reflected upon some of my journal entries, I realised that I also use gaming to regulate my mood, reduce feelings of depression and help myself recuperate from distressing events (Myers, 2019) that occurred under austerity and as a result of specific austerity policies. For example, the entry below was composed following a particularly psychologically harmful experience of disability assessment with which I still struggle mentally to this day:

> I am still feeling the effects of Thursday including intense internal feelings of anger and crying at random intervals. I have, for the moment, stopped keeping the official version of my mental state because I am sick of being doubted and having my representations of the seriousness of

> that state downplayed. To try and stop myself thinking about all of this I’ve been playing Lego Dimensions on PS4 and the house is becoming populated with Lego figures. In addition, my sister has discovered an enjoyment of building Lego models she never knew she had, so far she has built several cars, a television, a train, an arcade machine, the front of a Chinese restaurant (from the new Ghostbusters movie), a Bat Computer, the lobby from the movie Fantastic Beasts, and a TARDIS, and this is not a full list. (Journal Entry, 2015: 140)

I also use gaming to help me recover from and cope with other distressing events, like exclusion due to inaccessible environments, which is a common aspect of my experience under austerity and in a disablist society. For example:

> I have spent less than £50 on games today and I still feel guilty for having treated myself and trying to lift my mood after what has been another difficult week of dealing with people I can’t stand and being denied something I won or things I am entitled to because of who I am and what that means socially. I should have been in Newcastle watching a wrestling show, but they did not honour the competition win because I am a wheelchair user, those involved then made out on social media that I could not attend, when in reality they refused to let me. (Journal Entry, 2015: 163)

The time I spend gaming helps me to work through the complex feelings and emotions I have following distressing events like these. The psychological space and respite that gaming provides allows me time to reduce my anger, feel calmer, and lessen my own sense of despair. Therefore, gaming allows me to recharge following distress and helps me return to a psychological state where I can cope with the impacts of living in an austere society containing factors such as harmful assessments and repeated exclusion. I also have a virtual reality (VR) headset that attaches to my games console; this is particularly useful in allowing me to attain a deeper level of relaxation. When I am wearing the headset, I become completely immersed in the virtual world created for me within the game. Gaming in VR is useful in terms of self-care in that it allows me completely to forget where I am, particularly useful when I have had a traumatic or distressing day:

> My way of attempting to cope with my current level of psychological duress is to spend a bit more than I usually would on computer games and then spend some time actually playing them. I've got a headset which transports me to other worlds and environments, you become completely immersed in the game and forget where you are, which is useful for me right now. I've spent part of my afternoon under the sea, which is nice. (Journal Entry, 2015: 196)

As do other forms of gaming, gaming in VR allows me to have experiences I am unlikely to get the chance to do in my daily life, such as deep-sea diving, as in the example above. Gaming in VR is additionally helpful because the disconnection helps me to calm down and relax to an even greater degree than an ordinary game played with a standard controller. The fact that gaming helps me psychologically in these ways makes it a crucial aspect of my self-care. I feel I would be a less balanced, angrier, and more distressed person if it were not for the time I spend gaming and the role gaming plays in my life: giving me time and space to work through my emotions following distressing events, helping to regulate and lift my mood, and to reduce my anxiety have been particularly valuable. Gaming helps me to return to a psychological space where I can carry on, despite my disablist experiences. In a society that I experience as increasingly hostile, gaming is one activity that gives me hope.

Chapter eight, the comic self, explores the ways in which I watch and utilise comedy to help manage and endure experiences of disablism.

Chapter Eight

The Comic Disabled Self: How Comedy and Humour Helps Me to Manage and Endure the Experience of Disablism

Introduction

This chapter Is divided into two sections. Firstly, I explore the role and value of comedy for me as a viewer in helping me to manage and endure experiences of disablism, through the work of Stewart Lee, Mark Thomas, and Nina Conti. Using *The League of Gentlemen* and *Psychoville* as examples, I also discuss the role that the genre of dark comedy plays in helping me to manage and endure experiences of disablism. Secondly, I examine how I utilise comedy in my daily life to help me manage and endure experiences of disablism.

Managing and Enduring Disablism Through Humour

I have always enjoyed comedy. In my journal when I made a list of my favourite TV programmes past, present or current, 16 of the 42 programmes I included are comedies:

> *8/10 Cats Does Countdown, QI, One Foot in the Grave, Gimme Gimme Gimme* with Kathy Burke. *Dinnerladies, Bottom, Blackadder, The League of Gentlemen, Have I Got News for You, Stewart Lee's Comedy Vehicle, Charlie Brooker's Weekly Wipe, Dad's Army, Allo Allo, 2.4 Children*, Are *You Being Served? Celebrity Juice* (guilty pleasure). (Journal Entry, 2015: 52)

As you can see from the list, I enjoy a varied range of comedy: I have enjoyed watching situation comedies (sit coms) since I was young, and as an adult I find their familiarity comforting. I can recall and quote large sections of plots and lines from programmes such as *Are You Being Served? One Foot in the Grave*, *Gimme*, *Gimme*, *Gimme*, and *Dinnerladies*. I also like more contemporary comedy such as *The League of Gentlemen* because it is dark, and I enjoy the absurd view of the social world it presents. I enjoy *Charlie Brooker's Weekly Wipe* because it presents me with what I consider to be a more honest interpretation of the world than I encounter during the course of daily living. I enjoy Brooker's social and political satire and the vision of society he presents. I also enjoy *Weekly Wipe* because, as in The League of Gentleman, the humour and comedy presented is clever, and the wider the knowledge of culture and society you bring to it, the funnier it is. The comedians featured in this chapter are chosen because I find their work funny and enjoy their particular styles. I have not included comedians on the basis of whether they are 'disabled', or not, or define as such. Stewart Lee, for example, has a hearing impairment; I enjoy his comedy because of his political stance and the subjects he chooses to talk about on stage. I enjoy the work of 'disabled' comedians such as Rosie Jones, Laurence Clark, and Chris McCausland. At the time of writing my Journal there were not many disabled comedians featured on mainstream television, and this is still largely the case. My central consideration when watching comedy: is do I find this person funny? I acknowledge that comedy, including some of the situation comedies I enjoy, sometimes perpetuates oppressive stereotypes in relation to race, gender, sexuality, and 'disability' (Healy 1995; Kotthoff 2006; Renier 2017; Collings 2018). As DeCamp states:

> Stereotyping in some form – be it tacit assumption or overt statement – is bound up in the enterprise of stand-up comedy. This art form endows the performer with the platform to highlight public understandings of such constructions as gender, race, and sexual orientation. The inclination to lambaste or capitalize on stereotypical racial and gendered notions varies by comedian; however, these social divisions can rarely be addressed without reference to public assumptions about them. (2017: 1)

However, humour is also a form, and comedy a medium, in which stereotypes in relation to race, gender, sexuality and 'disability' can also be critically re-examined, confronted, subverted or critiqued (Healy 1995; Kotthoff 2006; Coogan and Mallett 2013; Lockyer; 2015; DeCamp 2017). As Renier (2017:

2) comments ‘comedy functions as a useful platform for creative retorts and political dissent to tackle sensitive topics like race’. The key point here, is that while comedy and situation comedies do sometimes perpetuate oppressive stereotypes, humour and comedy as a form can also be used as a means to challenge, critique or subvert stereotypes.

I enjoy comedy so much that I organised a trip to the Fringe Festival in Edinburgh, a yearly, month-long arts and cultural gathering that takes place in the aforementioned city every August and brings together artists and comedians from all over the world. The trip was a highlight of my Journal writings. I include below some recollections from my time in Edinburgh:

> On Wednesday we had dinner at a pub called The Royal Dick, (the name relates to the fact the pub was a former vet school), but I found it all very amusing, especially because we had to ring a bell to get in. I had a kind of cake I’d never eaten before. Whilst enjoying the Fringe experience I also managed to meet up with a friend from work, which just made my visit … Post Fringe diary entry. Got a pic with Shappi Korshandi, but I don’t like it because the pain I was in at the time is written all over my face. My right foot was giving me a considerable degree of jip at the time, it does when I’m sat in my chair for a long time. We saw Nina Conti, Paul Merton, Piff the Magic Dragon and Hyprov. Despite the sore foot, and the fact that the friend I went with decided to flush the loo, post wee, at 0630am, I would do it again in a second. (Journal Entry, 2015: 118)

I use comedy to manage and endure disablism because it helps me to regulate and level out my mood and stabilise myself psychologically. I use it to help me recover from endure and tolerate the repeated experiences of exclusion that are a common and reoccurring aspect of my daily life and a consequence of being ‘disabled’ in a disabling society that fails to provide equitable access, and, as in the example below, publicly justifies exclusion:

> I have once again been left upset because a venue I wanted to attend for wrestling is inaccessible to me. They even make a public statement about this on their website, the basic gist of which, is that people who can't walk aren't welcome. The venue concerned is The Dome, Tufnell Park. http://www.dometufnellpark.co.uk/ages-access/
>
> We currently do not have access for non-ambulatory persons to The Dome due to the fact that we cannot reasonably adapt the premises. The site does not currently have a 'disabled' welfare facility. We do, however, welcome disabled customers who are ambulatory.
>
> This feels exclusionary, discriminatory and potentially illegal, just saying.
>
> When you've been made to feel shit for the umpteenth time watch Stewart Lee.
>
> (Journal Entry, 2015: 157)

Comedy puts me back in a psychological space where I have the emotional resilience to feel relaxed, calm and balanced enough to experience disablism again, as I almost certainly will, due to the nature of the society l live in. Stewart Lee is a particular favourite, and I went to see him many times while keeping my Journal:

> I have tickets to see the comedy *Einstein* that is Stewart Lee, I cannot wait … I hope I feel better tomorrow in time for the much-anticipated Stewart Lee show, what can I say the man makes me happy, so excited, the phrase loving your work doesn't really cover it … I have not really had chance to reflect upon the Stewart Lee gig I want to last night, I didn't reach my bed till midnight. The man makes me feel better about being a human, the combination of subtlety, intelligence and tomfoolery is a complete pleasure to watch, the man even manages to make the concept of death hilarious, plus his set piece about nationalism was particularly socially relevant and very, very funny … Highlight of my week so far watching Stewart Lee live on Wednesday and meeting him afterwards and getting a picture and him signing my DVD … I left the house and 9am and didn't return until gone 11pm. I had a ticket for Stewart Lee in the evening. I love him

> and find his comedy medicinal. Really good day, and then I came home to discover the world is still a very messed up place. (Journal entries. 2015: 14;15; 128; 170)

Moon (2011) has said of Stewart Lee: '[h]is status can be measured not in terms of the size of the venues he plays or in the number of biographical "booky wooks" he sells, but rather in terms of the integrity and insight that he brings to the form of stand-up comedy' (Moon, 2011: 5). The subject position Lee adopts throughout his comedy makes me feel more hopeful both for myself as an individual citizen and for society as a whole. As Vilaythong *et al*. state: 'as a coping mechanism, humor (*sic*) may competitively inhibit negative thoughts with positive ones, thereby fostering hope in individuals. Hence, humor and hope are potentially significant factors to one's overall sense of psychological and physical well-being' (2003: 80). I particularly enjoy the fact that Lee is publicly critical of right-wing politics and right-wing politicians in his comedy. He puts these under a microscope and subjects them to a scrutiny which I often do not experience in the media. I enjoy the fact that Lee is prepared publicly and humorously to highlight the dangers of right-wing ideology and how the ideas that underpin them lack a sound educational basis. The extract below is from a sketch about The UK Independence Party (UKIP). It is commonly known as the 'UKIP' or 'Shitted Bed' sketch:

> A lot of people have been saying that they're voting UKIP as a protest vote, which I sort of understand, but when we were young, as a protest vote you'd vote for someone nice who might not get in like the Greens, or some funny, silly, amusing party like the Monster Raving Loony Party, or the Liberal Democrats. But people have been voting for UKIP as a protest vote, and they're nasty, and they might get in. I mean what kind of protest is that? That's like shitting your hotel bed as a protest against bad service, then realising you've now got to sleep in a shitted bed. (Laurens, 2014)

Avner Ziv (2010) has argued that comedy serves a corrective social function:

> Humour exposes other human phenomena (those that render the world almost unbearable) to mockery, in the hope of thereby eliminating them. Man makes a mockery of man. In his efforts at changing and improving mankind, man turns matters he thinks grave into absurdities. He does this sometimes with delicate casualness, sometimes with disrespect, and sometimes with ferocity, the laughter that derives from the perception of absurdity reforms the world. (Ziv, 2010: 16)

In his comedy and through his comic subjectivity Lee mocks human phenomena that render the world almost unbearable, or at least, much more difficult to live in, such as the policies and behaviour of right-wing politicians. Through the use of comedy and humour, I think he is attempting to highlight the detrimental impact of such politics and to enlighten people as to the social insidiousness of such politics. Part of why his comedy helps me to manage and endure the experience of disablism is that in his comic subjectivity he presents me with a funnier, kinder, and more equitable view of society. Ziv (2010) has argued that comedy acts as a form of release. Part of the release for me in watching Stewart Lee is that he holds ideas and people accountable, and subjects them to scrutiny as part of his comedy. Even in the arguably relatively toothless form of stand-up comedy, this has a social value, because those in power are otherwise commonly not held to account for their actions. Comedy generally, and the comedy of Stewart Lee specifically, serves a further social function in helping me to manage and endure disablist experiences. Ziv (2010) argues:

> In every oppressive regime there is this kind of underground humour, and it fulfils an important function: Laughter shared by the oppressed at the expense of the oppressor reduces fear and helps people to go on living under the regime with more ease. (2010: 17)

As I have outlined throughout this thesis the oppression I experience as a disabled person is enacted in neoliberal capitalist structures policies and procedures and there are many instances where I am not free to do as I choose, and I am not afforded the kind of liberty and freedom that many other people take for granted. As Ziv suggests, laughing at ideas and people that I perceived as having a detrimental affected on my life helps to reduce fear, and allows me to go on living in society despite my disablist experiences.

I also enjoy the work of the comedian and activist Mark Thomas. As is Lee's his comedy is political, yet in a different way. Thomas uses comedy to talk about, engage in, and achieve substantive social change. As Double (2015: 664) comments, 'the anti-authoritarian left-wing stance he espouses in his comedy is absolutely consistent with the political campaigning he conducts in his offstage life'. Lee and Thomas are both attempting to display integrity whilst being funny and engaging in activism. Mark performed at my workplace in April 2016 and I recorded this in my Journal:

> Mark Thomas left me elated, I could do with watching him 5 nights a week instead of one. I particularly enjoyed the swearing choir, the RBS 10K and his story about the impeachment of President Trump. (Journal Entry, 2015: 104)

I include below a couple of extracts from the show and accompanying book of the same name, *100 Acts of Minor Dissent*. Between May 2013 and May 2014, Thomas gave himself a year to commit 100 acts of minor dissent. If he failed to do so he promised to donate £1000 of his own money to the UK Independence party (UKIP) a political party he particularly dislikes (Thomas, 2015). The first example is Act Two of 100 Acts of Dissent, this one conducted in a campaign to support the right of Saudi Arabian women to drive. It is included here as an illustration of the inclusive and diverse character of Mark's activism in that he does not campaign solely in support of one specific social group or issue. At time of writing, Saudi women were forbidden to do so because of their sex:

> Act Two - Barbie Cars
>
> Fortunately, the target of act two reacted with the dignity and charm of a masturbating clown. I assembled a few friends to help with this act: my long-term collaborator Tracey Moberly (artist from the Welsh valleys), Dr Bipasha Ahmed (neighbour and psychology lecturer) and fellow comic Josie Long. I presented these intelligent, incisive and creative women with the most appropriate and meaningful gift I could find-a remote control Barbie car. A bright and stunning pink toy with the words 'Beautiful Girl' on the bonnet. 'Why do you do this?' You ask. 'Because I'm a feminist', I reply. One morning we took the cars up to Mayfair and then my friend raced them outside the Saudi Arabian Embassy … while we were taking the victor's photo, some of the diplomatic staff from the embassy ran up to the railings, shouting and furiously jabbing their fingers in the air.' If you let them drive, THEY KILL THEIR CHILDREN!' (Thomas, 2015: 15-16).

The second example is Act Five of Mark's 100 acts. This was about pressurising the company Love Film (now Amazon Prime Video) into captioning their streamed content so that deaf viewers can enjoy their content:

> Act Five - Love Film Hate Deaf People
>
> In 2011 tax-avoiding bookseller Amazon acquired the DVD rental company LoveFilm (now Amazon Prime Instant Video) and with it the ire of many of the 10 million in the UK with hearing loss. While in the US Amazon's on demand services provided subtitles, Amazon was refusing to do the same for its UK customers, or even provide information about which DVDs were already subtitled and which were not, making choosing a film a lottery if you are one of the 10 million. Why such a difference in policy, you ask? I have no idea except perhaps that Amazon is forced to subtitle in the US to comply with anti-discrimination legislation. On the Last Day of the 100

> Acts - 13 May 2014 - after locating Amazon's Swanky New Headquarters in Holborn, London, with the aid of some friends and a tallish lightweight aluminium ladder, we slapped a poster on the glass frontage of Amazon's HQ above the revolving entrance doors. AND … That evening Amazon announced a change in policy. (Thomas, 2015: 18-19)

The comic activism of Mark Thomas is so effective that when he was engaging in his hundred acts of minor dissent between 2013 in 2014 the Police employed legislation relating to domestic extremism to place him under surveillance. As Mark noted in his book *100 Acts of Minor Dissent*:

> Domestic extremism legislation mainly refers to individuals or groups that carry out criminal acts of direct action in pursuit of a campaign. They usually aim to prevent something from happening or to change legislation or domestic policy, but try to do so outside of the normal democratic process (Thomas, 2015: 33)

Despite this, his activism did not result in one single criminal conviction. His activism is funny and peaceful, and is carried out lawfully. He practically, overtly and often very publicly undermines and obstructs neoliberal practices, and attempts to be a force for social justice. As a disabled person who has experienced plenty of social injustices and whose life has been made more difficult by neoliberalism, to know that there are people out there willing to challenge them publicly, and often at personal cost to themselves, provides me with a great deal of comfort and hope. It is good to know that I share the world with people who are willing to stand up to injustice and challenge entrenched neoliberal ideas and beliefs.

Another performer whose comedy and humour I enjoy is comedienne and ventriloquist Nina Conti. I have seen her perform many times, including at my workplace and other local venues, and her act was a highlight of my trip to the Edinburgh Fringe Festival mentioned earlier:

> I also have a ticket for Nina Conti on Saturday night, the knowledge of Nina alone is enough to make me cheerful. I have a ticket in the middle of J row, the staff row of choice, I love her work … I'm going to see Nina Conti, if you don't know her name, you should. I'm just hoping she brings Monk. (Journal Entry, 2015: 57-58)

Nina, the daughter of actor Tom Conti, is a classically trained actress, who was inspired to try out ventriloquism by former lover and renowned theatre maker Ken Campbell (Kessler, 2016). Nina's most famous puppet is Monkey, affectionately known as 'Monk', a monkey glove puppet whose voice bears a strong resemblance to that of Scottish actor and former James Bond, Sean Connery (Kessler 2016). Williams (2008) has observed why Nina's act works so well and the foundation on which her comedy is based:

> At the heart of Conti's act lies a simple premise: she is a polite, well brought up lady, embarrassed by crude language and sexual references; Monkey is a foul-mouthed rapscallion who takes pleasure in giving his master reason to blush. (Williams, 2008, unpaged)

Monk acts as an outlet and conduit for things Nina herself either cannot say or would be regarded as social unacceptable or offensive, that is, if they were not voiced through a machine-washable monkey glove puppet (Irvine, 2012). As Price (2013) comments, while Monk's appearance may suggest a childlike interpretation, his profanity resists this and yet the fact that such words emanate from a toy monkey puppet is the source of much of the humour, allowing the boundaries of social acceptability to be crossed. In effect, as Nina herself acknowledged, in an interview in *The Big Issue* magazine (2016), Monk reduces Nina's accountability for the things she says:

> I think the art form of ventriloquism appealed to me so much because it solved a problem from my childhood. I remember feeling quiet and wishing I wasn't. I was shy and scared of getting things wrong, so it's no surprise that I found a liberating mouthpiece with Monkey that wasn't me – I didn't get into trouble or have to worry about accountability (Conti in interview with Holmes, 2016)

For me, part of the appeal of Nina and her comedy derives from the fact she is a woman operating in a traditionally male-dominated domain of stand-up comedy (Mills, 2005). She gives the appearance of being a polite, well dressed, educated middle-class woman and this contrasts to, and often jars with, the things Monkey says and expresses. It is from this juxtaposition the comedy arises. As Price observes, an adult female in dialogue with small toy monkey is already suggestive of comedy. Throughout the act the audiences are invited to identify and misidentify with Monk; the size difference between Nina and her puppet is played upon. The established power relations between Nina as the ventriloquist and the monkey as her puppet and the mechanics of ventriloquism (clearly, Nina is really in control) are manipulated to great comic effect. The outcome is that Monk often appears to be the central comic force in the performance (Price, 2013). I offer the examples below from one of Nina's first shows *Complete and Utter Conti* as an illustration of this:

> Monk: Am I real monkey?
> Conti: Yes you are.
> Monk: I don't understand the Velcro.
> Conti: Don't worry about it.
> Monk: And I've got a tag on my arse that says 'Made in Taiwan'.
> (Conti 2007)

> Conti: Why did the monkey fall out of the tree?
>
> Monk: Because he was dead.
>
> (*Drily*) Ha. Ha. Fuck you.
>
> (Conti, 2007)

My enjoyment of Nina Conti's comedy derives from Monk's profanity. I enjoy the shock value, the sense of unpredictability that is a hallmark of Nina's performances. However, if Monk were just profane, the act would not be anywhere near as appealing. As a character, Monk is at points sensitive and funny, and the audience is invited to empathise with him as if he were sentient. I also enjoy Nina's act because it allows her, as a polite, educated, middle-class, non-disabled woman, to say things that I, as a working-class disabled woman, feel I cannot. Whilst I could say them, I think they would be perceived differently, and I fear I would be criticised for my behaviour. My social survival is often predicated on the suppression of my emotions and, whilst I am not in the habit of swearing at people, I do enjoy swearing as a means of acknowledging my own emotions, getting rid of frustration and expressing my feelings. In this way Conti's performances act as a form of emotional release for me and help me to manage and endure disablist experiences by providing me with a relatively safe context and space to release my less socially acceptable emotions.

I also enjoy dark comedy. Dark comedy has been defined and characterised in a number of ways. For example, Bucaria observes that the genre involves 'making fun of situations usually regarded as tragic, such as death, sickness, disability, and extreme violence, or of the people involved or subject to them' (2008: 218-219). As Meszaros (2003) notes, dark comedy is 'a genre that discovers humour in pain, suffering, and even terror. An edgy, disquieting mode, it has no truck at all with decorum or sentiment' (Meszaros 2003, unpaged). In addition, Collings suggests that the humour which comprises dark comedy is humour which derives from ‘a mixture of the “Black” and the “sick”, sometimes vaguely satirical but rarely attributable to an especially noble agenda’ (2018: 2). I recognise that dark comedy is not for everyone, as with other forms of humour, given that it has the potential to cause offence, upset or distress. As Hunt acknowledges, the genre may function to: ‘[test] the boundaries of what is permissible on broadcast TV’(2008: 25). Given dark comedy’s focus on sickness, ‘disability’ and ‘illness’, a reader might question why the genre appeals to me as a disabled person, how I can watch and enjoy this form of comedy and how and why it helps me to manage and endure disablist experiences, particularly since, as Collings (2018) astutely observes, much of the humour in British dark comedy is predicated on, and derived from, ‘disability’ and impairment and even actively exploits disability for its own purpose. Collings (2018) observes that many of the characters in British dark comedies such as *Psychoville* and *The League of Gentlemen* imitate ‘disability’ as part of their characterisation, and that in such comedies, ‘disabled’ characters are not regarded as fully human or ‘proper persons’, to paraphrase her paper’s title. Referencing the work of Goffman on stigma she observes that in British dark comedies disability is a stigma symbol. She offers Mr Jelly from *Psychoville* as an example. He is a clown with a prosthetic hand which has a hook on the end, someone who wears a full clown costume whether working or not. Collings contends that characters in British dark comedies ‘are presented as overtly combining the aesthetics of ‘disability’ or impairment with traditional horror aesthetics, and as individuals who are lacking something; they are “incomplete”’ (Collings, 2018: 12).

Whilst it is possible to interpret ‘disability’ as the butt of the joke in dark comedies, and Collings’ analysis is enlightening and insightful, I wish to offer a different interpretation of the genre. I do not think I could derive any pleasure from watching dark comedy if I watched it purely from the point of view that my impairment was being mocked or ‘disabled people’ were being ridiculed. Arguably, most characters in dark comedies are odd or eccentric in one way or another, whether imitating impairment or not. For example, in the fictional world of Royston Vasey and *Psychoville*, everyone is strange, whether they are impaired or display physical evidence of ‘disability’ or not. If anything is being mocked in this dark comedy it is the oddness of human behaviour and the absurdity of human interaction. I am more inclined to interpret these types of dark comedies as reflecting the ways in which society responds to difference, including ‘disability’ and impairment - or indeed anything or anyone regarded as unusual or odd. Part of the reason such comedy helps me to manage and endure disablism, is that it reflects back to me, in a safe and humorous way, how society sees and responds to ‘disability’ and impairment. Rather than seeing the genre as mocking and ridiculing me as a disabled person, I interpret it more as a social critique. For example, one of my favourite characters from *The League of Gentlemen* is Pauline Campbell-Jones. Pauline works in Royston Vasey’s Job Centre and facilitates an employment course for those looking for work, known as Restart. Pauline regards her jobseekers with an unpleasant mixture of mockery, disdain, and derision. I include below a couple of illustrative extracts from the series. Her attitude towards those she is supposed to be helping is made immediately apparent by the way she addresses them. From the very beginning of this scene, she reminds them that they are unemployed and presents a stereotypical negative image of what unemployed people do during the day, including the indirect implication that they should think of themselves as worthless and pathetic:

> Hokey, cokey, pig in a pokey. Hello, gents! It’s half past nine. Time for men, men with jobs to go to work. Other men stay in bed ‘till dinner time watching Tots TV, thinking about how worthless and pathetic they are. Good morning job-seekers! (BBC 2, 1999-2002)

In the second example, Mickey, a learning-disabled male and one of Pauline’s jobseekers, has a job interview and wants to leave class to attend it. Pauline does not want to let him go and Ross, another member of the class, starts to argue with her in defence and protection of Mickey:

> Pauline says, “Where would I be if you all got work before the end of this course?” Mr Wadilove, another job seeker answers, “On the dole”. Pauline replies, “Exactly! I’d be sat here next to Mr Wadilove stinking of shit. This is my job we are talking about.” Ross disagrees, “No it’s not. It’s Mickey’s job. You go, Mickey!” While Ross and Pauline keep arguing, Mickey gathers the courage to speak, “Please, Pauline. I feel confident.” Pauline replies, “Well you look ridiculous. I know they put monkeys in space, but do you really think they’ll let one drive a fire engine. Sit down!” (BBC 2, 1999-2002)

Although an extreme example, the value of this caricature for the purposes of managing an enduring the experience of disablism is the public recognition that Paulines’ character is in some way real and grounded in lived experience of employment officials. As one of *The League of Gentlemen’s* writers, Reece Shearsmith, comments the character of Pauline was based on his own Restart officer:

> That was my restart officer from the olden times. And she was just a character. It was just there. Not quite like Pauline now, but I mean, I remember coming back everyday with stories about her, and it was just brilliant. (Dyson *et al*., 2005)

Pauline’s attitude to her jobseekers is so well observed that the attitude of some Job Centre staff can be publicly recognised and acknowledged. Although an extreme characterisation, Pauline articulates an attitude and social response that I have encountered many times when attending Job Centres and attempting to find employment. She voices an identifiable social and political discourse in relation to unemployed people and in terms of her characterisation accurately articulates the social stigma sometimes associated with unemployment and claiming benefits. I have met many ‘Pauline’s while attempting to find employment. For example, I have sat in Job Centres while those supposed to be helping me have argued over whose responsibility it is to pay my travel expenses, have been on many ‘disability’ specific and generic employment courses like these depicted in the show in my attempt to find work, and have witnessed similar social attitudes to those expressed. To have these attitudes and responses publicly recognised and acknowledged in a mainstream TV show helps me to manage and endure disablism, in that it serves as a form of catharsis. In watching Pauline, I am able to recognise the poor social responses I have received and to gain some comfort from the fact that this is being publicly recognised. Remembering Ziv's (2010) earlier comments in relation to oppression, Pauline's characterisation serves to reduce my own fear and makes it a bit easier to go on living in society, as the social attitudes she embodies and the institution she supposedly represents, the Department of Work and Pensions (DWP), are mocked and ridiculed. Moreover, unlike those who mistreated me in the past, or whose responses were inadequate, Pauline is held accountable for her actions and is subject to disciplinary proceedings. I enjoyed watching the episode in which she got her comeuppance; in an indirect way, it felt that some form of justice was served. Pauline ends up attending her own Restart course and is forced to take employment in a burger bar.

Much of my own enjoyment and pleasure of watching dark comedy derives from the fact that I do not have to maintain any particular pretence in terms of how society sees me or perceives impairment or social responses to 'disability'. I do not, for example, have to keep up the pretence of happiness that seems to have become a prerequisite for contemporary public life (Ehrenreich, 2009). I do not have to pretend that the world I live in is equitable or fair or that my needs are met. The darkness of dark comedy provides me with a safe space in which to acknowledge how I actually feel, which often contrasts sharply with how other people expect me to feel, or how I am 'supposed' to feel: an important reason why this form of comedy helps me to manage and endure experiences of disablism. I think a fair amount of human psychological distress derives from having to maintain the pretence of some form of contentment or happiness, either with ourselves as individual humans, or with the world we live in (Ehrenreich, 2009). When I watch dark comedy, in a small way, I feel released from this. I do not have to maintain the pretence that I am treated as a social equal as a disabled person. This realisation in itself helps me to manage and endure experiences of disablism. As well as enjoying watching dark comedy, my own sense of humour can sometimes be dark. The next section explores the way I utilise comedy, humour and laughter in my daily life.

My Use of Humour in Daily Life to Help Me Manage and Endure Experiences of Disablism

Below is an example of my own dark humour from my Journal:

> It's Grand National week, and I'm not betting on moral grounds, I don't think they should shoot the horses that pull up. I think they should take care of them instead of shooting them in the head and justifying it on the grounds of cost or ending the suffering of the animal. SOMETIMES I FEEL LIKE A HORSE, I AM A HORSE. (Journal Entry, 2015: 3)

I want to spend a bit of time unpicking and contextualising this because it illustrates both my style of humour and how I use comedy. When I was younger, we used to bet on the Grand National as a family tradition. As an adult, I have stopped doing so on ethical grounds. In this journal entry, I am also attempting to draw attention to the similarity with social responses to disabled people which can sometimes feel as if it would be better if we did not exist at all or were put down. My statement 'I feel like a horse, I am a horse' refers to the fact that I live amongst some people who would respond to me in this way and makes explicit the social devaluation of disabled people's lives to which we are often subjected. These attitudes towards disabled people may be implicit, but are readily socially identifiable (*see* Gallagher, 2013; Smith, 2020). They became more explicit in relation to the social and medical response to many disabled people during the Covid-19 pandemic (Smith, 2020). This attitude is also made manifest in the way that disabled children are treated in society. As Clements and Read comment, referencing Asch (2001):

> Asch (2001) points to the way in which the stigma and devaluation of life with 'disability' are evidenced in the acquittals or light sentences given to professionals or family members who decide to end the life of a 'disabled' child or adult. The fact that these outcomes would not be countenanced had the victims of the crimes not been 'disabled' might suggest that their lives are seen to be worth less, that they are assumed not to have lives worth living or that their personhood, on a par with others, is somehow being called into question. The violation of the most fundamental human right, the right to life, may not only be regarded by some as an understandable act from the perspective of the perpetrator, but on occasion, it may also be recast as being in the victim's interest: a mercy killing. (Clements and Read, 2008: 10)

I am using humour to convey a very difficult message and to reflect back how society sometimes sees me as a disabled person. To an extent I am also expressing my own fears at being subjected to such a social response. Obviously, I am not a horse (although I do confess a liking for carrots), but my use of such imagery allows me to reflect on how I am sometimes regarded socially, and showing this view back towards the society I am living in through my writing and use of humour. Lockyer (2015) has referred to 'disabled' stand-up comedians who reflect disabling discourses back at society as using a 'reversed disability discourse' which 'switches the comic gaze outwards towards disabling social norms and critiques disabling stereotypes' (2015: 1406). Whilst I am not a 'disabled' stand-up comedian, the above example from my Journal illustrates how I use comedy in my daily life to highlight disabling social norms and critique disabling stereotypes. Doing so on my own terms, and in my own words, is an important aspect of my management and endurance of my experiences of disablism. It allows me a degree of agency and control over how I, and my experiences, are represented and this is especially important to me in contexts where the impact of disablism upon me is minimised or ignored. It is a way to let others know that I am aware of how society often perceives impairment and the impact this can have on me as a disabled person. I also think it is important to highlight disablism as much as

I can in the hope that the society I live in will become less disablist and more accepting of disabled people. I also use similar techniques in the following example:

> My life often forces me into the role of an activist, but for the sake of my own emotional and psychological health I need some ‘days off’ from being that person, or I’m not going to have any memories worth keeping. If I chose to argue every time there wasn’t a ramp or the access was poor, or, as in this case, the organisation and logistics of transport were discriminatory, my life would be one long argument, oh wait. :). (Journal Entry, 2015: 73)

In the above example I am trying to communicate what it feels like to be impaired and live in the society I do, i.e., that life often feels like one long argument in which my impairment is often a central factor. The entry is written as if I am only realising this for the first time (‘oh, wait…’), as if in the act of writing this has just dawned on me, when in fact I have been aware of this realisation for a very long time. I am attempting to convey to any potential reader an aspect of what it feels like to live with impairment and some of the social implications of being impaired. I am referencing the fact that social interactions can be exhausting on top of actually living with the impact of my impairment. I am playing the fool in the attempt to enlighten and educate any potential reader, as to what being disabled sometimes feels like particularly when interacting with other people.

Toilet humour is a common and recurring theme of my journal. Below are two examples:

> My day so far…
> Work.
> Massive poo.
> Even bigger migraine.
> (Journal Entry, 2015: 14)

> Really quiet day at work, I took no money, but it was great to be back. Today's customers just seemed to want a chat and luckily for them I'd had a good poo before the start of my shift, so I was feeling in a chatty mood. (Journal Entry, 2015: 45)

The first example here that begins 'My day so far…' Is my own parody of a T-shirt worn by the professional wrestler 'Stone Cold' Steve Austin. The original t-shirt had the following words on the front positioned as I display them here:

> Arrive.
> Raise hell.
> Leave.
> (WWEShop.Com, 2022)

The second example is from an afternoon at work where most of the customers I encountered just seem to want to chat. The inclusion of so much toilet humour in my Journal is a conscious and deliberate act influenced by the following thoughts. My mood and health are often improved by a poo. In the context of 'disability' assessment, for example, ESA or PIP I am often pressed into rationally responding to questions about how I go to the toilet and I am required to give strangers very personal information in respect of this activity, which even in the context of assessment is really none of their business. I often want to respond to this in very straightforward terms, but refrain. Maintaining a sense of humour about this helps. In addition, as discussed in the excluded disabled self, chapter four, my right and need to go to the loo is not always upheld by society. For example, I cannot always go to the loo when I want or need to go because facilities can be either non-existent or inadequate and inaccessible to me. For me, because society often fails to provide these facilities, going to the toilet in a public space has become a privilege rather than an expectation. In not accounting for our most basic of human needs, society sends the overt message that disabled people do not matter. In including discussion of (in)accessible toilets in my research and my use of toilet humour I am trying to draw attention to an issue many disabled people face on a daily basis. The issue of improved accessible toilet provision for disabled people is ongoing and has been the subject of many a campaign (*see* MDC, 2014; Changing Places, 2018). By featuring it in my own research I aim to support such campaigning and to contribute to improving accessible toilet facilities for disabled people.

In this chapter I have explored ways in which comedy, both television comedy and my own personal use of humour in daily life helps me to manage and endure experiences of disablism. I suggest that comedy and humour gives me hope and makes the complexities of being impaired and living in a disabling society a bit easier to cope with by making these conditions explicit and recognised. In the Conclusion that follows, I summarise and draw together the main findings of my thesis and explore some potential areas of further research and exploration.

Chapter Nine

Conclusion

The central premise of my thesis is that social responses to disabled people, and neoliberal policies like austerity exacerbate disablism, and make the experience of living with impairment harder for many disabled people. Whilst this argument might not be new, my research illustrates how these policies make the experience of living with impairment harder, both broadly and in many specific, concrete ways, through my own experience and the experience of other disabled people. In order to show this, I have used existing concepts within disability studies and my work has been informed by them, this is especially the case in relation to psycho-emotional disablism. I suggest that these concepts help to illuminate and understand the depth of disablist oppression and discrimination, as experienced by people with impairments. This chapter will highlight specific conclusions that can be drawn from my research: what my research contributes to existing scholarship; possible limitations of my study, and pointers for further research.

The Disabled Self and Current Forms of Disablism

My research has broadened and developed my own understanding and perception of disablism. Before embarking on my studies, whilst I understood that discrimination, prejudice, and exclusion were common aspects of the experience of living with impairment, I did not then have the broader conceptualisation of disablism through which to explain and articulate my experiences.

My research has made me even more aware than when I started this Ph.D. of the barriers I faced as a disabled person living in England, and of the systematic nature of disablism. I am left with two main thoughts when reflecting upon my experiences. First, given my awareness of these barriers it makes what I have managed to achieve seem even more remarkable. Second, the awareness of the number of barriers I face has become a psychological barrier in itself. In the latter context, I am more likely to withdraw from society and less likely to attempt to accomplish goals such as seeking employment or obtaining the practical support I need to live the life I wish to have. Although not universally accepted, disablism is an aspect of contemporary society. Repeated experiences of disablism make me want to avoid future occurrences because they are very psychologically painful and damaging to me. In addition, my increased awareness of the barriers I face make them more challenging to endure, tolerate, and rationalise.

My research illustrates that disablism, as defined in chapter two, a social context for disablism, is human in origin and embedded within society. My research also highlights the disablist nature of both austerity and neoliberalism and the extent to which they exacerbate the lived experience of impairment for many disabled people. Disablism and its impacts are identifiable in the very organisation and structure of environments and by the inaccessible and exclusionary nature of many public and social spaces, as featured in chapter four, the excluded self. The social and relational nature of disablism is also illuminated in chapter five, the assessed disabled self, which describes disablist practices that are part and parcel of current assessment processes like Employment and Support Allowance (ESA) and Personal Independence Payment (PIP). This chapter explores how those who are subject to these types of assessments experience the process and highlights their inherent inequality and injustice, drawing attention to the fact that many ‘sick and disabled’ people find them distressing, traumatic, and damaging to their mental health.

The lived experience of disablism and its detrimental psychological impact is also established and developed in chapter six, the psycho-emotional disabled self. The experience of psycho-emotional disablism is evidenced by the reactions and psychological responses of disabled people to the social situations we find ourselves in and events that occur in our daily lives. Examples include, degrading experiences such as assessments, the repeated experience of structural disablism, the threat of and often the lived experience of disability hate crime, and the pressure that some disabled people with invisible impairments feel to display their impairment in the hope of not being confronted or abused while going about their daily lives.

Given the socially embedded nature of disablism, self-care as defined and discussed in chapter seven caring for the disabled self, may become an imperative for many disabled people, if it is not already. I feel it is important that disabled people document and theorise their own strategies for self-care, citing activities that provide us with pleasure and enjoyment, reduce stress, and aid recuperation. Such acts are not only important from a personal perspective; they may also be of practical help to others through fostering collaboration and community based on our shared and common experiences. In a society where so many disabled people experienced so much disablism, it is important to foster relationships of support where people can talk openly about their experiences, however they may represent them, share experiences and strategies that may help each other. In addition, in a disablist society theorising, naming, and discussing activities that disabled people enjoy can help to foster a sense of self that reduces the psychological and physical impact of living within a disabling society.

As evidenced in the core chapters of my thesis, the comprehensive task of naming disablism and explaining why and how a particular space, behaviour, act, or policy is disablist often falls to disabled people themselves, which in itself can be exhausting. As are other examples of disabled people's experience, disablism as a concrete aspect of disabled people's lived experience is often ignored, minimised or not acknowledged as real by many people. Disablism as a concept is not widely recognised and is often misunderstood. Like other 'ism's, disablism can be too easily explained away, justified or hidden in such phrases as 'we haven't got the money' or 'why should you get special treatment?' (Council of Europe, 2022). Alongside many other disabled people, I do not want special treatment. Special treatment is not even special treatment, it is equity, and often a very basic equity at that. I do not feel that disablism is taken as seriously as racism, for example, which is understood by many to be a concrete aspect of the lived experience of many black people (House of Commons and House of Lords, 2020). Arguably, if it were, society itself would be very different. For example, social spaces would be more accessible to me and to other disabled people and the experience of exclusion common to so many disabled people would be less prevalent. Arguably, if disablism received greater recognition, disabled people would have greater space to assert, and be confident in, asserting their own needs, and asking for help in the context of assessments for Employment and Support Allowance and Personal Independence Payment. Furthermore, if disablism were widely socially recognised and taken seriously then the psycho-emotional effects for many disabled people may be mitigated, reduced, or eliminated altogether. Moreover, if disablism and its impacts were more widely recognised and acknowledged, many disabled people might not have to devote energy to engaging in self-care to mitigate the effects of disablism, or at least disablism might not form such a large part of the rationale for doing so.

A Framework for Facilitating Change

In my use of autoethnography, and drawing on research conducted by disabled people, I hope that my thesis contributes to social change by documenting and prioritising the experience of disabled people from our own perspectives. I also hope that my research contributes to an understanding of the impact of disability in terms of how it feels to live with an impairment and how it is experienced. In particular, I hope that non-disabled people gain a better understanding of what it is like to live with impairment and thus improve public consciousness of the social model of disability and its implications for radical change. This is important because the views and perspectives of the mass of disabled people are commonly ignored or omitted when important policy decisions affecting our lives are being made. For example, in the reform to disability benefits assessments, the transition from Disability Living Allowance (DLA) to Personal Independence Payment (PIP) was a key austerity policy, yet the views and perspectives of those subject to these assessments do not appear to have influenced it, either prior to, during, or after its implementation. PIP remains subject to a deficit-based, medicalised assessment that conceptualises disability as a problem of the individual ignoring almost entirely the role that society plays in the experience of impairment. Furthermore, in documenting and prioritising disabled people's lived experience, and highlighting the human impacts of living in a disabling, neoliberal, austere society, I am making visible the inequality that many disabled people live with. For example, the excluded self chapter highlights the human impacts of inaccessible and exclusionary social spaces and environments, and the assessed disabled self chapter highlights the human impact of the assessment process for Employment and Support Allowance and Personal Independence Payments on disabled and sick people and their families. This is important because the detrimental impacts of this process are often denied are not widely recognised or understood. Although there have indeed been various political critiques of these policies (*see* Mendoza, 2015; O' Hara, 2015; Ryan, 2019; Clifford, 2020). Chapter five provides detailed insight into and raises awareness of how assessed people actually experience the process. It is this perspective that, despite a raft of media coverage in relation to people having their benefits stopped, and the impact of this, is largely absent from, or ignored, in the debate and discourse about welfare and disability benefit reform, and is chiefly impotent in terms of its influence on government policy, (for example, Vale, 2017; BBC News, 2017a). My research respects underrepresented voices and resistances within academia and scholarly practices such that it further informs more critically engaged disability studies and offers more nuanced, detailed analysis and understanding of the experience of disabled people, in order that arguments for social change and remedies for inequalities can be more powerfully made.

Throughout my thesis I discuss the challenges faced by many disabled people in finding employment, this features in chapter one, my autobiographical commentary, chapter two, a social context for disablism, and chapter five, the assessed disabled self. One clear illustration of my research is that employment for disabled people has to be meaningful, financially viable, and adjust for each impairment in ways that support a disabled person to do their job. Efforts must be made to create an employment culture in which disabled people are not automatically considered inferior to non-disabled people in the context of employment.

My research also illustrates, especially through chapter six, the psycho-emotional disabled self, the different ways in which some disabled people experience disablism, and how the experience of living in a disablist society has a detrimental impact on our psychological and emotional health. my excluded self shows that accessibility is an ongoing issue for many disabled people and more needs to be done to create a substantively accessible, inclusive society. One issue this chapter highlights, is that, in respect of equality in relation to 'disability', the legislation contained within the 2010 Equality Act needs to be both less flexibly worded and more meaningfully enforced (The Equality Act, 2010).

My research shows that much still needs to happen in order to facilitate the kind of social change that may bring about more substantive equality for disabled people. In broad terms, the U.K. needs a change of government, resulting in a move away from neo liberal politics and policies that focus almost exclusively on encouraging profit-making for the few, that offer little consideration of the human impact, or of the psycho-emotional consequences for people. For me, the interests of disabled people are best served within a broader, systemic set of social change, within which an emboldened framework of equalities legislation can support meaningful protections, rights and entitlements. Moreover, a political system strongly grounded in respect for equality and fairness, with public institutions making the same commitments, would be more likely to work with, rather than against, the grain of Equalities law.

To that end, as stated in chapter two, a social context for disablism, I favour a renationalisation of public services, regulation of capitalism and the financial system that enforces caps placed on profits, a more equal and distributive system of taxation, and greater monetary investment in public and social services (as opposed to cuts). I also think that large corporations should not be permitted to avoid taxation in the way that ordinary citizens cannot. I am additionally in favour of a substantive enforcement of the Human Rights Act, which is supposed to guarantee universal human rights for all and recognise that a wholesale shift in social attitudes to disabled people is required, where disabled people are more commonly regarded as humans in their own right and for their own sake by others (Human Rights Act, 1998). I acknowledge that progressive economic policies alone are insufficient to tackle inequalities that may be predicated upon other forces, such as prejudice and discrimination These need their own, more particular, remedies such as emboldened rights and equalities legislation and consciousness raising and education. However, I do not consider it accidental that neoliberals wish to abrogate from universal human rights commitments.

My Contribution to Existing Literature and Theory

My research is an in-depth piece of autoethnography documenting what it is like to live with an impairment, and to be a disabled person in England during a particular time of neoliberal austerity policy. As such, it principally contributes to the fields of autoethnography and disability studies. My employment of autoethnography for Disability Studies-based research shows how it can be usefully applied in different contexts, thereby expanding its reach and relevance. It might also be useful to the research field of Disability Studies in advancing the Emancipatory Disability Research (EDR) paradigm. For example, combining both EDR and autoethnography provides a way of making connections between the personal and the social and may help to address a key criticism of the social model of disability, that it ignores the personal, lived experience of impairment (Morris, 1996), given that autoethnography places the personal at the forefront of research.

I also feel my research is relevant to the education and socialisation of medical and para medical professionals because of the lived experience featured, the alternative ways of understanding disability and impairment presented, such as the social model of disability and the concept of psycho-emotional disablism. I feel that many professionals are either unaware of the extent of the barriers faced by disabled people, including the nature and scope of their impacts, or are in denial about it. Therefore, the inclusion of disabled people’s lived experience is central to the education of health and social care professionals if practice and disabled people's experiences of health and social care are to be improved. Based on my experience, I feel that that there is too wide a gap between theory and the practice of health and social care. In other words, the experience I am *supposed* to have, as compared to that which I actually experience lie very far apart.

My application of concepts like Kitchin's (1998), idea of disabled people's 'knowing their place' and being 'out of place', and Cooper's (2000) concept of 'The Bladder's Leash', expose the seriousness and complexities of disabled people's experiences in contemporary society. It illustrates the stark intersection of embodied and psychological suffering, segregation, degradation and exclusions which operate in everyday social life. Such illustration helps to make visible some of the additional barriers many disabled people face, and the sacrifices we make as a condition of our social participation. In doing so, it presents a challenge to the notion that England, in terms of its social response to disabled people is a civilised society.

My research adds to a growing body of work that looks at the personal, social and material impact of assessments on those who are assessed (e.g., Campbell *et al*., 2012; Burgess *et al*., 2014; Garthwaite, 2014; The Spartacus Network, 2015; Akers, 2016; Pike, 2018; Saffer *et al*., 2018: Morrison and Jay-R, 2021). Reforms to disability benefits were a key aspect of austerity. I feel that the voices and representations of those who are a direct target of these changes, the 'sick and disabled' of our population, have been ignored at all stages. In the context of both the discourse surrounding disability benefit reform and the assessment process for Employment and Support Allowance and Personal Independence Payment, disabled people continue to experience epistemic injustice, both testimonial and hermeneutical injustice as outlined and defined in my methodology (Fricker, 2006; Fricker, 2007). Given this, it is important that disabled people document their experiences from their own perspectives and talk about how it felt for them. Despite considerable media coverage, and perhaps in part because of the framing of some of it, which positioned disabled people as 'living lavish lifestyles on benefits' or 'scroungers' undeserving of financial or support, I still do not think that the impact of reforms to disability benefits on 'sick and disabled' people has been fully documented and is widely understood by the general public (Briant *et al*., 2013; Harrison, 2015; Chapman, 2016; BBC News, 2017a). Public empathy with and perhaps even solidarity for those subjected to the deeply probing assessments may require a more visceral account of the personal impacts of the kind that my research provides. I think that there are many untold stories yet come to light about the impact of reforms to disability assessments on many 'sick and disabled' people as will be felt for years to come. This is particularly true of the financial, social, and psycho-emotional impacts as outlined throughout my research. One explanation for the many untold stories is that people have a fear of reprisal and worry about having their benefits stopped if they speak about their experiences. This is particularly pertinent to 'sick and disabled' people who have been denied PIP and ESA, or had it withdrawn, and this has either contributed to or been cited as a direct cause of their deaths (*See* Mendoza, 2015; Mills, 2018). In addition, the stigma associated with being known as a claimant of benefits deters many from making a claim, as having lived experience of these assessment processes also can (Burgess *et al*., 2014; Garthwaite, 2014). I also hope that my research helps to challenge the common misconception that disability benefits are easy to obtain.

My work adds to the body of knowledge about how disabled people experience these assessments. For example, I developed the concept of 'decrepitification' to describe the process that claimants must go through to have a chance of being found eligible for disability-related payments like ESA or PIP. The process of 'decrepitification' as I define it involves three main components. First, claimants must engage in 'doublespeak', which involves writing in a way that conflicts with how you see yourself and employing language that is unhelpful and stigmatising because that is the best way to serve your interests as the claimant (Watts, 2018). Second, claimants must represent themselves as useless, deficient, and incapable. This in itself a representation trap because many disabled people have spent years arguing that we are capable as people, only to have to make representations of ourselves based on deficiency, incapability and non-productivity, which functions in support of political discourses forwarded about disabled people under austerity i.e., that socially we are unproductive, burdensome citizens and a financial drain on the state (Burch, 2018). Third, medical evidence must be provided which supports this deficit-based representation. It is possible and highly likely that the very representation required of 'sick and disabled people', as does the fear of reprisal, contributes to our silencing and also deters many from making a claim. I used the umbrella term 'decrepitification' in the recognition that all three components are necessary to have a chance of being eligible for ESA or PIP.

The concept of 'decrepitification' provides disabled people with a shared, shorthand language for understanding the experience of being assessed; it offers the potential for solidarity and collaboration across impairment groups. This is an experience that many 'sick and disabled' people have in common. In this respect, many disabled people provide psychological, emotional, and practical support to each other and also to campaign for reforms or an end to medical-based assessments. It also provides others with insight into the representations disabled people are required to make to be considered eligible for ESA or PIP. As an aid to understanding from the perspective of 'sick and disabled' people what it is like to be assessed, I feel my concept complements other terms used by disabled scholars. Examples include the 'fear and terror of the brown envelope', which has become a shorthand symbol for the anxiety and fear that the assessment process invokes in many claimants because letters and forms in relation to assessment and benefit claims are commonly sent in brown envelopes (Pike, 2018; Garthwaite, 2014). The concept of 'decrepitification' may also have wider applications. For example, as well as for 'physically disabled people', it could provide people who are 'chronically ill' or those who experience mental ill-health with a way of naming, contextualising and understanding their experiences of these and other comparable demanding assessment processes, such as social care assessments.

Another key contribution to existing literature and theory is featured within chapter six, the psycho-emotional disabled self. There, I apply Garfinkel's (1956) concept of successful degradation ceremonies to the assessment process for ESA and PIP. Garfinkel's concept has been applied extensively within the social sciences. It appears for example, in the context of criminality and violence, war, race, and higher education and social control (Schoepflin, 2009; Emerson, 1969; Benson, 1990; Doubt, 2004; Longazel, 2013; Welsh, 2009). However, I could find no examples of its being applied to contemporary disability assessment processes. Therefore, my research is not just contributing to knowledge about disablist austerity, but also adding to the corpus of knowledge about the application of this particular sociological concept, especially its usefulness under neoliberalism.

Strength and Limitations of My Research

For some, the fact that my research is personal, partisan, and subjective may be a limitation particularly given the entrenchment of ideas in relation to the need to be 'objective' within Western society for research to be considered reliable and valid. This may result in my research's being overlooked. By the same token, my research by its nature, seeks to challenge the idea that research has to be objective in order for it to be accepted as valid and reliable. I also think that given the extent to which disabled people, as do other oppressed groups, experience social injustice and the extent to which society is disablist, a position of partisanship is key to addressing this. Broadly speaking, adopting a position of neutrality does little to improve the lives of disabled people or serve the cause of equity or social justice; as a disabled person with a long-term impairment, I cannot sit on the fence. I do not think the adoption of a position of partisanship automatically equates to a lack of rigour in my research. If anything, being open about my partisanship makes the requirement for rigorous inquiry, proof and explanation greater because I am being open about my allegiances from the very beginning. If I had at the outset adopted a position of objectivity, this would likely not be the case.

Although I prioritised research by disabled people in my work, I did not carry out my own interviews with disabled people. I chose not to do this because I know from experience that disabled people are an often-over-researched social group. In addition, I self-funded my Ph.D. and did not have the money to pay disabled people for their time and insight. I am critical of not paying disabled people for their time, given that disabled people are commonly asked, even expected, to engage in voluntary work: I think it is unfair not to pay them, unless they consent or want to work for nothing. I also think in a neoliberal, capitalist society, given the socio-economic disadvantages experienced by many disabled people, not paying us puts us at a disadvantage. Whilst this may be considered a limitation in my research, there are plenty of other ways to access disabled people's views. For example, I was able to access testimonies, disabled-led research, official reports and reviews, Parliamentary briefing papers, and newspaper articles. Therefore, having featured disabled people's perspectives from a range of sources and contexts, I have been able to include a varied and diverse range of disabled voices in my research. To some degree this makes up for not being a position to carry out my own interviews with disabled people, because I have included a wide range of voices and perspectives from many different sources.

In addition, there are many other issues associated with living with an impairment in a disabling society that I chose not to cover in my thesis. Some of these elements were noted in my Journal but, for various reasons, I was not able to include them here. Some examples are: access to health and social care; the challenges and barriers to obtaining support; right to life and/or assisted dying and the experience of accessing leisure activities. This is because, in some cases, such as chapter five, the assessed disabled self, I wanted to prioritise issues pertinent to austerity and neoliberalism; in other cases, such as in relation to my attempts to access social care, I found these experiences too traumatic and painful to write about in detail. Another potential limitation of my research is that it focuses predominantly on the lived experience of wheelchair users as a specific impairment group. This is because my research is grounded in the personal and I am a wheelchair user, and thus the thesis relates to my own direct lived experience. The personal nature of my research may be seen as limiting in that I am only one disabled person, a wheelchair user giving my singular perspective. However, the inclusion of other disabled people's voices in my research makes my work more nuanced and generalisable. If the experiences I featured in my research, and the assertions I made, lacked validity it would be difficult to find evidence in support of them; yet I was able to find plenty of corroborating examples in the literature. I also feel that the individual nature of my research does not mean it lacks rigour or validity. My perspective is as valid and important as that of any other researchers', and also equally liable to critical scrutiny. As my research shows, there are many other disabled people with a range of different and similar impairments with whom I have experiences in common, and my research highlights many social issues and barriers that disabled people encounter. Arguably, the personal and individual nature of my research, the fact I used my lived experience as a catalyst, allowed for greater detail and specificity throughout. I have included personal information and testimony that would not usually be made public. I have made a conscious choice to look at my lived experience predominantly through the lens of disability and impairment. This is because, however you understand disability and impairment, whether in social or individual terms, I consider it to be the central basis of my own experience of inequality and disablism. To me, as someone who has lived with a lifelong impairment, it feels more determinant than other categorisations such as class, gender, and race.

The fact that the raw data of my research, my Journal, was gathered during a specific period of time may be seen as another limitation, because it may be seen as applicable only to the time period in which it was gathered. However, equally, my research documents a specific period in history, a point at which disabled people were openly subjected to specific political, economic and social policies, and directives. It was a period of neoliberal austerity, progressed by a Coalition and then a Conservative government and political regime, which specifically targeted many of us and exacerbated our experience of living with impairments. Moreover, sadly, I feel that the main assertions and findings of my thesis will be relevant and broadly accurate for the foreseeable future. I think it is highly likely that

England will become a more difficult place for many disabled people to live. Accessibility may regress, and many disabled people's material conditions may be worsened by the impact of the Covid-19 pandemic, increased pressure on resources and the social and ideological entrenchment and imposition of neoliberal, austere notions by corporations and governments. If anything, England may become a more disablist place to live (Abrams *et al*., 2020; Shakespeare *et al*., 2021).

Scope for Further Research

My thesis has raised the need for further research in a number of key areas. First, more research needs to be done in relation to disabled people's experiences of benefits assessments, including Employment and Support Allowance and Personal Independence Payment. Whilst there is quite a bit of work on this topic available, research that captures the experiences of disabled people from their own perspectives provides only a snapshot of an issue that has had a detrimental impact on many 'sick and disabled' people. Many of them have yet to speak out, or may fear doing so, about their experiences because of public ridicule, hostility, or the potential for their benefits to be stopped, if it were ever discovered that they had spoken out. I also feel that it is important to collate 'sick and disabled people's' experiences of benefit assessment processes; as yet they are fragmented among various places, including, social media, blogs, and charity reports. The job of research here is to encourage a greater number of disabled people who have undergone assessments to come forward and speak openly and anonymously (if they wish) about the experience, then to collect and collate disabled people's accounts of the assessment process in one volume or archive. This is particularly important since the government is planning further reforms to the assessment process, given the merger of Employment and Support Allowance (now Universal Credit for new claimants) and Personal Independence Payment. The government's stated aim is of cutting costs further and with the added public justification of having to pay for the cost of the Covid-19 pandemic (Pring, 2021).

Based on the lived experiences featured in my thesis, further research needs to be done exploring the experience of psycho-emotional disablism in relation to how disabled people cope with, survive, and negotiate benefit and welfare systems and processes. The experiences may be shared, for example, through peer-to-peer support, locating others who have undergone assessment and providing mutual and practical support, self-advocacy and advocacy, and groups led by disabled people offering practical advice and support in relation to benefits assessments. This can provide disabled people with the comfort that sometimes derives from talking to and with others who have been through similar experiences. It is important to foster a shared language as a counter-narrative and sense of solidarity that can develop from such activity, I hope my research will help in this regard.

I also discussed some of my personal experiences of disability hate crime, which has only been a crime in law since 2003. Although I found it difficult to write about, given its detrimental impact, I felt it was important to add my account of the psycho-emotional effects of disability hate crime to the growing body of work on the subject which documents disabled people's experiences, including the varied responses of police, family members and other services involved in the many cases (Vincent *et al*., 2009; Richardson *et al*., 2016; Hall and Bates, 2019; Healy, 2020). My experience helps to illustrate how the psycho-emotional effects of disability hate crime can be compounded when friends, family or others fail to be supportive. My experience also makes me want to carry out further research following my doctoral studies, to document disabled people's experiences and contribute to the broader social aims of reducing instances of disability hate crime, ensuring that it is consistently regarded as a criminal act and taken seriously when reported.

I feel that the importance of writing about my experience of gaming in the context of self-care lies within the fact that it is an activity I enjoy and find pleasurable. There is so much negativity in relation to the experience of disability, and disabled people, that it is vital for our sense of self, and how others represent us, that we highlight things we enjoy and that give our lives meaning. It became apparent during my research that relatively little academic attention has been paid to activities from which disabled people derive pleasure, such as everyday activities that disabled people might enjoy. My own current list includes, reading, writing, food, podcasts and exercise. One reasonable explanation for this is that there are more pressing issues that need advocating for such as housing, education, and employment. Exploring those activities that disabled people enjoy may get marginalised or pushed to the back of what, for many, may be a very long queue. Lack of research surrounding disabled people's enjoyments and pleasures may also be an indicator of the degree of social oppression experienced by disabled people in that many may not have the opportunities to do whatever they enjoy, or may be reluctant to speak about them out of concern they may be prevented or stopped from doing these activities.

In the context of gaming, there are some studies that recognise the benefits for self-care or therapeutic purposes (*see* Myers, 2019; Freddolino and Blaschke, 2008). However, much of the literature in relation to disabled people focuses upon computers as assistive devices to increase independence, gaming as an aid to education, or improving accessibility; much of it occurs in the context of a patient, in a medical professional relationship (Garrido *et al*., 2009; Kwon 2012; Vergés-Llahı *et al*., 2015; Hofman and Halvacs, 2015; Rinne, 2016; Israel *et al*., 2016). A focus on children and young people is also a common theme of research in this area. (e.g. Ellis and Kao, 2019). However, adult disabled people's accounts of their experiences of gaming (and gaming for fun) are largely absent from the discussion (Romano, 2014). Therefore, this is another area I would like to research further. Specifically, I would like to explore whether, or how, disabled people's experiences of pleasure are similar to or different from my own, other disabled people's or non-disabled people's. It would be interesting to explore whether there is something specific about gaming as an activity that makes it particularly attractive to disabled people, in the sense that it does not include too much interaction with an inaccessible, often disablist social world. It may be one way of mediating and controlling engagement with such a world. Relatedly, in chapter eight, the comic disabled self, I look at some ways in which I use humour to help manage and ensure my experiences of disablism, by watching comedy shows and using humour in my everyday life. I am interested to find out if other disabled people use comedy in similar or different ways to me and whether my experience and use of comedy are shared with other disabled people. If my own research is any indicator, disabled people need all the support we can get to recuperate and/or recharge from interacting with a disablist social world.

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