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# Fair Welfare?
# Understanding the Lived Experiences of Disabled Welfare Claimants

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*Dedicated to those we lost along the way -*

*My courageous Father, Alan Brown (1950-2015)*

*My resilient Nanna, Joan Fitt (1936-2015)*

*& my wonderfully wise friend, Les Roadhouse (1947-2017)*

# Abstract

The Welfare Reform Act (2012) introduced significant changes to the provision of social security within the UK. These changes not only dramatically impacted disabled people's experiences of accessing welfare support but also illustrate a transformation of the way 'deservingness' is perceived, both publicly and politically. Disabled people have been the hardest hit by such reforms, which have been characterised by punitive eligibility criteria and the extension of conditional welfare arrangements.

This thesis draws upon semi-structured interviews with 36 disabled ESA claimants and 5 key informants from third sector organisations. Findings illustrate a unique insight into the key issues that disabled people experience when going through the claims process and situate these experiences within the context of punishment and violence inflicted by the UK welfare system.

The thesis firstly establishes the policy context by considering how disability-related policies within the UK have served to contain, compensate and control disabled people (Drake, 1999). It then explores the conceptual context of this study, drawing upon Morris' tenants of citizenship (2005) and the concepts of identities and violence. The methodology provides a reflexive account of my role as a disabled PhD student as I negotiated and challenged my own identities throughout the PhD journey, drawing clear parallels to some of the experience's interviewees discussed.

This study provides unique empirical data that illustrates not only the inefficacy of welfare conditionality when applied to disabled people, but also, the detrimental impact that conditional approaches to social security have on disabled people's citizenship, identities and physical and psychological wellbeing. It starkly illustrates how the process and environment of punitive welfare arrangements serve to erode people's citizenship and enact a form of institutional violence (Cooper and Whyte, 2017; 2018).

The concept of identities is utilised to explore how interviewees' experiences were influenced by the dominant rhetoric of 'shirkers' and 'scroungers'

(Garthwaite, 2011) and how interviewees internalised such narratives. The process of ‘othering’ served as a justification of welfare reform and therefore removed culpability from the government and placed responsibility on the individual. Interviewees frequently engaged in processes of othering which often reinforced the negative narratives and justified increasingly conditional policy approaches. However, several interviewees challenged such justifications and asserted that welfare reforms were an ‘attack on disabled people’ (Pring, 2017).

Political engagement was identified as a key factor in how disabled welfare claimants chose to identify with their ‘disabled’ or ‘claimant’ identities. This thesis presents an original typology as a means of understanding identities in relation to *being* a disabled welfare claimant and interviewees’ levels of political engagement.

Overall, this study presents original empirical evidence that demonstrates how welfare changes have led to the erosion of disabled people’s citizenship (Morris, 2005) and substantiates recent conceptualisations of ‘Institutional violence’ (Cooper and Whyte, 2017; 2018). I argue that welfare conditionality is not only an inappropriate tool but instead is an insidious tool which serves to remove welfare entitlement and punish those citizens perceived as no longer ‘deserving’ of support from the state. I argue that the outcome of such policy decisions has enacted a form of institutional violence. Therefore, this study challenges both the ethicality and efficacy of UK policy approaches towards disabled welfare claimants.

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Most importantly, thank you to the people who shared their stories with me. I hope that this thesis does justice to our conversations and illustrates your experiences in a meaningful way.

# Author's Declaration

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

Printed Name: Joanne Brown

Signature:

# List of Abbreviations

**AtW** – Access to Work

**DDA** – Disability Discrimination Act

**DED** – Disability Equality Duty

**DLA** – Disability Living Allowance

**DPAC** – Disabled People Against Cuts

**DWA -** Disability Working Allowance

**DWP** – Department for Work and Pensions

**ESA** – Employment and Support Allowance

**ESRC** – Economic and Social Research Council

**FfW** – Fit for Work

**HAP** - Health Assessment Provider

**IFS -** Institute for Fiscal Studies

**ILF** – Independent Living Fund

**JCP** – Jobcentre Plus

**JSA** – Jobseekers Allowance

**KI** – Key Informant

**MS** – Multiple Sclerosis

**NDDP** – New Deal for Disabled People

**ONS** - Office for National Statistics

**PIP** – Personal Independence Payment

**PtW** – Pathways to Work

**SG** – Support Group

**UC** – Universal Credit

**WCA** – Work Capability Assessment

**WP** – Work Program

**WRAG** – Work-related Activity Group

# A Note on Terminology

This section highlights the key terms adopted throughout this study. It explains their definition and rationale within the context of this study.

It is important to note that the language around social security and welfare is contentious and divisive (Lister, 2013). This is largely due to the rhetoric in the public domain that associates the act of claiming welfare support with being negative or shameful, rather than necessary. This narrative must be challenged. By using terminology, which is sometimes avoided due to such connotations, the language of welfare can be reclaimed. The language of welfare should reflect a universal experience that affects the majority of people's lives, not a 'dependent' minority.

**Benefit or Welfare Claimant** – The term 'claimant' can be linked to negative connotations of dependency and entitlement. Initially, the term 'recipient' was adopted. However, within the context of this study, it is important to distinguish that those who participated were at various stages of the claiming process and their journey was by no means linear. Therefore, 'claimant' was adopted to include those people who had attempted to access support or were in the process of accessing support, as well as those who were currently receiving ESA. This term also reflects the fluidity and complexity of the process, especially for claimants who experienced re-assessment, appeals and shifting of eligibility criteria.

**Disabled Person** – This study adopts the term 'disabled' in relation to those who experience disabling barriers imposed by a disabling society. This is characterised by a society which exhibits physical, social, economic and educational barriers to equal participation. This term is used in line with the language promoted by the Disabled People's Movement and is reflective of the social model of disability perspective that this study adheres to.

**Impairment** – The term 'impairment' is used to describe the condition someone experiences. This is individual to the person experiencing it and a person who has an impairment may or may not chose to identify as a disabled person. It is important to note that peoples’ experiences need to be understood in the context of a disabling society and to also consider their lived experiences of impairment effects.

This section has set out my personal rationale for using the key terminology within this study. It cannot be assumed that this reflects the views of the participants I directly quote, so this should not be used to interpret the words or values of this study’s participants.

# Chapter One: Introduction

> *‘Weighing six stone and barely able to move - this man was denied vital benefits and told to go and look for work’* (Liverpool Echo, 2019).
>
> *‘Minister apologises after woman in coma was told to find work’* (The Guardian, 2014).
>
> *‘One in five Britons with disabilities have their rights violated, UN told’* (The Guardian, 2018).

The above headlines illustrate merely a few of the many austere experiences disabled people face at the hands of the UK’s punitive welfare system. From reading such experiences, it is not surprising that the United Nations independent investigation found ‘grave and systematic violations’ of disabled people’s rights and called for an overhaul of the overall approach to social security by the UK Government (United Nations Committee, 2017). This study is set at a time of unprecedented reforms to social security for disabled people and unequivocally illustrates not only the unsuitability of current approaches to welfare policy but also, an erosion of people’s citizenship (Morris, 2016) and an attack on disabled people’s rights and wellbeing (Pring, 2017).

## 1.1 Background

The Welfare Reform Act (2012) introduced significant changes to the provision of social security within the UK. The Act built upon foundations established by the Conservative and Liberal Democrat Coalition government’s (2010-2015) predecessor, New Labour (1997-2010). The political rhetoric of the time was characterised by notions of ‘welfare dependency’, individual responsibility and ensuring ‘fairness’. These notions served as justifications for a raft of reforms which impacted a range of people, particularly those who were not deemed as ‘economically active’ (Baumberg *et al.*, 2012). The aim was stated as being to:

> *'make the benefit system fairer and more affordable to help reduce poverty, worklessness and welfare dependency and to reduce levels of fraud and error'* (DWP, 2015, unpaged).

However, the changes over this period impacted disabled people disproportionately (Franklin and Marsh, 2011; The Hardest Hit, 2012; Edwards, 2012).

> *'The Coalition government were championing and cheering on a round of cuts that are increasingly devastating in their impact upon disabled people'* (Franklin and Marsh, 2011, p.45).

The reforms were set against a backdrop at a time of economic recession, limited employment opportunities and extensive cuts across the public sector. As disabled people have historically, and continue to, face barriers to equal participation in the labour market (Berthoud, 2011; Roulstone 2012) the imposition of work-based welfare inflicted a dual disadvantage. They were faced with changes that promoted the importance of employment, whilst simultaneously experiencing the same level of barriers to meaningful entry into the labour market.

It is evident within the policy of this time that there was limited recognition of the structural determinants of unemployment. By addressing these, policy would promote a sustainable means of participation over the long term. However, by focusing solely on incentivising individuals to work, this showed an emphasis on short-term fixes which neglected to address the real, long-standing issues surrounding the employment and welfare of disabled people.

This approach to social security continued to be at the forefront of the subsequent government agendas under the Conservative government (2015-2017 and 2017-). A key principle that underpinned several policy approaches of the time was 'welfare conditionality' - based on the contested assumption that people needed to be 'activated' into the labour market (Lindsay and Houston, 2011; Dean, 2006). This assumption is arguably a misconception of the problem (Patrick, 2011b) and reinforces narratives of dependency.

> *‘Welfare conditionality links eligibility for collectively provided welfare benefits and services to recipients’ specified compulsory responsibilities or particular patterns of behaviour’* (Dwyer *et al.*, 2018, p.8).

In many ways, social security entitlement has traditionally been linked to fulfilling certain citizen responsibilities. However, policies and narratives under the New Labour government and its successors illustrated a key extension of conditional welfare support to particular groups of people who were historically exempt, including disabled people (Roulstone and Prideaux, 2012; Lindsay and Houston, 2011).

This shift impacted disabled people’s experiences of accessing welfare support and illustrated a transformation of the way ‘deservingness’ was perceived both publicly and politically. The Work Capability Assessment (WCA), alongside the promise to move one million people off disability-related benefits (DWP, 2017b) and onto mainstream Jobseekers Allowance (JSA), is a clear example of redefining who is considered ‘deserving’. The process of shifting the ‘disability category’ (Stone, 1984) is particularly problematic when the WCA was effectively, *‘separating people who are sick and/or who have impairments into subgroups of claimants dependent upon medicalised perceptions of their sickness and/or impairment’* (Garthwaite, 2011, p.371).

The implementation of highly conditional welfare provision can be seen as removing the safety-net, which protected the most vulnerable members of society (Marshall, 1950) and the retrenchment of the welfare state. Deacon (2003, p.3) states that:

> *‘The central objection to conditionality in principle is that it imposes further burdens upon those who are already the victims of social and economic injustice. It is punitive because it penalises people for things over which they have little control’*.

This study, therefore, explores the gap between policy approaches to conditionality and disabled people’s lived experiences. A robust range of literature (Dwyer *et al.*, 2018; Manji, 2017; McNeill *et al.*, 2017) has been developed simultaneously over the duration of this study which has asserted that welfare conditionality is not an effective way of promoting labour market participation.

This study instead illustrates disabled people's lived experiences of the claiming process, in particular, the process of accessing Employment and Support Allowance (ESA), as the key out-of-work benefit for people at the time of data capture. These experiences therefore not only solely illuminate the issues around the efficacy of welfare conditionality but also provide narratives of how conditionality is experienced in practice.

It specifically draws upon concepts of citizenship, identities and violence when interpreting people's narratives and argues that welfare conditionality is not only inappropriate, when applied to disabled people, but also acts as a mechanism of 'institutional violence' (Cooper and Whyte, 2017; 2018). It explores how the operation of welfare policy often erodes people's citizenship through limiting people's ability to exercise self-determination, participation and contribution (Morris, 2005). Furthermore, it identifies a significant disconnect between policy goals which aim to 'activate' people into employment and policy outcomes, which effectively move people further away from labour market participation and serve to punish those who are unable to comply.

This section has presented an overview of the background to this study. The following section outlines the overarching aim of this study and the key research objectives it addresses.

## 1.2 Research Objectives

The overarching aim of this study was kept purposefully broad, to ensure people with lived experience had the opportunity to discuss what aspects were most important to them. The aim was to understand, 'What are the lived experiences of disabled ESA recipients?'.

This was initially focused specifically on welfare conditionality; however, those I interviewed had limited experience of the most conditional aspects of welfare reform and their experience could often not be isolated to one aspect of policy approaches. People’s experiences were varied and as this thesis aimed to be directed by what mattered most to those people with lived experience, the focus was altered to reflect the raft of policy changes which combined to form the punitive welfare support and context of the time.

As discussed, the extension of welfare conditionality was one of a range of measures imposed on disabled people. Although the dominant narratives which justified the implementation of the Welfare Reform Act (2012) were centred on independence and fairness, rhetoric was also paired with suspicion and the reinforcement of the notion of fraudulent claimants. This meant that it was impossible to consider welfare conditionality in isolation to this context and the numerous other policy changes which accumulated to significantly impact disabled people’s lives.

In order to achieve the overarching aim three research questions were identified:

1. What are the lived experiences of disabled people when encountering the conditional welfare system? [RQ1]

2. How does the process of engaging with this system impact disabled people's identities and wellbeing? [RQ2]

3. To what extent is there a gap between policy provision for disabled people, and the lived experience of *being* a disabled person within the conditional welfare state? [RQ3]

The methodological approach to addressing these objectives centred on several semi-structured interviews to gain an insight into the lived experiences of people during various stages of their claimant journey.

This section considered the objectives of this study. The following section presents an overview of the thesis structure to outline how the objectives will be explored.

## 1.3 Thesis Structure

This section presents the thesis structure by outlining the primary content of each chapter. Each chapter includes an introduction, to summarise the objectives and structure of the chapter, and a chapter conclusion which outlines the key themes within the chapter and how this is appropriate to the overall study.

This chapter sets the scene by presenting the background to the study and introducing the overarching aim and objectives the thesis will address. It presents a note on the terminology adopted, including a rationale for using the terms ‘benefit/welfare claimant’, ‘disabled person’ and ‘impairment’, reflecting social model definitions of disability (Oliver, 1983; Oliver and Barnes, 1998).

Chapter two presents the political landscape by exploring the historical context of relevant disability and welfare related policies within the UK. It presents Drake (1999) and Oliver’s (2004) models of disability policies as a framework to understand the policy context. It then provides a chronological overview of policy from the establishment of the welfare state to the policies that were in effect at the time of data collection and, as well as current policy changes which continue to impact disabled people. It particularly explores how policies have become increasingly conditional and begun to challenge conceptions of who is deemed as ‘deserving’ or ‘undeserving’ of support from the state.

Chapter three scrutinises the existing literature base to which this study contributes and identifies the gaps this study addresses. It particularly explores the concepts of ‘citizenship’, with a focus on Morris’ (2005) tenants of self-determination, participation and contribution. It draws upon ideas of symbolic interactionism to explore how disabled welfare claimants’ agency and identities are influenced by the process of claiming ESA. It then explores the concept of ‘identity’, specifically considering how Goffman’s notion of ‘spoiled identity’ can shape how disabled welfare claimants view themselves and others. Finally, it outlines the literature which theorises austerity and violence which this thesis substantiates.

Chapter four presents the methodology and approach that this study adopted to effectively address the research objectives. It outlines an overview of the semi-structured interviews, discusses the analysis process and identifies any ethical considerations and challenges faced. It also presents a reflexive account of my experience throughout the PhD journey. This links to the identities literature in chapter three and further illustrates the fluidity of identities. It considers my own experiences as a disabled PhD student and how this influenced both my approach and experience of the process. It also outlines this studies limitations and what steps were put in place to overcome them.

Three findings chapters follow, which are guided by empirical narratives from disabled people who have had unique experiences of navigating the welfare system. They also draw upon narratives from interviews with a range of voluntary sector staff and volunteers who work directly with disabled welfare claimants.

Chapter five introduces interviewees' lived experiences of the claiming process. This includes; experiences of the WCA, the inappropriate support offered through mandatory work-related activity, thoughts on being 'left on the shelf' or conversely being one of 'the lucky ones' in the ESA Support Group (SG), the impact of 'presenting yourself at your worst' and finally the role of sanctioning. It also reflects on how the current processes involved in both claiming and maintaining ESA often limit people's ability to 'self-determination', 'participation' and 'contribution' (Morris, 2005). Overall, it illustrates how the process and context of welfare reform are characterised by violence and punitive welfare

Chapter six explores interviewees' perceptions of citizenship and how this is embedded within their lived experiences. It considers how interviewees perceive citizenship as a disabled person and highlights contractualist views through the importance interviewees placed on 'giving back' or reciprocity. It also explores the right to work and the right to a good standard of living, which were often not experienced by interviewees due to societal barriers, but also the internalisation of stigma which made people question their own 'deservingness'.

Chapter seven then considers how claimants' identities were constructed and negotiated as disabled ESA claimants and how this shaped their views of self. It presents a typology as a method of exploring the relationship between political engagement and the acceptance of identities. The typology is paired with case studies to illustrate the spectrum of responses. Finally, it considers the processes which impact claimants constructing and negotiating their identities including the prevalence of stigma, shame and 'othering'.

Chapter eight brings everything together to present a discussion and address the research objectives, identifying key issues which emerged and areas for further research. It argues the detrimental impact that the punitive welfare system has on disabled benefit claimants and calls for action.

## 1.4 Conclusion

This chapter has introduced the background to this study and the main objectives it will address. It has also presented the structure this thesis follows. The following chapter presents the policy context and situates the study within this context.

# Chapter Two: Policy Context

## 2.1 Introduction

This chapter explores the development of disability-related policies, specifically those relating to employment and welfare support, to contextualise the research project. It explores the history and development of disability policy, anti-discrimination legislation and work-based welfare support. It considers the state's interaction with disabled people, from the initial development of policies that considered disabled people as a collective group with specific needs through to contemporary policy which has become increasingly conditional on fulfilling particular obligations. The chapter begins by exploring the key goals and themes that emerge throughout disability policy, using Drake's (1999) typology of disability policies as a framework to highlight the key shifts. It considers the values underpinning how disability policy has been implemented by successive UK governments and increasingly contractualist approaches which have impacted on who is considered 'deserving' of support from the state.

The main body of the chapter provides a chronological overview of disability-related policies within the UK. It begins by exploring the post-war priorities for the work and welfare of disabled people and the emergence of the 'classic' welfare state. It then considers the importance of the Disabled People's Movement and the move towards equality and anti-discrimination legislation. It presents an exploration of the key shifts in thinking that underpinned welfare policy, specifically examining the change towards neoliberal ideology and the extension of work-related conditionality, which is a crucial aspect of this study. It discusses the recent policy developments under the Conservative government (2015-2017 and 2017-) and the predecessor Coalition government (2010-2015) which reflect the shift towards even greater conditional welfare arrangements and was the political context at the time of this study.

The following section highlights two useful frameworks of UK policy goals and models that identify common themes within disability-related policy. Then the consecutive sections consider the extent to which the models influenced the emergence of disability policy.

## 2.2 Goals and Models of Disability Policy

### 2.2.1 Containment, Compensation, Control and Citizenship

Drake (1999) suggests that there are four key overlapping themes appearing in policy discourses around disability in Britain, evident both historically (dating back to the late Victorian period) and through to contemporary policy. These themes have been:

- *'to effect the containment or segregation of disabled people;*
- *to provide redress for social exclusion, and especially to compensate disabled people for injuries received in war or at work;*
- *to provide welfare through social services, ostensibly as an attempt to reintegrate disabled people into society and also as an attempt to 'normalise' or control them;*
- *to secure rights and citizenship, and, where necessary, reconfigure the social and built environment'* (Drake, 1999, p.45).

Drake's typology demonstrates that disability policies have been primarily concerned with the notion that disabled people must be either: contained or segregated, compensated, and 'normalised' through social services. These objectives are largely built upon assumptions of abnormality and individual deficit with compensatory approaches being largely influenced by the increased numbers of people injured through war. However, Drake's final theme shows a development towards rights-based policy which considers the societal factors which impact disabled people's lives.

It is important to note that these themes have been subjected to continuities and change (Lewis, 1998). These continuities and change mean policy developments cannot simply be captured by linear progression and instead can exist simultaneously. Lewis, therefore, argues that *'a simple notion of linear development fails to convey'* (Lewis, 1998, p.268) the complexity of social and political change which underpinned such policy approaches.

However, the utility of Drake's (1999) framework is that it provides a useful tool to understand the history and motivation of disability policies. The policy aims identified evidence a significant focus on addressing change on an individual level with minimal regard for the social and structural factors in play. This is reinforced by Castles *et al.* (2012) when stating that:

> *'From this [individualised] perspective, the most appropriate policy responses were either to compensate disabled people for their perceived loss, to help them adjust through rehabilitation, or to provide alternative, less valued, social roles through segregated institutions. Whilst disability might commonly have been viewed as a deserving claim for welfare within this paradigm, it was less likely to be viewed as a legitimate claim for social inclusion'* (Castles *et al.,* 2012, p.407).

It is clearly not only policy objectives that govern the experience of disability and Drake's framework is useful in exploring the development of different models of societal and government responses to the issue. Drake also identifies five contrasting policy models – negative, laissez-faire, piecemeal, maximal and rights-based. In its most simplistic terms, negative policy models are characterised by the deprivation of human rights. Whereas laissez-faire translates to 'let do' which reflects an approach that is minimalist and requires nominal government interference, laissez-faire may result in some assistance but is uncoordinated and seen as a favour, not a right. Piecemeal policy approaches tend to occur gradually, they are still uncoordinated, sometimes meaning to assist the person but from the standpoint of 'otherness' and unvalued people, so guessing rather than asking what services would be useful and effective, and often characterized by substandard services at a minimal cost. This contrasts with a maximal approach which incorporates a robust level of support and involvement. Finally, a rights-based approach is underpinned by ensuring citizens are involved in claiming their rights and the policies and practices they determine. In this context, the maximal approach would seek to redress the imbalance of rights and opportunities for this group but again with services often designed for 'disabled' people by non-disabled people. Finally with the ascendancy of consumer and customer power in many other aspects of community life comes the rights-based movement for 'disabled' people - where individuals assert their rights as full citizens to robust levels of support to enable full inclusion in society.

In terms of disabled people, Drake asserts that the negative policy model actively denies disabled people’s rights and in turn their status as a citizen. Such negative policy models rested on the idea that disabled people were faulty, and who by logic should be at best ignored, or physically and mentally distanced from wider society or at worst eliminated. An example being a policy favouring eugenics in World War II within Nazi Germany.

Laissez-faire policy models minimalize the input of the state and were commonly utilised by the New Labour government within the UK. Laissez-faire involved some movement to state responsibility but with the onus still very largely on the individual. The adoption of a laissez-faire approach would mean:

> *‘disabled people who have neither resources nor avenues of support may compete unsuccessfully in a world designed by non-disabled people for non-disabled people’* (Drake, 1999, p.39).

The piecemeal policy approach responds to disablement but often on an ‘*ad hoc’* basis with rehabilitation or particular services as and when. Although this demonstrates some moves towards state aid for ‘rehabilitation' to assist integration into society and work, still the onus is on individuals to utilize such help and make progress.

The maximal policy model responds with a more robust amount of provision and more co-ordinated initiatives but still depends on the ‘disabled' person adjusting to non-disabled people’s societal norms rather than vice versa and therefore is still inherently underpinned by the medical model.

The last model in the framework, the rights-based approach, turns this on its head by understanding that disabled people are disabled by society and that the state has a clear role in redressing this imbalance of rights and making full citizenship attainable for all disabled people. These approaches to disability policy draw a distinct parallel to the policy themes identified previously and present a further way of understanding the goals and rationale behind disability-related policies. Within the context of this study, disability-related policies around work and welfare are most important to exploring people's lived experience of claiming ESA.

### 2.2.2 Humanitarian, Compliance and Citizenship

Oliver (2004) provides further analysis of the approaches to policy for disabled people which can be understood through humanitarian, compliance and citizenship approaches. Oliver's analysis draws parallels with Drake's framework and links can clearly be drawn between the humanitarian approach and compensatory approach, the compliance approach and the citizenship approach and the rights-based approach.

The humanitarian approach is based on a belief that '*services are provided out of goodwill and the desire to help individuals and groups perceived as less fortunate*' (Oliver, 2004, p.28). This links to Drake's compensatory approach to welfare and reflects notions of personal tragedy, undermining disabled people's equality. This approach was evident in the development of social services and specific disability policies from the 1970s onwards.

The compliance approach is concerned with complying with laws in order to satisfy basic requirements. Sapey (2010) states that:

> '*providers adopt a minimalist approach to meeting the legislation and this has become more common as disability policy has focused on rights*' (Sapey, 2010, p.135).

Finally, the citizenship approach identifies disabled people as full, equal and valued citizens with economic, political and moral rights and obligations, drawing parallels with Drake's rights-based approach. Although this approach could be likely perceived as the most egalitarian, it is important to consider how it could also be utilised by policy-makers to diminish state involvement or deliver a minimalist approach by adopting the narrative of equality.

When exploring the British policy developments concerning disabled people, both Drake's (1999) and Oliver's (2004) approaches are considered to understand the rationale behind policy-making and how they were implemented within work and welfare-related disability policy.

The subsequent section follows these themes and explores how policies for disabled people were developed in the post-war period. The section provides the starting point for the chronological exploration of disability policy within the UK.

## 2.3 Post-War Priorities for the Work and Welfare of Disabled People

### 2.3.1 Compensating those injured in World War II (1939-1945)

The 1940s brought about the first policy developments addressing disabled people as a collective group. Prior to this, legislation since the Victorian Era, was often concerned with the containment of disabled people, as evident in the Poor Laws and the establishment of workhouses and asylums. However, distinctions between different groups of disabled people were evident throughout this era, such as people with visual impairments being perceived as more 'deserving' of support than people with learning difficulties (evidenced through policies such as the Idiots Act (1886)), this binary trend between 'deserving' and 'undeserving' continued throughout the development of the welfare state.

New compensatory policy developments aligned with significant reconstructions for the British welfare system, as the classic British welfare state was established (Digby, 1989). A major catalyst for this was the post-war reconstruction and 'rewarding' of citizens following World War II (Thane, 1982). Therefore, government responsibility was deemed necessary to support those citizens who fought for their country. It is important to note that during the war thousands of men and women had left the labour market to join the armed forces, leading to significant labour shortages and the government looking to those previously not considered to enter the labour market (e.g. women and disabled people) (Shah and Priestley, 2011).

In 1946, the National Assistance Act and the National Assistance Act (Industrial Injuries) meant that financial assistance was extended to those who became unable to work through war or work-related injuries. Policy thinking at this time linked to Drake's (1999) compensatory approaches by providing a level of support for those injured in the war, as reinforced by Borsay (2005, p.5) when suggesting that the 'citizenship of entitlement' was prevalent after WWII.

### 2.3.2 The 'Blueprint for the Welfare State'

Another key policy announcement during WWII was The Beveridge Report (1942) entitled 'Social Insurance and Allied Services' which provided a *'blueprint for the welfare state'* (Fraser, 2009, p.2). This report promoted the need for non-means-tested social insurance, alongside a smaller safety net of social assistance for those unable to participate in the labour market. Before this, unemployment insurance was restricted to those who had contributed (initially insurance was limited to one week of benefit for every five weeks of contributions). Therefore, assistance was available for those who had 'earned' entitlement, rather than those who needed social assistance.

Within this report Beveridge identified five '*Giant Evils on the road of reconstruction'*: *'Want, Disease, Ignorance, Squalor and Idleness'*. He argued that these 'evils' should be combated by a revolutionary approach to social security. Giddens (1996) argued that,

> *'The new welfare policies were designed to treat all citizens as part of a more inclusive national order and in doing so recognise state responsibility for caring for those who were prevented from active economic participation'* (Giddens, 1996, p.65).

These policies were not solely concerned with 'caring' for but also the rehabilitation of disabled people. As evidenced by the Minister of Health at the time (1944) when stating that 'The aim of the government is to rehabilitate them [disabled persons] wherever possible' (in Shah and Priestly, 2011, p.6). Although care and rehabilitation could have a positive impact on disabled people, they also served to reinforce ideas of individual deficit.

The first significant policy development that considered disabled people as a collective group was implemented in the form of the Disabled Persons (Employment) Act (1944). This Act aimed *'to make further and better provision for enabling persons handicapped* [sic.] *by disablement to secure employment, or work on their own account'* by implementing industrial rehabilitation courses, vocational training and a register/quota system. However, the policy failed to successfully include disabled people within the labour market, despite the inclusionary intentions (Oliver and Barnes, 1998; Borsay, 2005). This was most notably due to the implementation of an unsuccessful quota system which Roulstone and Prideaux (2012, p.27) argue was '*more concerned with not upsetting employers'* than securing employment opportunities for disabled people. Although the lack of enforcement mechanism rendered it ineffective it was a symbolically important achievement in terms of disabled people's inclusion within the labour market. The quota system had a maximum sanction of £100 for non-compliance with the obligation to hire 3 per cent of their workforce from the Disabled Person's register (Parliament, 1944). As no effective enforcement measures were implemented, both public and private sector employers regularly failed to meet the quota, yet only 10 prosecutions have been made since the Act's implementation (Roulstone and Prideaux, 2012). The 1958 amendment to this Act enabled the provision of 'special sheltered workshops'. This reflected Drake's (1999) approaches of the segregation and containment of disabled people in social policies. As Borsay (2005) stated:

> *'[although the Act] was represented as conferring the right to work, its quota system was never enforced and the focus on segregated workshops and manual labour was retained. Therefore, social citizenship was an empty promise for the many disabled people who were not properly integrated into the labour market'* (Borsay, 2005, p.139).

Sheltered workshops, whilst meant as good intentions, only reinforced the previous ideas of 'otherness' and failed to make wider society acknowledge and address its role in disabling people. However, this Act did provide a stepping stone towards inclusive employment, despite the segregated elements as the Act proposed providing rehabilitation into work rather than compensation for those who were out of work.

The 1948 Amendment to the National Assistance Act presented further provisions for those who were unable to pay contributions, including individuals with physical impairments, providing the non-contributory social security benefits that Beveridge's report had supported.

### 2.3.3 Universal Human Rights

A step towards acknowledging the rights of disabled people arose with the establishment of the 1948 Universal Declaration of Human Rights. The Declaration stated that:

> *'Everyone has the right to a standard of living adequate for the health and well-being of himself [sic.] and his family, including food, clothing, housing and medical care and the necessary social services and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control'* (Article 25, United Nations).

By including the consideration of 'sickness', 'disability' and 'old age' this showed an apparent 'appreciation of impairment' (Borsay, 2005, p.5). This was then expanded on by the 'Declaration on the Rights of Mentally Retarded Persons [Sic.]' (1971) and 'Declaration on the Rights of Disabled Persons' (1975, article 7). The latter states that:

> *'Disabled persons have the right to economic and social security and to a decent level of living. They have the right, according to their capabilities, to secure and retain employment or to engage in a useful, productive and remunerative occupation and to join trade unions'.*

Although these declarations began to acknowledge the challenges disabled people were facing, they maintained their emphasis on individual responsibility, rather than on the societal barriers that impact people's meaningful inclusion. This is evidenced by the statement, 'according to their capabilities' which devalues the initial declaration that people have the right to employment by suggesting that an individual's capabilities will determine what sort of employment was deemed as suitable, if any. The declaration reinforced the notion of the previous 1948 Declaration when stating that people have the right to economic and social security and ‘a decent level of living’. However, the meanings of terms such as ‘decent’ and ‘adequate’ are somewhat ambiguous, meaning that subjective interpretations of what is considered ‘decent’ can differ from person to person on an individual basis.

This section has discussed the emergence of the welfare state and how this impacted the lives of disabled people. It considered how compensatory approaches were adopted following WWII and disabled people continued to face segregation or rehabilitation, based on perceptions of individual deficit. It also highlighted the steps towards equal rights under the Disabled Persons (Employment) Act (1944) and the Universal Declaration of Human Rights (1948) in promoting labour market opportunity and economic and social security. The following section now explores the subsequent policy shifts which were largely influenced by the Disabled People’s Movement and the re-conceptualisation of how ‘disability’ is defined and understood.

## 2.4 Disability Activism and The Struggle Towards Equal Rights

### 2.4.1 Early Disability Activism

The emergence of the Disabled People’s Movement in the late 1960s provided a new way to think about disability, by challenging the paternalistic forces embedded within society (and therefore reflected in policies). Early activism initially campaigned for sufficient income for disabled people who were unable to enter employment (e.g. The Disablement Income Group), as an attempt to get the state to share the economic prosperity with the disabled population. This was followed by numerous campaigns across areas such as accessible transport and equal rights. Paul Hunt, a significant disability activist of the time argued,

> *‘We are challenging society to take account of us, to listen to what we have to say, to acknowledge us as an integral part of society itself. We do*

> *not want ourselves, or anyone else, treated as second-class citizens and put away out of sight and mind'* (Hunt, 1966, p.157).

The Disabled People's Movement was established in opposition to traditional care and compensatory responses to disability. The self-organised movement of disabled people called for the removal of segregation and opposed the commodification of disabled people by challenging the use of services run for disabled people solely by non-disabled people (Cameron, 2013). This challenge to welfare paternalism or a state knows best approach continued to be prominent throughout the 1980s and 1990s and argued against the view that disabled people are 'identified as objects of pity and charity' (Morris, 2011b, p.10).

### 2.4.2 Re-defining Disability

The Chronically Sick and Disabled Persons Act (1970) was widely regarded as a substantial legislative development towards securing the rights of disabled people (Shah and Priestley, 2011). Although the Act was implemented without the consultation of disabled people, it covered numerous aspects of everyday exclusionary structures and practices. The main issues covered include: education, housing, access to buildings, care provisions and the local authority's responsibility for the welfare of disabled people. While the Act was considered progressive, it has been argued that the provisions outlined only built incrementally on the previous National Assistance Act (1948) (Topliss and Gould 1981; Shah and Priestley, 2011).

A significant step towards securing disabled people's rights came about during the 1970s. This was the redefinition of disability as a social construction by the Union of the Physically Impaired Against Segregation (UPIAS, 1976):

> *'Impairment: lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body.*
>
> *'Disability: the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of*

> *people who have physical impairments and thus excludes them from the mainstream of social activities'.*

This redefinition also underpinned the starting point for the social model of disability (Oliver, 1983). However, despite the popularity of the new definition garnering support for the social model, the definition was not fully implemented and integrated into policy discourse. Instead, it maintained an individualised response to disability. Hahn (1998) states that:

> *'Fundamentally disability is defined by public policy. In other words, disability is whatever policy says it is'* (Hahn, 1998, p.36).

This is problematic as disability continued to be largely defined as an individual problem within policy, rather than rooted in social barriers. For example, The Disability Discrimination Act (DDA) 1995 framed disability through a medical model, which focused on individual deficit. The adoption of the UPIAS (1976) definition would provide a conceptualising tool in policy change which considers societal barriers to participation. Consequently, as Hahn implies, if disability were defined through a social barriers approach in public policy this would allow for disability to be defined this way generally. The Disabled People's Movement and the redefinition of disability over this period paved the way for significant successes of policy activism. Future policy changes including anti-discrimination legislation and direct payments for disabled people were evidently borne out of the disability activism of the time.

This section has briefly explored the development of the Disabled People's Movement in the UK and how a changing definition of disability began to impact the way that disability is defined. However, this was not largely evident within policy discourse of this era. The next section discusses the reconstruction of the classic, post-war Welfare State which was characterised by both cuts to public expenditure and increased consideration of benefits for disabled people.

## 2.5 The Transformation of the Classic Welfare State

### 2.5.1 Increasing Social Services

The so-called universalist approach to welfare provision began to take effect with increasing public expenditure leading to both Labour and Conservative parties contesting the benefits of the classic welfare state in the 1970s. However, commentators have argued that welfare provision has never been truly universal for disabled people (Stone, 1984) and was often conditional on impairment, circumstance or behaviour.

To return to Drake's approaches, this was a period whereby policy aimed to 'provide welfare through social services'. However, Fraser (2009) states that during this time the welfare state became labelled as a:

> *'burden on the British economy, by consuming disproportionate resources and crowding out necessary investment in economic growth… [it was]no longer perceived as wholly beneficial. Or even negative as it created dependency'* (Fraser, 2009, p.281).

In contrast to the discourses of the time, the introduction of additional costs and earnings replacement benefits in the 1970s meant benefits for disabled people were increasingly rising. These emerged in the broader context of 'welfare support' and the emergence of social work as a profession (e.g. 1975 Social Security Benefits Act). Policy began to be concerned with meeting needs, rather than solely providing compensation for injury through war or industrial injury Dalley (1991). Therefore, this was a time of ambivalence with a notable expansion of provision for disabled people, particularly those people who were not disabled due to war or injury, alongside the withdrawal of principles previously implemented.

### 2.5.2 The Rise of Neo-liberalist Thinking

The economic decline within the UK paved the way for a new way of thinking about citizens as consumers. Neo-liberalist ideology was at the forefront of

Conservative manifestos throughout the 1980s, placing emphasis on personal responsibility for everyone, which clearly also extended to disabled people. This ideology is clearly articulated in Thatcher’s notable quote:

> *‘And, you know, there's no such thing as society. There are individual men and women and there are families. And no government can do anything except through people, and people must look after themselves first. It is our duty to look after ourselves and then, also, to look after our neighbours’* (Thatcher, 1987, unpaged).

The restructuring of the classic welfare state coincided with the rise of neo-liberalism as cuts to public expenditure and privatisation were imposed as a means of ‘recovering’ the economy. Hills (1998, p.1) supports this, stating that when,

> *‘Taking the period of Conservative Government from 1979 to 1997 as a whole, four themes stand out as central to policies towards the welfare state: Attempts to control public spending; Privatisation; Targeting; Rising inequality’.*

Beveridge’s ‘cradle to grave’ ideology which underpinned welfare provision in the post-war era was rejected with a conflicting emphasis on means-testing eligibility and the privatisation of the public sector. This attempted to control and reduce public expenditure, although it has been questioned to what extent actual spending reduced during this time (Taylor-Gooby, 2001).

The Thatcher administrations (1979-1990) adopted a more laissez-faire approach to policy with a significant shift in the way citizenship was established. Citizenship became linked to economic contribution in contrast to the previous emphasis on entitlement. Therefore, it considered individual responsibilities as a means of gaining citizen rights. This demonstrated a shift from notions of welfare paternalism to liberal paternalism, – ‘*where the state aims to ‘help people to help themselves’ – which applies more malicious stereotypes to people who are not economically productive’* (Morris, 2011b, p.10). A key factor in the significant restructuring was the Fowler Reviews of Social Security (1988).

However, this was not attempted until the 3rd Thatcher term in 1987 had been secured.

Thatcher administrations argued that individuals all had to play a part in wealth making activities with the notion that such wealth would then trickle down to those who were 'less-able'. This inevitably led to cutting public expenditure on people who were not deemed as 'economically productive' (Morris, 2011b) and investing public money to support privatization to businesses which would compete with 'moribund' public services. Inevitably this period was characterised by significant reductions to public services and the targeting of support for only those seen to be in direst need.

### 2.5.3 Understanding Disabled People's Barriers to the Labour Market

The 1990 White Paper, 'The Way Ahead: Benefits for Disabled People', established that disabled people had lesser opportunities to work and when in work were often less well-paid, therefore arguing for a revision to the way social security for disabled people was provided. Consequently, Disability Living Allowance (DLA) and Disability Working Allowance (DWA) (1992) were introduced, replacing both Attendance Allowance and Mobility Allowance. These benefits were established to cover the additional expenses that may arise for working-age people living with impairments, which was especially important in the context of the broader discourse on cutting welfare expenditure of the time.

The establishment of DLA also evidenced a policy shift towards the rights-based and citizenship approaches (Drake, 1999; Oliver, 2004) previously identified. It was available to disabled people in and out of work and considered a symbolic achievement towards acknowledging the extra costs associated with disability and securing equality for disabled people (Drake, 1999). DLA was widely popular and provided crucial support for people to carry out everyday tasks (Roulstone and Prideaux, 2012). The Access to Work scheme (AtW) was established in 1994 and tackled barriers to work by helping both disabled employees and employers of disabled people with additional costs and practical assistance.

In contrast, these positive policy steps which acknowledged the financial impact of being disabled, were paired with the continuation of contributory thinking. The Social Security Act of 1994 followed the contributory based policy trend, with the implementation of a stricter 'Incapacity Benefit' (IB) replacing the previous invalidity and sickness benefits, available to working-age adults who were deemed unable to work. This was a contribution-based benefit rather than means-tested which meant that entitlement had to be earned through working.

### 2.5.4 Improving Choice and Control

The 1990s witnessed a move towards 'Choice and Control' - a realization that people knew best how to deal with their own challenges. This meant the promotion of agency and autonomy for disabled people. On the other hand, there was still a prevalent view that the welfare state had become too large and had allowed the emergence of people exploiting the system. These two competing views would continue to vie with each other into the future

Significant developments towards greater control for disabled people were made towards the end of the Major administration (1990-97) as the Community Care (Direct Payments) Act (1996) came into force in 1997. This gave disabled people greater choice and control over what their social care budget was used on, which was previously determined by local authorities. The Act took numerous attempts to get the policy on the statute as concerns around exploitation and fraud were raised by members of government at the time (Riddell *et al.,* 2005).

Once implemented, under the Conservatives, it was arguably a major victory for the Disabled People's Movement at the time. This had been a major campaign focus throughout the 1980s. This achievement aligned with their goals towards redistribution and recognition, not only giving disabled people the opportunity to exercise choice over the support they receive; but also, re-framing disabled people as employers (Barnes, 2004).

The Act built upon the foundations underpinning the Independent Living Fund (ILF) (1988) which also assisted independent living within the community. It provided discretionary financial support for disabled people with the highest support needs to enable them to live independently (e.g. to employ support workers). The ILF was established following the Fowler Review of Social Security (1983) to substitute the additional monies paid through means-tested supplementary benefit to cover disability-related costs, which had been removed. Although the ILF was initially fought against by the disability movement due to its charitable associations, it won favour because it allowed severely disabled people access to cash payments to buy their own support – rather than residential care - which were separate from local authority funding. The ILF was closed in 2015 under the Coalition government in England but remains open in Scotland and Northern Ireland.

The discourse of conditional policy in the welfare state over this era was largely inconsistent as often policy shifts contradicted ambiguous political discourses. For example, the implementation of the Benefit Integrity Project (BIP) (1997) towards the end of the Conservative administration, was set up as a means of assessing the legitimacy of claimants of DLA and highlighted the emergence of perceived fraudulent claimants (Roulstone and Prideaux, 2013). This demonstrated a disconnect between the narratives of the time which began to focus on rights, control and independence.

This section has considered the transformation of welfare provision during the Conservative administration (1979-1997) and how this impacted disabled peoples' lives. The policy during this time demonstrated evidence of the movement towards contributory-based policy. Disability policy reflected some elements of social model thinking by establishing key policies that identified barriers to work and economic security. However, political narratives and policy approaches were often inconsistent with the emergence of rhetoric about the legitimacy of welfare claimants.  The following section considers the significant policy developments under the New Labour administration (1997-2010) which demonstrated a clear extension of work-related conditionality for disabled people and links clearly with the objectives of this study.

## 2.6 Towards a Rights-based Approach?

### 2.6.1 Election of New Labour

The New Labour administration (1997-2010) saw significant changes in the welfare provision available for disabled people. Neo-liberal ideology and the extension of work-related conditionality meant that New Labour reverted to elements of a laissez-faire policy model in which the state has minor input in the lives of disabled people who are left to 'fend for themselves'. Drake (2000, p.425) suggested that New Labour enforced a 'three-pronged approach to disability policy'. This approach witnessed the tightening of social security benefits (for groups such as disabled people and lone parents); the introduction of numerous work-related initiatives and programmes aimed at encouraging and supporting labour market participation; finally, the acknowledgment of societal barriers to equal opportunities, which produced initiatives such as the Disability Rights Commission and the Disability Rights Task Force (Drake, 2000).

Further progressive shifts included, the reform of the DDA, rights-based policy and initiatives such as 'The New Deal for Disabled People' (NDDP) and 'Pathways to Work' (PtW) which were put in place and focused on opportunity and empowerment. This challenged the paternalist nature of welfare support and aimed to tackle 'dependency'. NDDP and PtW provided practical assistance for disabled jobseekers with regards to suitable training, identifying and applying for jobs. These schemes failed to significantly decrease numbers claiming benefits (Weston, 2012) and therefore effectiveness was often contested. However, they came alongside more demanding Incapacity Benefit assessments which focused on an individual's perceived ability to enter employment as opposed to the effects of their impairment, therefore support from such schemes became conditional on fulfilling specific obligations.

### 2.6.2 New Labour and Conditional Welfare Policies

New Labour's 'carrot and stick' approach to welfare was evidenced by harsher eligibility conditions and mandatory 'work-focused interviews' with the threat of sanctions for those who failed to attend (Roulstone and Prideaux, 2012; Dwyer, 2010). The primary focus of welfare policy was based on a 'hand up rather than a handout' (Blair, 1997) and was most definitely concerned with helping recipients to enter paid employment so that they no longer 'needed' state support. However, those who were successful in obtaining paid employment were often those closest to the labour market originally, neglecting those persons of the greatest distance from the labour market. This indicated practices of ‘creaming’ and ‘parking’ of welfare recipients (Wright, 2012; Davies, 2008). Additionally, the quality and suitability of jobs obtained through such schemes were not considered, often leaving disabled people in poorly paid, insecure jobs due to assumptions based on capabilities (Hyde, 2000).

Although New Labour policy acknowledged some elements of structural and environmental barriers to labour market participation, it relied heavily on notions of individual impairment and placed a firm focus on the disabled benefit recipient (Drake, 2000). This led to a greater emphasis on citizens’ responsibilities and the behaviour change of recipients, as opposed to improving the distribution of welfare provision. Dwyer (2004) reinforces this idea suggesting that New Labour policies were based on ‘conditional entitlement’ therefore undermining notions of ‘welfare rights’ and a citizenship approach (Drake, 1999). Morris (2011b) supports this when stating that:

> *‘the nature of paid work in industrial urban societies means that many people with impairments and/or poor health are excluded from the labour force. Currently, many more are excluded than need to be because of discriminatory attitudes and a lack of adaptations, equipment and support. But it is important to recognise that many people will always be excluded from paid work as long as work is organised in the way it currently is’* (Morris, 2011b, p.15).

Disabled people are significantly less likely to attain or sustain employment (Berthoud, 2011), meaning work-focused conditionality places disabled people at a disadvantage when both in and out of work. As the welfare policies of this era emphasised the role of economic contribution through paid work, disabled people would be dually disadvantaged in and out of the labour market.

### 2.6.3 The ‘Underclass’ and Individual Responsibility

New Labour policy was significantly influenced by commentaries from academics such as Charles Murray (1990), whose rhetoric often assumed that poverty is caused by individual behaviour rather than circumstance (Deacon, 2002, p.52), and Lawrence Mead (1997) who promoted the ‘workfare’ approach adopted in the United States. These commentaries discussed the presence of an ‘underclass’ who were perceived as behaving irresponsibly, leading to increasing welfare expenditure and becoming a burden to the state. Murray, therefore, argued that the ‘underclass’ were actively choosing not to engage in paid work (Murray, 1990). This argument failed to reflect structuralist interpretations which discussed the role of de-industrialisation and declining employment opportunities in the production of the ‘underclass’ (Watts and Fitzpatrick, 2018).

Policy, therefore, reflected such individualist notions of the ‘underclass’ and social obligations were viewed as a necessity as a means of promoting ‘responsible’ behaviour and decreasing state expenditure. Roulstone and Prideaux (2012, p.81) state:

> *‘This so-called underclass, of which commentators and politicians did not originally include disabled people, was commonly believed to represent a significant drain on the public ‘purse’ and, in part, was seen to contribute to the destabilisation of the economy’.*

As Roulstone and Prideaux allude to, the ‘underclass’ was initially defined through misbehaviour rather than impairment. However, with the emergence of the rhetoric of ‘shirkers and scroungers’ (Garthwaite, 2011) and concerns over fraudulent disability benefit claimants increasing, disabled people later became included in debates about who was considered the ‘deserving’ or ‘undeserving’ poor (Williams, 2013). Patrick (2017) argues that welfare conditionality consensus does not just focus on who requires support but also, who is deemed as ‘deserving’. This notion was clearly emerging within the New Labour government of the time and continued to be established as a key focus of the thinking behind future welfare reforms.

This shift paved the way for New Labour’s ‘Third Way’ (Giddens, 1998), meaning citizens gained rights by fulfilling specific responsibilities or behaving in a particular way (Dwyer, 2004; Giddens, 1998). Dwyer (2004, p.266) states that:

> *'Third Way welfare reforms that stress reduced access to public welfare provision, a strong link between rights and responsibilities, and an increasingly moral agenda meet the requirements of cost containing governments rather than the needs of citizens. The welfare rights of those deemed 'irresponsible' because they cannot, or will not, meet certain state endorsed standards or regulations may be withdrawn or reduced. This enables politicians to place the blame for the predicament of those whose right to publicly funded welfare is reduced or removed firmly at the door of the individuals concerned'* (Dwyer, 2004, p.266).

This section has considered the New Labour approach and narratives in relation to disability and social security policies. There was a clear emphasis on fulfilling responsibilities in order to receive rights, this idea underpins the rationale of conditional welfare policy as a behavioural change mechanism and is of central importance to how disabled people experience welfare policy within the context of this study.

The following section continues to discuss developments during the 1990s. This focuses on the progression of anti-discrimination legislation for disabled people, chiefly the DDA (1995) (and the subsequent amendments) which addressed barriers to entering the labour market. This is important to consider alongside welfare policies as conceptualisations of work and welfare were clearly intertwined within social security policy and political narratives of the time.

## 2.7 Tackling Employment Discrimination

The DDA (1995) was a significant development for disabled people during the 1990s. This came after considerable campaigning and continual refusal by the government to develop civil rights legislation for disabled people. Even though characteristics such as race and gender were addressed almost 20 years prior (Race Relations Act 1976; The Sex Discrimination Act 1975), disability was not regarded a legitimate rights issue (Cameron, 2007). The DDA meant that employers with more than 15 employees were unable to discriminate against potential employees based on impairment and included the implementation of 'reasonable' adjustments, which demonstrated steps towards acknowledging that work structures themselves often posed barriers to disabled people entering employment. It was crucial that this was addressed in a time where welfare and work policy was heavily influenced by labour market participation. However, due to the vagueness of what was considered ‘reasonable’ and the lack of an effective enforcement system, the original DDA was heavily criticised (Woodhams and Corby, 2003). The Disability Rights Commission came into place under Labour in 1999 to support the enforcement of the DDA. This was notably a significant achievement for the disability movement after continual refusal by the Conservatives to acknowledge disability discrimination as an issue.

A primary criticism of the Act was based upon its individualised definition of disability (Cooper, 2000; Woodhams and Corby, 2003). The Act defined disability as ‘*a physical or mental impairment which has a substantial long-term adverse effect on his / her ability to carry out normal day to day activities*’. Therefore, legislation and policy during this administration were still evidently rooted in the medical model of disability. Further exploration of this Act is provided in section 2.9, whereby discussion focuses on the implementation of anti-discrimination legislation during the Coalition Government.

The 2005 amendment to the existing DDA (1995) strengthened anti-discrimination legislation for disabled people. Under recommendations from the Disability Rights Task Force (1999), several progressive amendments were made to existing provisions across education (which was included for the first time after being omitted from the 1995 Act), employment and accessibility. Most notably, the definition of disability was amended to assist those diagnosed with mental health conditions, HIV infection, MS and cancer and, the Disability Equality Duty (DED) was put in place. The DED put a responsibility on public bodies to address the needs of disabled people more effectively and engage in user-involvement with disabled people. This was significant as it was the first proactive form of disability legislation, requiring public sector organisations to change their practice.

The DED came into force under the DDA, in 2006. This was followed by The Single Equality Duty which set out requirements for public sector organisations to develop pro-active strategies to promote the rights of disabled people as service users or employees. However, there are arguably disparities around establishing and maintaining effective user-involvement under the Duty, especially regarding those with mental health conditions or learning difficulties (Pearson *et al*. 2011a, 2011b; Shah and Priestley 2011). The level of effective user-involvement was often influenced by the street-level bureaucrats (Lipsky, 1980; Wright, 2012) who implemented the duty (Pearson *et al*., 2011a, 2011b). Nonetheless, the DED and Single Equality Duty provided a significant positive step towards equality for disabled people within policy through the requirement of public sector organisations to be proactive in their support of disability rights. Subsequent considerable cuts to the EHRC budget under the Coalition government have weakened the Single Equality Duty (Brett, 2013), thereby undermining collective support for disabled people.

A significant development towards adopting a barriers approach to disability policy was evident in the publication of ‘Improving the life chances of disabled people’ (Prime Minister’s Strategy Unit, 2005). This policy document was authored by leading disabled academics, activists and commentators from across the UK and worked with government departments to set out a framework to increase opportunity and the quality of life of disabled people across a range of areas (including independent living, education and employment). In doing this, it distinguished disability, impairment and ill-health, furthermore, it identified key policy, physical and attitudinal barriers to equal opportunities in need of consideration. When considering access to employment, the strategy set out to:

> *‘increase the number of disabled people in employment while providing support and security for those unable to work’* (Prime Minister’s Strategy Unit, 2005, p.19).

Therefore, the strategy continued to acknowledge the significance of work but showed an acknowledgement that not all disabled people could enter employment. However, it failed to consider structural issues around geography, de-industrialisation and to consider how previous policy initiatives had often shifted the ‘disability category’ (Stone, 1984; Roulstone and Prideaux, 2012). ‘Improving the life chances of disabled people’ was substantially significant in how the government considered disability and responded to disability in social policies. Despite being welcomed by the Labour administration, its influence disappeared upon the election of the Conservative-Liberal Democrat Coalition in 2010.

This section considered the strategies in place to challenge the labour market disadvantage of disabled people at this time. This specifically considered how anti-discrimination legislation was implemented during an era of increased work-related policies for disabled people. The following section considers the subsequent policy strategies that were adopted as a means of incentivising work for individuals deemed as able to enter the labour market.

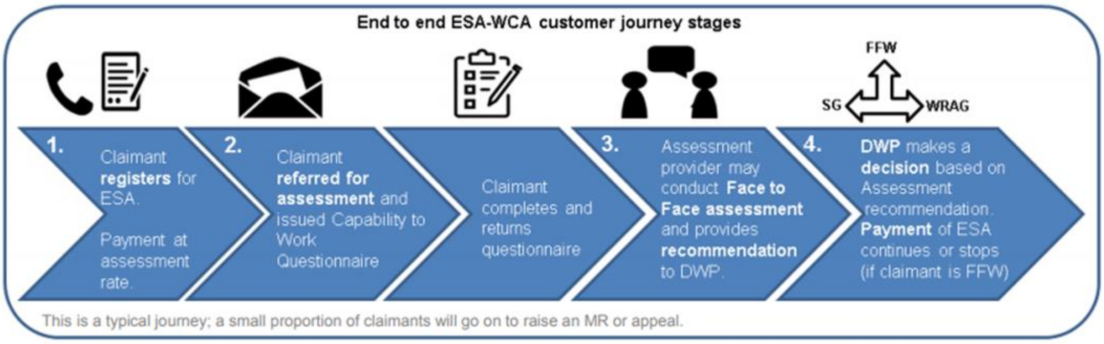
## 2.8 Work-based Welfare Reform

Under New Labour, Incapacity Benefit (IB) was replaced in October 2008 with ESA. This reform was under consideration throughout successive Conservative administrations, although not implemented as thought to be too contentious.

### 2.8.1 The Work Capability Assessment

The stated intention of ESA was to provide financial support for those unable to work and provide practical ‘support’ for those who were deemed as able to work (Government, 2017). The move from IB to ESA followed the increasingly work-first trend to social security, which academics have argued often ‘advocates moving people into employment as quickly as possible, irrespective of the quality of the job or the barriers faced by the individual’ (Lindsay and Dutton, 2013, p.183). Eligibility for ESA was decided upon by using the WCA which attempted to address whether an individual’s health or impairment would affect their ability to work. This was informed by the biopsychosocial model of disability (Waddell and Aylward, 2010) which was contentious as the model neither fully adopted medical or social model thinking but still located the issue with the individual. The biopsychosocial model did not solely focus on a person’s impairment but instead the way the impairment is perceived and justified, leading to the re-assessment of those who had previously been deemed unable to work under previous policies. It is important to note that this model has been largely criticised as it was developed from a study with a limited evidence base which focused on a specific type of impairment and therefore cannot be applied to understand the experiences of all disabled people (Jolly, 2012).

The WCA was implemented through The Welfare Reform Act (2007) to establish eligibility and distribution of ESA; this included the re-assessment of people who had been long-term IB claimants. The assessment was conducted by the Health Assessment Provider (HAP), ATOS healthcare, through both initial paper assessments and face-to-face assessments. The diagram below illustrates the 'typical' process a claimant would go through to claim ESA (Fig. 2.1).



(Image Source: DWP, 2018)

The process was often described as much more complex than illustrated in this diagram (see chapter three). As discussed in chapter three, the nature and effectiveness of the WCA is contested. Roulstone and Yates (2013, p.463) stated that the transition from IB to ESA:

> *'reconceptualised the disability welfare system as no longer grounded in broad-based support, but fundamentally concerned with individual capacities to 'move towards work' as decided by medical assessments of ability 'to work beyond a certain level'.*

The assessment procedure is based on a static points system, where assessors award points based on a person's ability to carry out certain tasks. The amount of points then indicates which category a person falls into, either: Fit for Work (FfW); limited capacity for work or limited capacity for work-related activity. Those labelled as FfW are not entitled to ESA and are moved directly to mainstream JSA. Those perceived as having a limited capability to work are assigned to the work-related activity group (WRAG), in which carrying out work-related activity is the condition for receiving benefits, with the hope of assisting persons in this category to move back into paid employment. Additionally, a lower financial rate is received, and sanctions may be imposed if conditions (such as attending regular work-focused interviews and completing an action plan) are not fulfilled (Roulstone and Prideaux, 2012; Dwyer *et al.*, 2018).

The final group, the Support Group, is assigned for those assessed as having limited capability for work-related activity (Litchfield, 2013). This group of people are therefore deemed 'deserving' of unconditional welfare support. The principles of categorising and dictating who is considered *disabled enough* to be deemed as deserving of welfare support is problematic and link to Stone's (1984) work on shifting disability categories. Stone (1984) suggests that often the disability category is a restrictive mechanism with the purpose to '*keep everyone in the work-based distributive system except for the very neediest people'* (Stone, 1984, p.188). This was evident in the development and adoption of the WCA to assess disabled people's eligibility for ESA.

### 2.8.2 Paternalism and Supply-Side Policies

The further use of workfare ideologies, which underpinned New Labour policy, was evidenced in the former Work and Pensions Secretary's White paper 'Beveridge for the 21st century', which put a clear emphasis on securing work for disabled people. Although, as noted previously, earlier attempts to promote employment for disabled people such as AtW (1994) initiatives were often concerned with targeting those closest to entering the labour market (Stafford, 2015).

Roulstone and Yates (2013, p.460) state that:

> *'New Labour did produce policies attempting to account for and address 'barriers' to transition and long-term employment associated with disability. However, at the heart of their policy focus for disability, training and employment, in line with the trends outlined above, was a conceptualisation of the disabled individual as essentially responsible for their own employability, and of the central role of policy and services*

> *being to support the development of such employability by individually responsible agents'*.

New Labour's approach draws parallels to paternalist approaches to welfare and elements of laissez-faire and piecemeal policy approaches, providing limited support from the state whilst asserting the importance of individual responsibility. The approach also demonstrated a shift towards contractualist ideas behind welfare in which citizens are expected to fulfil responsibilities to gain rights. Griggs and Bennett (2009) suggest that there are numerous explanations behind this policy shift including the importance of paid employment within New Labour policy approaches, such as '*work as a route out of* poverty' (Griggs and Bennett, 2009, p.8) and the increasing focus of supply-side approaches to employment.

The New Labour policy emphasis on the supply-side approach to employment is further evidenced by Peck and Theodore (2000) when suggesting that a 'supply-side fundamentalism' underpinned New Labour policy (in Roulstone and Prideaux, 2012, p.91). Therefore, this meant that the government focused '*on improving access to "existing" employment opportunities rather than addressing the nature of available employment'* (Hyde, 2000, p.338). Fletcher (2011) reinforces this thinking and argues that the shift from welfare to workfare programmes '*is signalled by the punitive nature of programmes which attempt to recast 'supply-side' problems as the product of deficient work ethic'* (Fletcher, 2011, p.445). The lack of consideration to demand-side barriers to employment is particularly problematic when considering disabled people's unequal opportunities in the labour market.

Peck (2001) states that 'The boundary between welfare and work, is, socially constructed and perpetually reconstructed' (Peck, 2001, p.49). This section has considered how the boundary between work and welfare was initially reconstructed under the Labour Government (1997-2010). For disabled people, the WCA and engagement with work-related activity are key sites of this reconstruction. The continued reconstructing of welfare and work was clearly evident from the election of New Labour and was developed further under the Coalition government that followed.

## 2.9 The UK Coalition (2010-2015) and Anti-Discrimination Legislation

This section considers the changes to anti-discrimination legislation that closely preceded and continued to develop under the Coalition administration.

A major restructuring of previous anti-discrimination legislation came into force in the shape of The Equality Act (2010), closely followed by the 2010 election which resulted in a Coalition government administration of Conservative and Liberal Democrat parties. The Equality Act (2010) consolidated all groups of ‘protected characteristics’ (i.e. race, gender, and disability) into one piece of anti-discrimination legislation. This repealed the DED with the hopes of strengthening anti-discrimination legislation, however, this is often disputed (Paulley, 2010). The primary areas the Act addressed were; employment, education, training, housing and the provision of goods, facilities and services. However, the Act remained contentious as it failed to address several of the existing criticisms of the DDA (e.g. reasonable adjustments and the individualised definition of disability).

The Equality Act (2010) states that:

> *‘A person has a disability if—*
>
> *(a) the person has a physical or mental impairment, and*
>
> *(b) the impairment has a substantial and long-term adverse effect on the person's ability to carry out normal day-to-day activities’*

This definition continues to focus on the impact impairment may have on ‘ability’ and perceptions of what is considered ‘normal’ to define disability. Unlike the original DDA (1995), a useful distinction between disability and impairment is made, although ‘disability’ is still defined in medical, individualised terms. Furthermore, as the Equality Act (2010) covers discrimination based on numerous protected characteristics, it can be hypothesised that the Act had the potential to dilute disabled people’s rights

(Paulley, 2010). In contrast, Dickens (2007) suggests that the Equality Act shows a positive shift away from not only tackling discrimination but attempting to promote equality. The Act was strengthened by the Equality Duty which placed responsibility on public authorities to tackle discrimination, advance equality and foster good relationships.

The previous section considered the changes to anti-discrimination legislation for disabled people under the Coalition (2010-2015). The following section looks specifically at the Welfare Reform Act 2012 and the challenges this raised for disabled people. This was the main legislation in force during the time of this study and impacted a number of people including disabled welfare claimants.

## 2.10 The Welfare Reform Act 2012

The Coalition came into power in 2010 with the majority Conservative Party promoting rhetoric surrounding the creation of a 'fairer' welfare system (Cameron, 2011; DWP, 2010). This was enforced in the Welfare Reform Act (2012). The initiatives drew parallel with New Labour's emphasis on work as the best route out of poverty and attached punitive sanctions and support to social security as a means of tackling the fiscal deficit caused by a 'culture of dependency' (Duncan Smith, 2005). A key paper that outlined the Coalition's policy entitled 'Simplifying the Welfare System and making sure Work Pays' (2013) aimed to:

> *'make the benefit system fairer and more affordable to help reduce poverty, worklessness and welfare dependency and to reduce levels of fraud and error'* (Government, 2015, unpaged).

This narrative drew parallels to debates around 'welfare dependency' as a rationale for welfare reform and increased emphasis on fraudulent claims.

The Act followed the initial white paper 'Universal Credit: welfare that works' (2010), and extensively changed the way welfare was structured and delivered. Key disability policy changes included:

- The introduction of Universal Credit (UC);
- The introduction of Personal Independence Payments (PIP) in replacement of Disability Living Allowance (DLA);
- Restrictions to Housing Benefit Entitlement (Spare room subsidy or ‘bedroom tax’);
- The continuation of moving existing Incapacity Benefit claimants to ESA;
- Time-limiting the contributory ESA to 12 months.

The overall theme for welfare support emphasised the contested notion of a ‘Broken Britain’ (Duncan Smith, 2009) in which people needed to be incentivised to work and no longer ‘depend’ on social security. Slater (2012) provides a key argument against this when exploring the ‘Myth of a Broken Britain’ who uses an agnotological approach to explore how the relationship between misinformation and state power enact an ‘assault on the British welfare state’. Morris (2011a, unpaged) reinforces this when stating:

> *‘Politicians from all parties are fond of talking about the way that applying conditions to the receipt of out of work benefits will encourage individuals to take responsibility for their own destiny. In fact the application of conditions and sanctions increases the power of the state. Far from promoting individual responsibility, conditionality creates paternalism and a loss of autonomy/self-determination’* (Morris, 2011a, unpaged).

The interpretation of the problem as individual responsibility meant that an effective response strategy would be the stricter conditionality measures enforced by the Coalition administration. However, academics such as Patrick (2011a) argue that this is based on an inaccurate diagnosis of the ‘problem’:

> *‘New Labour, and now the Coalition, seem to neglect this in their policy approach, which concentrates too much on supply-side issues, with a neglect of demand-side barriers. This suggests an incorrect analysis of the problem, and the work-related conditionality solution may be ill-fitted to cope with the problems highlighted by the disabled people participating in this research’* (Patrick, 2011a, p.315).

The way in which disability policy was framed and approached over the Coalition administration was widely criticised. Numerous criticisms reinforce the views of Patrick, surrounding a lack of consideration for demand-side barriers and supply-side fundamentalism (Wood and Grant, 2010; Roulstone and Prideaux, 2012; Weston, 2012). Wood and Grant (2010) add to this and suggest that the Coalition's welfare policy was not grounded within the reality of the current economic climate, which was rife with extensive public sector job losses, regional disparities in unemployment rates and a majorly competitive labour market. The Coalition's focus on sustainable employment without considering these factors are argued to be 'both naïve and dangerous', especially when disabled people were deemed as 'less-employable' than others. Wood and Grant (2010) called for the Coalition to 'incorporate the social model of disability into a holistic 'capacity-capability' test for ESA claimants' (Wood and Grant, 2010, p.91) to address these issues.

Roulstone and Prideaux (2012) argue that the Coalition should have explored a critical long-term perspective on disability policy which may question 'populist strands of Coalition thinking and provide an alternative policy agenda' (Roulstone and Prideaux, 2012, p.179). They suggest that this would address the need to connect welfare to work programmes with economic opportunities. If this was not addressed, then arguably the process of incentives and disincentives would be deemed redundant. This is reinforced by Weston (2012) when challenging the effectiveness of conditionality for benefit recipients, stating that:

> *'findings help to argue for greater recognition of the heterogeneity and diverse levels of need among disability benefits claimants, demonstrate advantages and disadvantages of conditional benefit receipt, and highlight the limited effectiveness of incentives and sanctions. Furthermore, findings suggest a need to reconsider the emphasis in government policy on conditionality, where this obscures messages about the availability of personalised support'* (Weston, 2012, p.515).

It is important to note that another implication of the increasingly conditional welfare state was the reinforcement of perceptions on economic contribution solely through labour market participation. This can consequently be argued to de-value any other means of contribution disabled people make to society (Morris, 2005) (see chapter three). Page (2002) discusses this in relation to citizenship and argues that conditional welfare policies have established ‘employment-based citizenship’.

This section has focused on the initial impact of the Welfare Reform Act 2012, the key legislation impacting those in this study. It has also considered the literature in response to the Act which explored the impact it would have on disabled people’s lives. The following section considers the main policy implications which affected disabled welfare claimants at the time of this study.

## 2.11 Policy Context

The interviews conducted for this study took place between 2015-2016. This overlapped with the election of a new majority Conservative government in May 2015 and an even greater emphasis on continuing to implement the conditionality regime and enforce the Welfare Reform Act (2012). It was against a backdrop of cuts being rolled out and the Institute for Fiscal Studies’ (IFS) ‘Green Budget 2014’ which stated that by February 2014, around 60 per cent of the cuts were still to be implemented (IFS, 2014). This meant that often narratives and policy changes were not clearly understood by claimants and subject to potential changes under the new Conservative government.

This continually changing period aligned with the rollout of UC in parts of the UK, although this had not yet been implemented in the areas in which this studies interviews took place. UC’s focus on contractual obligations and the ideology of ‘activating’ benefit recipients meant that policy continued to be significantly underpinned by welfare conditionality. This was also extended to those in employment which had the potential to place additional barriers on people with impairments who need a gradual approach to entering employment or work part-time.

This was also at a time where the WCA continued to receive significant criticism and private contractors ATOS stopped delivering assessments (March 2015).

Another private contractor, Maximus, took over as the HAP which carried out the WCA, however, the assessment remained largely the same, with significant issues around its delivery and appropriateness still impacting many people who were attempting to newly claim or be reassessed for ESA. Therefore, the key changes interviewees were facing were mainly surrounding the shift from a Coalition to Conservative leadership, the increased conditionality regime (including tightening of WCA eligibility) and the imminent rollout of UC. This meant often interviewees were uncertain or anxious about their benefits entitlement and what was to come.

## 2.12 Recent Policy Changes

The rollout of UC (April 2013-December 2018) was widely criticised (Dwyer *et al.*, 2018; Millar and Bennett, 2017) and despite failings causing claimants to be without benefit receipt for several weeks, it has continued to be implemented across the UK. Millar and Bennett (2017, p.175) argue that:

> ‘*Universal Credit seems designed to suit the people that ministers believe claimants should become, rather than starting from where they are now. This aim to achieve transformational cultural change underpins the strong focus on conditionality, with the aim of strengthening connections to the labour market through enforcement of work requirements*’.

Data has already demonstrated the significant damage caused by the implementation of UC; including, the increase in sanctioning which left JSA and ESA claimants more than six times as likely to be sanctioned under UC (Scottish Government, 2018a).

> *‘Since 2011, 70,000 ESA claimants across Great Britain eligible for disability premiums have been underpaid due to DWP’s errors and lost an estimated average of £5,000 by 2018/19, the year in which the DWP intend to repay affected claimants. The department expects to pay out up to £500 million of underpayments by April 2019, but do not plan to*

> *pay any compensation to reflect the value of lost passported benefits'* (Scottish Government, 2018a, p.50).

In March, the Welfare Reform and Work Act (2016) was passed and continued to promote the implementation of a punitive system and implemented a further benefit cap and freezes on benefit amount for certain groups of people. However, this was closely followed by The Scotland Act (2016) which devolved significant powers over social security to the Scottish Governments control[1].

The Scottish Government, as critics to the current welfare agenda, passed the Social Security (Scotland) Act (2018) as their first major Act as a devolved Scotland. This Act introduced key changes to the way social security is delivered in Scotland including the ceasing of means testing of disability-related benefits, increasing Carers Allowance and a promise to take into account disabled people's experiences through the 'Disability and Carers Benefits Expert Advisory Group' whose role is to facilitate the engagement in social security of people with lived experience. They also stated that:

> *'the system will be designed with the intention of significantly reducing the number of individuals required to attend a face-to-face assessment to determine their eligibility to Disability Assistance…[and] all Social Security Scotland staff involved in making decisions about eligibility to Disability Assistance will undergo robust training reflective of the Agency's values of dignity, fairness and respect'* (Scottish Government, 2018b, unpaged).

The Scottish Government state that where a face-to-face assessment is deemed necessary, this will be no longer conducted by a private contractor. These steps demonstrate a significant shift towards a rights-based approach (Drake, 1999) to welfare and challenge the dominant political ideology of the UK government. This was clearly reflected in the Act which states that '*social security is itself a*

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[1] The devolved Scottish Government gained control over: Disability Living Allowance, Personal Independence Payment, Attendance Allowance, Severe Disablement Allowance, Industrial Injuries Disablement Benefit and some elements of Universal Credit.

*human right and essential to the realisation of other human rights*' (Scottish Government, 2018).

This section has presented an overview of the key changes to welfare policy since the time of data collection. It has explored how the Scottish Government challenged the UK government's approach to social security and used their devolved powers to move towards a rights-based approach. Continued evaluation and comparison of the impact that adopting a rights-based approach to social security has in Scotland may present an opportunity for reframing how welfare policies are developed more broadly across the UK.

## 2.13 Conclusion

This chapter has explored the key welfare and employment policies which impacted disabled people from 1940- 2016. It is important to consider these policies also fall within a myriad of policy developments that impact disabled people's lives and economic and social inclusion such as education and housing policy. It identified both Drake's (1999) and Oliver's (2004) framework of disability policies and identified where they were evident in policy and legislation over this time period.

It is clear that some changes in disability policy have improved the rights of disabled people during the last 20 years such as anti-discrimination legislation and the move towards more rights-based policy approaches (Drake, 1999). Simultaneously, there have been shifts towards an increasingly conditional approach to welfare which has negatively impacted disabled people. The 'ability' to work has become a contested territory in a person's eligibility or 'deservingness' to receive support from the state. This is highly problematic as it fails to acknowledge demand-side problems and the inaccessible structure of the labour market. The Disabled People's Movement and the emergence of a social model of disability has enabled policy to engage with debates around rights and citizenship that were often absent from disability policy discourses before this. However, this often failed to adequately represent those with mental health conditions and learning difficulties.

When considering Drake's (1999) framework of disability policy models, UK policy has largely been influenced by laissez-faire and piecemeal approaches, with minimal evidence of truly rights-based policies. There was a distinct shift towards more rights-based policies in the years post-New Labour, however, this is paired with a clear focus on conditional welfare arrangements which direct responsibility onto the individual with minimal input from the state.

This chapter has evidenced how often governments live in policies; however, it is people who live in the detail. This study aims to address the implications of applying conditional welfare arrangements to disability policy. The way in which disability is framed and altered throughout policy discourse is of particular significance to this study, as this dictates which welfare claimants are considered 'deserving' or 'undeserving' of state support. The final objective of the research is to understand 'To what extent is there a gap between policy provision for disabled people, and the lived experience of *being* a disabled person within the conditional welfare state?'. By initially identifying the significant policies, clear distinctions can be made between the data collected in order to identify the gap between the lived experience of the participants and conditional welfare policy approaches.

The following chapter sets out the key concepts that this study draws upon to address these objectives. It illustrates the existing literature in the field and identifies how this study provides a new contribution to what is known about disabled people's experiences of claiming ESA.

# Chapter Three: Understanding the Citizenship, Identities and Challenges of Disabled Welfare Claimants

## 3.1 Introduction

The previous chapter provided an overview of the historical and contemporary policies which have contained, compensated, and controlled disabled people claiming welfare support. This chapter interrogates the existing literature that shapes what is already known about the policies that impact disabled welfare claimants. It investigates how this literature has contributed to the current field whilst also identifying the gaps that this thesis addresses.

It presents and interrogates the main conceptual and theoretical literature to identify the concepts that are used to analyse the findings of this thesis. It first considers the notion of citizenship, particularly drawing on Morris' (2005) exploration of self-determination, participation and contribution and how this can be utilised to understand disabled people's experiences of welfare policy. The concept of identities is then explored by drawing on identity theory and Goffman's (1963) notion of the 'spoiled identity', both providing a useful lens for understanding welfare claimants' and disabled people's lived experiences of welfare policy.

This chapter concludes by critiquing the most recent literature base that this thesis contributes to. It explores current research that not only reveals the experiences of disabled welfare claimants but also asserts that these experiences are borne out of a policy underpinned by 'an incorrect analysis of the problem' (Patrick, 2011a, p.315).

The following section explores the relationship between disabled people and citizenship, before focusing on Morris' (2005) citizenship approach.

## 3.2 Citizenship

To fully understand disabled peoples' lived experiences of contemporary conditionality and welfare reform, the long-standing relationship between disabled citizens and the state must be scrutinised. Building on the policy context (in chapter two), this section argues that the politicised concept of citizenship (Hindess, 1993, p.19) is core to understanding ‘the changing role of the state in relation to welfare provision’ (Dean, 1999, p.213).

Faulks (1998) identifies three common definitions of citizenship: legal, philosophical and socio-political. For the purposes of this thesis, philosophical definitions are most relevant for analysing the rights and responsibilities of citizens in relation to how the state meets their needs. Secondarily, socio-political definitions also provide a way of understanding citizenship concerning the existing power relationships in society. Debates about welfare conditionality are often rooted in Marshall’s (1950) classic distinction between civil, legal and political citizenship, highlighting changing social rights and responsibilities (Griggs and Bennett, 2009; Watts and Fitzpatrick, 2018).

Several well-established critiques of Marshall’s typology are relevant to understand the experiences of disabled people, including; the lack of sufficient consideration of the responsibilities attached to the attainment of citizenship status (Morris, 1994); the limited and ambiguous definition of social rights (Powell, 2002) and the lack of consideration for cost implications of social rights (Dwyer, 2000). Overall, Marshall’s explanation is largely relevant for ‘able-bodied’ males in full-time employment but demonstrates little consideration of ethnicity, gender or impairment related differences to attaining citizenship rights. This has, therefore, led scholars to develop further definitions and understandings of citizenship (Morris, 2005; Beckett, 2005; Lister, 1997) that consider those that Marshall’s definition overlooks.

### 3.21 Disability Studies and Citizenship Debates

Within the context of this study, a key consideration is how the operation of welfare policies impact disabled people's lives. Academic literature has significantly increased the focus on disability and the conceptualisation of citizenship over the last three decades (Sepulchre, 2016). A major contributing factor to this increase is the emergence of disability studies and the focus on rights-based approaches to understanding the relationship between the individual and society.

Whilst UK Government discourses around some welfare policies often tend to focus on issues of responsibility with limited consideration for rights (Barton, 1993), disability studies scholars have argued for meaningful representation of disabled people's voices within citizenship debates. Oliver (1992) goes as far as to argue that disability is the denial of citizenship. Similarly, Barton (1993) describes disabled people as 'voiceless' and 'marginalised' within citizenship debates. These arguments provided the strong rationale behind the Disabled People's Movement championing anti-discrimination legislation (see chapter two).

In 2005, the Disability Rights Commission (DRC) set out a pledge that disabled people should have equal opportunities to participate and contribute in the social, economic, civic and community life by 2020 (DRC, 2005). This pledge also stated that these contributions should be 'valued and welcomed' by other citizens, communities and institutions. Over the last 15 years social and economic circumstances, and therefore these aspirations, have significantly changed. Now in 2020, progress towards this goal has stalled and reversed in relation to social security and adequate income. This has been driven by the increased policy emphasis on welfare conditionality, the redefinition of the 'disability category' (Roulstone, 2015) and the removal of entitlement through punitive measures such as benefit sanctions. The Disabled People's Movement made significant progress in achieving steps towards independent living and anti-discrimination legislation (see chapter two). However, disabled people's opportunities to participate and contribute have been considerably eroded by increasingly punitive and conditional approaches to welfare policies.

In response to this pledge Morris (2005) presented a scoping paper developed for the Disability Rights Commission that set out an approach to citizenship for disabled people. Morris' (2005) definition of citizenship is important because it both conceptualises the notion of citizenship, but also reflects on the barriers that remain 15 years on.

In her paper, Morris (2005) outlined three key tenants which define citizenship and discussed the tensions each can have to achieving citizenship as a disabled person: self-determination, participation and contribution. Self-determination concerns people making decisions about their lives for themselves (Morris, 2005;

Duffy, 2003), reflecting the concept of autonomy within traditional citizenship debates. Morris argues that for disabled people to exercise self-determination, the removal of barriers is imperative but also, in some cases, the 'provision of assistance which makes self-determination possible' (Morris, 2005, p.7). Policy approaches promoting self-determination include directives such as direct payments and personalisation as a means to secure independent living. These characterised key policy developments during the New Labour era (see chapter two). However, Morris also argues that economic assistance has proven to be an inconsistent effort provided alongside such approaches to enable disabled people to effectively exercise self-determination.

Participation considers people's involvement within community and family life including political activities. The fulfilment of citizen responsibilities or contribution is the final aspect of Morris' approach. Communitarian conceptualisations of citizenship stress the importance of such responsibilities in order for citizens to access rights, in essence, reciprocity is a fundamental element of the citizenship contract. A key difference between Morris' (2005) approach to citizenship and more classic approaches, such as Marshall's (1950), is the consideration of the 'tension between citizenship's universalist promise and the recognition of difference' (Lister, 2006, p.54).

Morris' approach provides a framework for this chapter's exploration of existing literature and helps to identify where this research aligns within current conceptual and theoretical debates. It particularly considers how disabled people's ability to exercise self-determination, participation and contribution are impacted by conditional approaches to social security policy within the UK, as Morris reflected in a more recent commentary:

> *'Current government policies are removing the assistance required to promote our self-determination, participation and contribution. And in the process, people feel less safe, are more likely to live in poverty, are denied opportunities open to others, and in some cases have shortened life expectancy. Government policy, in other words, far from promoting our citizenship, is actually doing us harm'* (Morris, 2016, unpaged).

Morris' contribution to citizenship debates is utilised to interpret disabled people's experiences and understand how they are characterised by the relationship between welfare policy, the citizen and the state. The following sections critique each of Morris' tenants of citizenship in further detail and the barriers disabled people face to achieving them within the current policy context. The first tenant explored is self-determination.

### 3.22 Disabled Welfare Claimants and Self-Determination

Self-determination links to the notions of agency, autonomy and 'the ability to determine the conditions of one's life and to pursue one's life projects' (Lister, 1997, p.16). It is therefore characterised by individuals having the ability to exercise choice and be purposive and creative actors (Lister, 2003; Twine, 1994; Giddens, 1991). Lister (2003) states that 'citizenship as participation represents an expression of human agency in the political arena, broadly defined: citizenship as rights enables people to act as agents' (Lister, 2003, p.37). However, the expressions of agency within the notion of 'active citizenship' are contested. For example, the lack of acknowledgement of less formal forms of responsibilities such as community engagement (Lister, 2003; Barnes, 1999).

A key barrier to self-determination rests in the medicalised ideas of disability that dominate societal perceptions. This perspective reflects notions of individual deficit and dependency and, circumscribes disabled people as unable to exercise full autonomy. Elements of the welfare process, such as the Work Capability Assessment, illustrate how these notions are still reflected in contemporary policy and how often policy can serve to reinforce perceptions of deficit and dependency. The social model of disability challenges individualised conceptions of disability by identifying it as a social construct whereby people are disabled by an inaccessible society (Oliver, 1990) (See chapter two).

Paternalism presents a further barrier to state welfare for disabled people. Paternalist thinking argues that rights must be dependent on fulfilling civic duties or responsibilities to achieve citizenship status (Mead, 1997). This poses questions around the loss of universalism (Standing, 2011); although, to what extent welfare support has ever been universal is contested, particularly for disabled people. Paternalism is also underpinned by the notion that 'that the person interfered with will be better off or protected from harm' (Dworkin, 2017). This perception of 'state knows best' limits a person's autonomy.

Morris (2005, p.11) identified such barriers and consequently outlined three key statements that must be considered when disabled people exercise self-determination. The first statement asserts that requiring support with decision making is not an excluding prerequisite to self-determination. Secondly, Morris states the importance of a society working towards removing barriers to self-determination, whilst also enabling support for people to exercise it as a means of enabling equal opportunities. The final key assertion states that any action should be determined by disabled people themselves. These three statements provide a useful framework to interrogate whether welfare policies align with these statements and therefore provide an opportunity for disabled welfare claimants to exercise meaningful self-determination.

The ability of disabled people to 'self-determine' is significantly impacted by how they can act as autonomous agents. When engaging with the current welfare system this can pose a clear challenge. Claimants are constrained by both the conditional and paternalistic elements of welfare policy. The behaviours that are deemed appropriate are dictated, whilst claimants are simultaneously expected to exercise agency through fulfilling activities such as job searches and work-focused training. Morris (1994) reinforces this challenge when arguing that civic duties can be 'at odds with the operation of welfare' (Morris, 1994, p.51).

Based on Morris' approach, a key tenant of citizenship involves exercising self-determination, but welfare support for disabled welfare claimants is determined by conditions implemented by the state. Therefore, full autonomy is weakened by the need to fulfil the conditions in order to receive support. Consequently, an individual's behaviours and actions may be influenced by the structural influence of the state as well as the agency exercised by the individual.

Overall, when reflecting on Morris' approach to citizenship, exercising self-determination is often about making choices. However, despite often adopting the language of choice and control, the increasingly punitive and conditional aspects of contemporary welfare policies (e.g. the sanctioning regime) have the potential to remove choice and promote state control. This poses a direct contradiction to promoting self-determination and therefore, under Morris' approach, can be seen to significantly hinder disabled people's opportunity to gain full citizenship.

### 3.23 From Self-determination to Participation

Morris describes participation as disabled people's social and economic involvement in the public sphere and within familial, community and political spheres. This corresponds to Marshall's definition of social and political rights. Actively participating can be a challenge for disabled people who have historically been excluded from participation within mainstream society. This is particularly problematic when considering notions of 'active citizenship' which have been at the forefront of political agendas since New Labour (see chapter two) and emphasise the importance of individual responsibility for you and your family.

The extent to which disabled people can exercise 'active citizenship' is contested; often individuals have been denied the ability to control welfare with many charities and policies rooted in paternalism (Dwyer, 2004). In terms of social security, the way welfare support is provided is often underpinned by a 'state knows best' philosophy where elements of hard and soft paternalism are enacted to 'help people to help themselves' (Morris, 2011). Therefore, policymakers and medical professionals often determine the 'best' ways disabled people should be supported, meaning disabled people's agency and control over welfare support are diminished. This is reflected by Morris' citizenship approach whereby she argues that poverty, 'the operation of the benefits system' and other issues are key barriers impacting on disabled people's ability to achieve full participation.

Shifts towards paternalistic approaches to welfare policies increase dependency and penalise autonomy (Boreng, 1991), this impacts disabled people's participation in daily life in a multiplicity of ways. Practical barriers to participation posed by the welfare system include financial barriers posed by reductions to eligibility and sanctioning and, the lack of involvement in the development of welfare policies meaning that disabled people's voices remain absent from the decision-making process. The lack of disabled people's voices in policy-making is a key consideration for this study, especially when exploring the gaps between lived experience and the implementation of welfare policy. The voices of disabled people are still often missing in the development of social security policy, although as discussed in chapter two, recent changes by the Scottish Government have introduced experience panels and an expert advisory group to ensure policies are shaped by people with lived experience (see chapter two).

More nuanced barriers to welfare claimant’s ability to participate emerge in response to societal perceptions. Literature evidences that people can feel anxious being seen to be actively involved (Baumberg, Bell and Gaffney, 2012) for example engaging in physical activity (Johnson and Spring, 2018), for fear of repercussions on benefit entitlement. The internalisation of stigma and shame around benefit receipt (Baumberg, 2016; Garthwaite, 2015) also perpetuates the fear of participating in a society which delegitimises welfare claimants.

Although these barriers to participation remain, disabled people have not been ‘passive actors’ when considering their political response to the changes in welfare support. Many people have collectively come together to rally against the cuts to support, most notably DPAC (see chapter two) who were initially formed to protest against austerity cuts in 2010. Therefore, participation within the political sphere is happening as a response to the lack of participation with state policies and decision-making processes.

### 3.24 Welfare Policy and Contribution

To understand the disconnection between policy approaches and lived experience a discussion of how contribution is framed within welfare policy is particularly important. In chapter two rationales behind policy-making were explored; however, it is also important to consider the academic debates around contribution.

Social responsibility is a concept at the core of accounts of welfare state change. In  particular, social responsibility is increasingly evident in the shift from ‘old style welfare rights’ (Goodin, 2002, p.579), which place responsibilities on the state to realise the rights of citizens, to a new politics of welfare, within which the responsibilities of citizens are emphasised (Fitzpatrick, 2005; Griggs and Bennett, 2009). Fitzpatrick (2005) refers to a ‘politics of welfare obligations’ and Plant (2003) to ‘obligation-based citizenship’. The growth in the emphasis on responsibility in the UK is often associated with the New Labour government (Clarke, 2005) and is seen to have continued post-2010 under the Conservative-led coalition and successive Conservative governments (see chapter two).

As noted, understandings of citizenship rooted in communitarian approaches often emphasise the significance of the reciprocal relationship between citizen and state, specifically concerning economic contribution and labour market participation. Traditional understandings often situate paid work as the ‘primary obligation’ which holds ‘the ‘key to citizenship’ (Lister, 2002, p.521). A significant disadvantage of adopting a citizenship approach linked with the principle of solely economic contribution is the denial of citizenship status for those who are unable to meet such requirements. Contribution as a determinant of citizenship therefore often limits disabled people’s opportunity to achieve equal citizenship.

Morris’ approach does not solely focus on financial contribution through labour market participation, making it a more inclusive conceptualisation of citizenship and civic duties such as caring and volunteering. Reflecting on all three tenants of citizenship, meaningful contribution is not possible unless people can both self-determinate and participate. If the state imposes a non-inclusive notion of contribution, then disabled people’s ability to exercise self-determination is significantly eroded. In addition, disabled people’s ability to contribute is also substantially impacted by the structural determinants of employment rather than being linked to the motivation of an individual. Therefore, policy approaches (see chapter two) have often been at odds with this inclusive conceptualisation of contribution when based on a misinterpretation of the ‘problem’ (Patrick, 2011a).

## 3.3 Identities

The previous section explored the relationship between disability and citizenship, specifically Morris’ (2005) concepts of self-determination, participation and contribution. This section analyses the concept of identities, focusing on the relationship between disability and welfare receipt and the relationship between self and society. It engages with existing arguments specifically focusing on how disabled benefit claimants construct and determine their own identities against the backdrop of a conditional welfare regime.

A significant consideration of this section is the focus on how individuals negotiate their identities in relation to the welfare system and interactions relating to benefit receipt. Disabled welfare claimants are often portrayed as a group who are ‘deviating’ from societal norms, whilst also sharing their collective experience of facing multiple barriers to equal participation. It is important to understand how these experiences can shape an individual’s understanding of self within the context of welfare policy.

How the operation of the welfare policy can impact on people’s sense of self, specifically in relation to experiences of stigma and shame are demonstrated by Garthwaite (2015) and Baumberg (2016). The following section foregrounds such work by exploring the concept of identity before outlining how identity will be utilised within this thesis.

### 3.31 Conceptualising Identities

Identity is an important theme within disability studies literature (Watson, 2002; Thomas, 1999), drawing on multi-disciplinary insights from a range of theoretical positions, with roots in symbolic interactionism (Blumer, 1962; Mead, 1934) and perceptual control theory (Powers, 1973). To how disabled benefit recipient’s construct and negotiate their identities, it is important to first explore how identity is defined within the existing literature. This section explores the concept of identity and outlines how it is used to understand how disabled welfare claimants’ identities are influenced by the operationalization of welfare policy.

The word identity derives from the Latin word ‘idem’, translating to ‘same’. Lawler (2014) discusses how the foundations of identities are situated around sameness and difference. His interpretation of identities is largely political, he suggests that some differences and norms ‘count socially’ and solely exist because of the power relations that mark these differences. Jenkins (2014) states that identity can be described as the human capacity of knowing ‘who’s who’, which involves the process of knowing who we are, knowing who others are, them knowing who we are, us knowing who they think we are and so on’ (Jenkins, 2014, p.6). Identity can be understood as a dynamic process, rather than a static position, which includes both perceptions of the ‘self’ and the ‘other’ and the interplay between them. Defining identity comprehensively is often a great deal more complex than this.

The difficulties in defining identity are echoed throughout sociological and psychological literature, as often making sense of this term is linked to how varying disciplines theorise the concept. Therefore, one overarching explanation of identity fails to adequately define the complexity of this issue (Lawler,2014). This has previously led to a distinction between different forms of identities (Goffman, 1968; Jenkins, 2014; Burke, 2013). The multiplicity of identities is particularly important to recognise to effectively understand how disabled welfare claimants negotiate and navigate their identities when interacting with the welfare system. Within this study, identity is used broadly as both a way of understanding how the claiming process can impact disabled welfare claimants’ sense of self and how dominant rhetoric surrounding welfare receipt provides a hotbed for feelings of stigma and shame. This allows consideration of how both disabled claimants perceive themselves and feel they are perceived by others.

### 3.32 Interactions with the Welfare Setting and the State

Insights from symbolic interactionist theory (Mead, 1934) are useful for understanding disabled people’s lived experiences of welfare conditionality. This research is informed by insights from symbolic interactionism, specifically in relation to how self and identities can be negotiated through social interactions. This is particularly useful when understanding how welfare claimants interact with front-line workers during the claimant journey.

Symbolic interactionism or the situational approach to self and society, where both self and society influence the other reciprocally, is based on the idea that ‘actors’ and society are in the continuous process of influencing each other (Blumer, 1969). Therefore, behaviour is impacted by interactions, the context and social group. By drawing on insights from this approach, the way disabled claimants’ identities are influenced and navigate in relation to interactions within the welfare system and the social context of welfare reform can be explored. Although not originally coining the term ‘symbolic interactionism’ George Herbert Mead’s work on the ‘Mind, Self and Society’ (1934) presented a significant contribution to how we understand this theory today.

Building upon Meads work, Nehring (2013, p.123) argues that although behaviours are often experienced as our own, they are 'inseparably entwined with the social worlds in which we conduct our everyday lives'. Therefore, reinforcing Mead's earlier assertion that 'the self is not so much a substance as a process' (Mead, 1934, p.178). Stryker (1980) similarly commented on the reciprocal relationship between self and society, asserting that 'self' influences society (through people coming together as networks, organisations and institutions) and 'society influences the self through its shared language and meanings that enable a person to take the role of the other, engage in social interaction, and reflect upon oneself as an object' (Stets and Burke, 2003, p.128).

In relation to disabled people's experiences, Swain and French (2008) describe the key ideas behind the notion of identities, specifically about disabled people:

> *'It involves active engagement, individual and/or collectively, in the continual processes of identity formation and maintenance, In affirmation of identity the personal becomes social/political and the political becomes personal, Identity involves shared identification with some people and not with others, through a myriad of social interactions, symbols and meanings, It also involves a tension between the control the individual has in constructing his or her identity and the social constraints limiting and determining identity formation'* (Swain and French, 2008, p.67).

The notion that the process of identity formation and maintenance is continually in fluctuation through interactions, symbols and meanings reinforces the symbolic interactionist perspective. Swain and French's acknowledgement of the tensions which arise between the individual control and social constraints of identities is particularly useful when understanding disabled people's experiences. Especially when considering that disabled people experience a number of social constraints, including experiencing significant inequalities and stigmatising perceptions from others, which impacts the control they have when constructing their identities.

Through lived experiences, one's identities can be perpetually altered and transformed. Swain and French (2008) argue that:

> *‘our sense of who we are, our own identity in relation to (sometimes versus) the identity of others, are part of the parcel of our lived experience and interwoven, and created within, our interactions with others’* (Swain and French, 2008, p.67).

Therefore, within a social interaction, we perpetually negotiate who we are and our identities. This notion that identity is ‘constantly being reworked and retold’ (Barnes and Mercer, 2003, p.79) is central when looking at social interactions. Therefore, drawing on elements of symbolic interactionism to consider how interactions and social context influence identities helps to understand that disabled, ESA claimants’ identities are influenced on a micro-level through the day to day interactions, such as the WCA, but on a much wider level by their societal context.

When exploring identities in relation to interactions within the welfare process, it is important to note the discrepancies between ‘accounts of agency grounded in the lived experiences of social actors (policy-makers, front-line workers and service users) and hypothetical models of individual agency (e.g. ‘rational economic man’)’ (Wright, 2012, p.309). Wright argues that often policy development is significantly influenced by the latter which fails to allow for meaningful critique of welfare policies that consider the interests and motivations which impact individuals agency. This discrepancy is particularly important to this research’s exploration of the gaps between welfare policy and the lived experiences of welfare claimants.  Therefore, exploring welfare interactions as lived experience may help to subvert the negative rhetoric around receiving benefits and mean that policies are developed from actual lived experiences.

This section has explored how the relationship between self, society and social interactions is particularly important when considering the lived experience of disabled welfare claimants. In particular when exploring how the WCA process and interactions with the welfare system can influence people’s identities. The following section continues the focus on identities by drawing on the work of Goffman’s (1961; 1968) ‘spoiled identity’ in relation to the challenges experienced by disabled ESA claimants.

### 3.33 ‘Spoiled identity’ and benefit claiming as a ‘discrediting attribute’

A significant contribution to contemporary sociological understandings of identity is Goffman’s (1961; 1968) influential work on stigma and identity. He identified three distinct types of identity: the ‘personal identity’, the ‘social identity’ and the ‘ego identity’. He first considered the ‘personal identity’ in terms of the unique attributes of a person or ‘what marks out the person as distinct from all others’ (Smith, 2006, p.85). Secondly, the ‘social identity’ considers the everyday ways in which people can be categorised by both structural and personal attributes (i.e. social status and more personal qualities). The ‘Ego Identity’ (or ‘felt identity’) refers to how people feel about themselves. Goffman breaks these concepts down further by exploring the social identity in relation to both one’s ‘virtual social identity’ and ‘actual social identity’. The usefulness of this distinction is an area of contention as it is argued that it does more to complicate than clarify the distinction between assumed identity and proven identity (Smith, 2006; Burns, 1992). Although this distinction is deemed as useful within the context of this research when understanding how disabled benefit recipients are perceived to initially be (their virtual social identity) and their actual social identity.

Another significant contribution was made by Goffman’s (1968) notion of the ‘spoiled identity’. He argues that those who are stigmatized (due to perceived discreditable attributes) are ‘disqualified from full social acceptance’, meaning they become both ‘discredited’ and ‘disqualified’. Goffman further distinguishes between attributes that are discredited, where stigma is visible and discreditable, where stigma is concealable. Within dominant societal rhetoric, both disability and claimant status are often perceived as ‘discrediting attributes’ and ‘discreditable’ attributes, with the idea of worklessness as an increasingly ‘discrediting’ indicator of a disabled persons ‘deservingness’ of welfare (Garthwaite, 2005). Goffman’s notion of the ‘spoiled identity’, therefore, provides a useful analytical tool for understanding how disabled welfare claimants construct and negotiate their identities in relation to their perceived ‘discrediting attributes’.

### 3.34 Disability Studies and Identity

Academic discussions have evolved within a distinct body of work dedicated to understanding disability. Early disability studies lacked consideration for the conceptual understanding of identities; however further disability studies literature conceptualizes identities (Watson, 2002). The tensions between conceptual understandings of identities and disability studies are interlinked with the conflicts between medical and social model understandings of disability (Borsay, 2002). These tensions are unique to other theories of identities (such as race) due to the non-binary nature of disability and the 'lack of agreement about whether disability is intrinsically problematic, less than ideal or whether it only becomes a problem when other factors operate as well' (Scully, 2012, p.110).

The tensions are reflected by Hall (1996) when arguing that there are two historical approaches to the construction of identities, the first and most frequently used social model within disability studies which is grounded in:

> *'the assumption that there is an essential, natural or intrinsic meaning to any identity. This identity is based on either a shared social experience, origin or structure'* (Hall cited in Watson, 2002, p.509).

In contrast, the secondary model rejects shared experience as an understanding of identity whereby:

> *'Identities exist only as opposites, they are multiple and temporal, and to propagate the concept of, for example, a male and female identity, or a disabled and non-disabled identity serves only to strengthen essentialist arguments'* (Watson, 2002, p.510).

As asserted by Watson, the binary between the disabled and non-disabled identity is problematic as disability does not describe a static position, but instead a spectrum which has the potential to alter throughout a person's life. A spectrum takes into account the idea that disability can be a transitory or temporary status as well as one that is fixed. Within broader sociology, the increased rejection of binary notions can be evidenced in relation to various identifying characteristics, such as gender identities, which are now seen as more fluid than simply male or female (Linstead and Pullen, 2006). Similarly, the movement away from this distinction in relation to non-disabled and disabled identities is a useful step in considering the transitory and unfixed nature of 'disability' throughout the life course.

The movement towards non-binary notions of disability is a key aspect of understanding how disabled people negotiate their identities. As discussed in chapter two, a primary consideration of this thesis is how conditional welfare policies are put into practice. Binary notions of disability within welfare policy have the potential to impact both the access to support and the provision of appropriate support for people experiencing fluid, cyclical and temporal impairments.

Another way in which identities have been explored in disability studies is Fraser's (1995) 'identity model'. Her approach to identities differs greatly and highlights two forms of justice – recognition and redistribution: recognition being the symbolic aspect and redistribution relating to socioeconomic injustice. Recognition of difference is therefore important, and Fraser suggests that misrecognition or non-recognition can be a type of oppression. Alcoff (2007, p.255) suggests that Fraser's model is 'almost unique in its effort to account for the role that difference plays in structures of oppression'. When exploring the changing dynamics of disabled people and the state, Fraser's work is pertinent.

This section outlines how binary notions of disability fail to adequately address disabled people's identities and considers how identities have been explored within the field of disability studies. The conflict between binary and fluid notions of disability provides a key consideration in how disabled people's identities are negotiated within the welfare system, particularly in relation to how eligibility can be assessed for people with non-static impairments. The following section further examines the relationship between 'self' and 'society' and how this impacts how one's self-identity is developed and negotiated, within the wider context of a disabling society.

### 3.35 Negotiating the Self in a Disabling Society

> *'…Identity is constructed on the basis of other people's definitions'*
> (Oliver and Barnes, 1998, p.67)

Disabled people's identities have been shaped in relation to a societal response to a perceived ‘deviance’ from the ‘norm’. Identifying people based on their ‘disability’, Shakespeare (1996) says fails to consider the collective experiences of disabled people but instead maintains the focus on medical differences. These approaches, therefore, imply that the negative identity of oneself is due to the medical differences of disabled people, rather than the social relations of disability or the stigma attached to being constructed as a ‘disabled’ person. The social model (of disability) can negate the ‘spoiled identity’ by considering disability as a social construct and experience of oppression. Therefore, how disabled welfare claimant’s identities are constructed and negotiated need to be explored within the context of a disabling society. Watson (2002) questions:

> *‘Do disabled people know who they are because of the fact that they have an impairment, because of the fact that they face discrimination or because of who they, ontologically, believe themselves to be? These are fundamental questions in any analysis of disability’* (Watson, 2002, p.512).

The work of Carol Thomas is useful in understanding this process. Her approach to disability both considers the social impact and the psychological impact by being rooted in peoples lived experiences of impairment. Rooted in the concepts of ‘barriers to being’ and ‘barriers to doing’, whereby ‘barriers to doing’ relate to challenges of agency, Thomas’ (2007) theorisation links to Morris’ (2005) notion of self-determination. Conversely, ‘barriers to being’ is in relation to ‘self-esteem, personal confidence and ontological security’ (Thomas 2007, p.72). Conversely, ‘barriers to being’ is in relation to ‘self-esteem, personal confidence and ontological security’ (Thomas 2007, p.72). Therefore, the barriers to doing are often challenges of a social level and barriers to being are on an individual level. However, this is not to say that they are two separate challenges, as often barriers to doing will compound barriers to being and thus they interact in relation to each other, in the same way, that structure and agency can influence each other. Both the social impact and the psychological impact on disabled people’s lived experiences of engaging with the welfare system can be understood through the lens of ‘barriers to being’ and ‘barriers to doing’.

A significant contribution to the understanding of disabled people's identities was made by Watson's (2002) study. The study explored people's self-identification and found that only three of the 28 participants interviewed included disability as part of their identity, with the majority suggesting that their impairment did not impact their sense of self. A clear example of this was presented in the personal account of Joyce:

> *'Well, I know this is going to sound very strange to you, but I don't see myself as a disabled person. I see me as an ordinary person, sort of being a housewife, being an Auntie, just doing ordinary things that ordinary people do'* (Watson, 2002, p.516).

This illustrated a lack of emphasis on disability and also a challenge to the negative presumptions attached to disabled people's ability to carry out 'normal' tasks or be considered an 'ordinary person' [sic]. Impairment was part of their everyday life experiences and considered therefore as 'ontologically, unimportant' (Watson, 2002) in the shaping of their identities.

The desire to be perceived as 'normal' and to not identify as disabled is problematic when considering those who require access to health and social care services. This is even more significant when considering welfare policy, for example, ESA claimants going through the WCA process. This has led to guidance from activist groups and those with experience of the process which suggests you must present yourself at your worst (Black Triangle Campaign, 2011) to obtain access to disability-related benefits such as ESA and similarly PIP (see chapter two). This concern is also raised historically by Linton (1998) who discusses the necessity of seeming helpless to receive social benefits but is even more significant within current welfare regimes.

The desire to achieve normality, Watson (2002, p.521) suggests, has the potential to 'reproduce disablist practices' when disabled people reject and distance themselves from other disabled people. This rejection of the notion of the 'spoiled identity' and the disabled identity draws parallels with the rejection of what Goffman described as 'discrediting attributes'. The reproduction of disablist practices within welfare operationalisation is particularly important as often claimants view benefit receipt as a 'discrediting attribute' to be concealed or reinforce narratives of the 'deserving' and 'non-deserving' claimant.

### 3.36 Claimant identities, Stigma, Shame and ‘Othering’

When considering the existing literature that specifically explored disabled people’s experiences of engaging with the welfare system, Riach and Loretto (2009) explore the concept of identity specifically in relation to older disabled people disengaged from the labour market. They found that the gatekeepers or street-level bureaucrats had significant power of the identities imposed upon disabled and older welfare recipients. This is reflected by Letkemann (2002, p.512) when referring to unemployment as an initial stigma that leads to several ‘derived’ stigmas, drawing parallels to Goffman’s notion of the ‘spoiled identity’.

This concept is supported by Fraser’s (1995) ‘identity model’, as the significance of the ‘spoiled identity’ and ‘the struggle for recognition’ has ‘a particularly profound meaning for this group which goes beyond the demands for citizenship: it is the struggle to be recognised as fully human’ (Ferguson, 2003, p.81). This struggle to be recognised as human is echoed by Goffman’s (1968) assertion that those who are stigmatised are dehumanized.

More recently, the idea of identities in relation to long term sickness benefit recipients is explored by Garthwaite (2015b). Utilising Goffman’s notions of stigma and shame, she found that the construction of identities was highly influenced by social relations and the popularist media accounts which pose to ‘discredit’ benefit recipients. This idea was also bought into by those benefit recipients themselves. This stigma is notably synonymous with feelings of shame (Walker, 2014; Sutton et al., 2014) which are often internalised by those in receipt of disability-related benefits (Chase and Walker, 2012) and often lead to behaviours which distance oneself from others or exercise ‘othering’.

The concept of ‘othering’ (Lister, 2004) describes the process of categorising people who are recognised as different from your perceived self. It has been identified as a mechanism in which welfare claimants distance themselves from those viewed as illegitimate (Patrick, 2017). It categorises ‘those that are thought to be different from oneself or the mainstream, and it can reinforce and reproduce positions of domination and subordination’ (Johnson et al., 2004, p.255). Therefore, leaving those who experience othering are placed or remain in a less powerful position within society.

Recent accounts of disabled benefit recipient's identities also demonstrate that negative feelings associated with claiming welfare support often contributed to critical assessments of self (Patrick, 2016; Saffer *et al.*, 2018). This not only impacted claimants' identities but also impacted their self-esteem and led to a decline in their mental health. Critiquing their own non-working behaviours, demonstrated the internalisation of the dominant narrative around benefits receipt as being shameful (Baumberg, 2016).

> *'The constant demand to demonstrate deservingness is experienced as a questioning and undermining of one's own entitlement, which inevitably –even as it is resisted – impacts on how affected individuals feel about themselves'* (Patrick, 2016, p.155).

This is explored in terms of 'claims stigma' when interactions within the welfare setting amplify the impact of existing personal stigma around claiming benefits and links back to theoretical notions of symbolic interactionism. Academics have argued that this reproduction of stigma could be a deliberate tactic of social control (Tyler, 2013).

Saffer *et al.* (2018) study about the impact of benefit changes for disabled people, specifically those with physical impairments, presents a theoretical model to understand how benefit changes are experienced by claimants. The model provides a useful framework for understanding how people's identities are shaped in relation to their claimant experiences by outlining three key processes: navigating a dehumanising system, living in a judgmental society and clinging onto my sense of self. Each process can clearly link to how a person experiences personal stigma, social stigma and institutional stigma (Baumberg *et al.*, 2012), through the process of claiming benefits or what Saffer *et al.* describe as 'navigating a dehumanising system' (p.1571).

This section has explored the existing literature surrounding identities that helps our understanding of how disabled people negotiate their identities within the context of welfare policy and operation. It identified several approaches that are useful when understanding disabled people's lived experience of welfare policies including Goffman's (1968) 'spoiled identity' and Thomas' barriers to being and barriers to doing. It finally outlined what literature shapes our current understanding of how welfare claimants perceive themselves and others. This raises questions about how disabled benefit recipients negotiate multiple identities.

The following section examines literature that has made a significant contribution to the understanding of how welfare conditionality is impacting on disabled people's experiences of claiming ESA. Specifically, this section explores the rationale and impact of applying conditional welfare policies to disabled people. It also considers how recent literature has explored it as a tool of retrenchment, to re-categorise or shift the disability category (Stone, 1984; Roulstone, 2015) or as a form of violence (Mills, 2018; Grover, 2018; Cooper and Whyte, 2017).

## 3.4 The Role of Welfare Conditionality for Disabled People: Retrenchment, Re-categorisation or Punishment?

As discussed in chapter two, the implementation of conditional welfare policies for disabled people has been justified as a means of reducing 'welfare dependency'. The rationale behind this is largely led by paternalist notions (Murray, 1990; Mead, 1997) of 'activating' people back into the labour market. Critics of conditional welfare support for disabled people (Patrick, 2011a; 2011b; Dwyer, 2004; Dwyer et al., 2018) consider this notion as a misconception of the problem (Patrick, 2011b). They challenge the emphasis on individual claimant behaviours by not only identifying the structural barriers that impact on people's ability to work (Barnes and Roulstone, 2005; Barnes and Mercer, 2005), but also, by arguing that the current system often inaccurately assesses disabled people as fit to work.

Critical analysts view welfare conditionality as an inappropriate tool for supporting disabled people back into the labour market and an insidious tool that intentionally punishes and harms benefit recipients (Wright *et al.*, 2020). The concept of 'structural violence' has been used to highlight the 'harmful diswelfares' of the conditional welfare state (Mills, 2018; Grover, 2018). Similarly, arguments have been made that welfare claimants are criminalized by contemporary social security reforms (Wright and Fletcher, 2018). However, these recent developments in critical theory have not yet been applied to analyse empirical qualitative data on disabled people's experiences of claiming benefits. This study will address this gap in understanding by providing empirical data that illustrates and illuminates the conceptualisations of violence and punishment within the existing literature in this field.

When considering the impact of welfare conditionality on disabled people, the literature explored so far has illustrated how recent welfare policies have had a detrimental impact on peoples' citizenship, by eroding social rights and limiting self-determination, and influenced people's identities leading to increased stigma, shame and othering. This questions the rationale of welfare conditionality but also what these detrimental impacts *feel* like and the lived experience of disabled welfare claimants.

### 3.41 Understanding Lived Experience

The term 'lived experience' is increasingly utilised within social research. However, it is often used without an exploration of its meaning or how it can be understood in any great depth (McIntosh and Wright, 2018). Broadly, lived experience can be understood as the:

> '*representation and understanding of a researcher or research subject's human experiences, choices, and options and how those factors influence one's perception of knowledge. . . [it] responds not only to people's experiences, but also to how people live through and respond to those experiences' (Boylorn, 2008, p.490).*

The concept of 'lived experience' was originally founded by the German Philosopher, Husserl in the early 1900s, and emerged as part of the thinking around phenomenology. It stated that the world should be explored as it is lived rather than experiences being constrained by binary thinking or abstract theory (van Manen, 1990). In challenging this binary thinking or dualism, it asserts that lived experiences cannot be separated into either mental or physical experiences. More recently Mcintosh and Wright (2018, p.4) have argued that:

> *'Lived experiences are especially relevant where they are shaped and mediated by policies, policy-related discourses and the practices of front-line welfare agencies'*

Therefore, within this context 'lived experience' can provide a greater understanding of the experiences of disabled people which are shaped by conditional welfare policies. The application of lived experience is a way of ensuring people's subjective experiences of welfare policy enacted is at the forefront. This section introduced how 'lived experience' will support this research's understanding of welfare conditionality *feel*s for disabled welfare claimants. The section below now outlines the existing arguments that demonstrate how disabled people are being detrimentally impacted by the current welfare regime.

### 3.42 Retrenchment of the Welfare State and the Re-conceptualisation of the 'Disability Category'

The re-categorisation of disability as an administrative category is not solely evident within recent policy initiatives (such as the reduced eligibility of ESA entitlement through the narrowing of the WCA criteria). Historically, a significant contribution was made by Stone (1984) when examining the formation of disability as 'a formal administrative category'. This category aimed to maintain people's engagement in a work-based system, apart from those deemed as the 'most needy'. Therefore, it is reasonable to hypothesize welfare conditionality as another means of the restricting access to 'the disability category' (Stone, 1984) and further retrenchment of the state.

More recently, Roulstone (2015) draws upon Stone's work when discussing how the shift in, and shrinking of, the 'disability category' is evident within contemporary policy approaches (see chapter two). Concerningly, Roulstone identifies that this shift has recently run parallel to the adoption of the language of The Disabled Peoples Movement. Therefore, changes in eligibility measures such as the distance a person can walk unaided has been paired with the rhetoric around independence. Most notably this can be seen in the benefits change from DLA to PIP.

The narrowing of the eligibility criteria has seen a significant reduction in the uptake of benefits for disabled people. The DWP Benefits Statistical Summary in 2018 highlighted that 93 thousand fewer people are claiming ESA than the previous year (DWP, 2018). This could be argued as a successful measure of reducing the perceived 'dependency' and increasing labour market participation. However, the high level of appeals overturned (DWP, 2017a) following the initial assessment for ESA shows that this reduction could instead be a consequence of the shrinking disability category.

### 3.43 Conditionality as an Insidious Tool of Punishment

Since the implementation of the WCA (2007), academics (Grover, 2018), journalists (Ryan 2017; 2018a), activists (Pring, 2017) and disabled peoples organisations[2] have argued that the issues arising from the application of increased conditionality are intended policy outcomes, rather than incidental consequences.

> *‘When ministers design a social security system based on how much money they can cut, unqualified assessors and bloated appeal bills aren’t a sign of a policy gone wrong – it’s a sign that it’s going exactly as planned’* (Ryan, 2018a).

The notion that these detrimental policy outcomes are intended and disproportionately affect disabled people (O’Hara, 2014) led campaigners to call for a cumulative impact assessment. Understanding welfare conditionality within this context, it is important to consider how policy is enacted as a tool of punishment. A clear example of how disabled people are punished by recent policy shifts is the extension of sanctioning (to those on the ESA WRAG). Fletcher and Wright (2018) use the lens of Wacquant’s (2009a) theory of the ‘centaur state’ when demonstrating how welfare reforms have ‘replaced job match support with mandatory digital self-help, coercion and punishment’ (Fletcher and Wright, 2018, p.323). Furthermore, Wright *et al.* (2020) conceptualise the harm caused by welfare conditionality as ‘social abuse’. They draw upon narratives from people claiming unemployment benefits and found that the punitive welfare system ‘often caused symbolic and material suffering and sometimes had life-threatening effects’ (p. 278). This can be evidenced within mainstream unemployment benefits but also is becoming an increasing part of disability-related unemployment benefits.

Financial penalties are only one way in which disabled people are punished within the current welfare system. Cooper and Whyte (2017; 2018) draw on the notion of ‘structural violence’ (Galtung, 1969) and conceptualise recent

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[2] Disabled activists including, but not limited to, DPAC, The Black Triangle, The Spartacus Campaign, The WOW Campaign, have tirelessly campaigned for Disabled Peoples rights. They have produced a wealth of evidence documenting the lived experiences of the WCA and impact of austerity. Due to their lobbying noticeable achievements have been made in the fight against austerity and those who are hardest hit.

austerity measures through the lens of institutional violence. Originally introduced as a concept by Galtung (1969), structural violence refers to the avoidable constraints that society puts on groups of people which stop them from achieving their basic needs (Lee, 2019).

Cooper and Whyte build upon Galtung's (1969) notion of structural violence in their conceptualisation of institutional violence. They argue that where structural violence is often understood as something that occurs indirectly and without an actor, this fails to explain how decisions made by individuals can be experienced as violent. The use of institutional violence as a concept is adopted to ensure the decisions and actions of individuals that lead to violence are included within their conceptualisations of violence.

This has been specifically highlighted by journalist and activist, Pring (2017) who describes welfare reforms as an 'attack on disabled people' (p.53). He argues that disabled people face violence through the changes to the welfare system. He relates this in particular through the use of the WCA which he describes as 'possibly the most violent and discriminatory tool ever handed to a government department' (Pring, 2017, p.51). This thesis utilises this concept to understand, how and to what extent people have experienced welfare reforms as violent.

When considering violence through the mechanisms of welfare reform it is impossible not to note the suicides attributed to welfare changes[3] and often referred to as 'austerity suicides' (Mills, 2018). Ryan (2019b) starkly states that:

> *'Death has become part of Britain's benefits system'* (p.51)

Although it is difficult to attribute a particular cause to a person's suicide, significant figures released by the DWP (2015) showed that between December 2011 and February 2014, 2650 people died shortly after being deemed as FfW by the WCA and another 7200 died after being placed in the WRAG. It is important to note that although these figures cannot be directly attributed to 'austerity suicides', it is widely acknowledged that the WCA has a significant impact on several people's mental wellbeing. A significant study by Barr et al. (2015) found that:

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[3] Calum's List (http://calumslist.org/) is a memorial site for those who have died due to welfare reforms. It lists a number of people's deaths which have been linked to changes to their welfare support and calls for an end to such changes.

> *'the Work Capability Assessment was independently associated with an increase in suicides, self-reported mental health problems and antidepressant prescribing'* (p.339).

A substantial contribution to the academic understandings of people's experiences of austerity is provided by Mills (2018). She draws on aspects of colonialism to examine the psychological impact of austerity measures. In her paper, 'Dead people don't claim', she demonstrates how a 'hostile environment' (Mills, 2018) which labels disabled people as an 'economic burden' has been crafted and consequently internalised by disabled people themselves with dramatic consequences.

> *'It is not a coincidence that some people deemed a 'burden' by neoliberal market logic would end their lives. People are killing themselves because they feel exactly the way the government is telling them they should feel – a burden. Put another way, people are killing themselves because austerity is killing them. Austerity suicides may be read as the ultimate outcome of the internalisation of eugenic and market logic underlying welfare reform driven by austerity'* (Mills, 2018, p.317).

Within the UK, average life expectancy has recently decreased (ONS, 2018) and commentators have argued that the cause can be directly attributed to austerity (Jones, 2018). Exploring austerity through notions of structural violence and a neo-Marxist analysis of current welfare policy, Grover (2018) asserts that austerity measures, such as welfare conditionality, can operate as 'violent proletarianisation', leading to social murder. Drawing on Engel's work on social murder, Grover asserts that this involves the reproduction of unequal power and financial resources with 'detrimental consequences' that are 'both known and avoidable' including the creation of 'diswelfares' (Grover, 2018, p.1). When examining how this phenomenon operates, Grover breaks this down into 'social murder by suicide', linking to Mills (2018) work, and 'social murder by destitution'. Both categories provide a useful way of exploring how disabled people are punished through the conditional welfare state.

Increasing levels of destitution is a common theme within recent literature on welfare reform. Existing studies have illustrated a range of strategies people employ when coping with punitive welfare support including parents skipping meals to feed their children (Patrick, 2017), significantly increased usage of food banks (Perry et al., 2014), and the uptake of ‘survival crime’ (Dwyer and Bright, 2016; Dwyer et al. 2018). As disabled people are at much greater risk of experiencing poverty (Disability Rights UK, 2016), the implications of reducing financial welfare support for those already at risk is a key concern.

This section has examined the existing literature on welfare as a form of punishment that is characterised by a shift in eligibility and, embedded within the context of welfare retrenchment. It has argued that conditionality is not just an inappropriate tool for supporting disabled people back into the labour market, but can also be operationalised as a form of ‘institutional violence’ (Cooper and Whyte, 2017) linking to key arguments on ‘social murder’ (Grover, 2018) and ‘austerity suicides’ (Mills, 2018). This study explores welfare policy through these concepts to understand how the detrimental impact of welfare reform is experienced by those that are ‘hardest hit’.

## 3.5 Conclusion

This chapter has presented the existing literature exploring the complex relationship between disability, citizenship and identities to explore how the lived experiences of disabled ESA claimants can be best interpreted. It has introduced Morris’ (2005) tenants of citizenship to explore how disabled people’s citizenship is being eroded by recent welfare policy and outlined the complex relationship between the operation of welfare and identities. It has also discussed emerging literature which theorises how disabled people are experiencing violence through the state. The following chapter presents the chosen methodology used to gather empirical data on disabled people’s lived experiences of the conditional welfare system.

# Chapter Four: Methodology

## 4.1 Introduction

This chapter presents the methods used throughout the research project to understand the lived experiences of disabled ESA claimants. The main body of this chapter focuses not on the ESA claimant journey, the topic that was being researched, but instead my journey as a PhD researcher. The parallels between each journey were evident. This was reflected in the process of negotiating my own identities as a PhD researcher and my avoidance and then engagement with my own disabled identity. Another parallel was drawn when through experiencing the assessment process I undertook to fulfil the administrative category of a 'disabled student' in order to receive the support I needed.

The chapter begins by reviewing the objectives of the research and how the methods applied were appropriate to meet these. It then positions my role as a researcher and the underlying assumptions that may have impacted the study design. It considers the research process as a whole; looking at how participants were sampled and recruited, how the data was collected, stored, managed and analysed, in accordance with the ESRC Framework for Research Ethics[4] guidelines. Finally, I reflect on my position as a researcher, volunteer and student throughout the research process. I use this to further reflect and strengthen my exploration of the fluidity of people's identities, which is a significant theoretical consideration within this thesis.

The primary objectives of this study are:

1. What are the lived experiences of disabled people when encountering the conditional welfare system? [RQ1]

2. How does the process of engaging with this system impact disabled people's identities and wellbeing? [RQ2]

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[4] See ESRC Framework for Research Ethics via University of Glasgow www.gla.ac.uk/media/media_326706_en.pdf

> 3. To what extent is there a gap between policy provision for disabled people, and the lived experience of *being* a disabled person within the conditional welfare state? [RQ3]

In order to answer these questions, semi-structured interviews were conducted with 36 disabled people about their experiences of attempting to claim ESA and 5 key informants (KIs) about their experiences of supporting service-users to go through the claiming process. Data was collected between March 2015 and January 2016. The overarching objective was to capture the lived experiences of those facing increasingly conditional welfare policies on the ground level.

This study is situated within the context of the wider ESRC Project ‘Welfare Conditionality: Sanctions, Support and Behaviour Change’[5] and was funded by the College of Social Sciences at the University of Glasgow. My research explored the conditional aspect of welfare that the larger project is concerned with but provided a unique perspective by focusing on disabled people claiming or attempting to claim ESA, the main out of work benefit for disabled people at the time this study was conducted.

The following section begins by considering my role as a researcher and my positionality in relation to the research subject and process.

## 4.2 Positionality

> *‘We need to consider respondents as real people, whose lives may be influenced by our presence and our findings: to reflexively question the way we position ourselves in relation to others in the research in our methodology, interactions, and research accounts’*
> (Cunliffe and Karunanayake, 2013, p.385).

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[5] This is an ESRC Large Grant funded project which is exploring the efficacy and ethicality of welfare conditionality for a range of welfare recipients, looking at both sanctions and support. The large project, running between 2013-2018, considers the experiences of a number of people including; unemployed people claiming Jobseeker’s Allowance, individuals and households claiming Universal Credit, lone parents, disabled people, social tenants, homeless people, people subject to antisocial behaviour orders or family intervention, migrants and offenders, policy makers and practitioners.

In order to conduct my research project effectively and ethically, a primary concern was around being a reflexive researcher. Therefore, whilst planning the research design and throughout the process, I consistently reflected on each decision in order to challenge my own underlying assumptions.

> *'Our narratives tend to be used to situate us, and frame our identities; our narratives entail a sharing of self'* (Rinaldi, 2013, unpaged).

When considering my positionality in general as a PhD researcher, I entered the role as a white, female, 22-year-old researcher from a working-class background that was part of the first generation of the family to go to university. As with many people, disability had been something that had touched my life from a young age, and this only strengthened my motivation to pursue my academic focus on disability studies. Caring for my father, who was diagnosed with Multiple Sclerosis, meant that I had not only observed the impairment effects he faced daily but also the social exclusion that impacted on his participation in society. I also had direct experiences of the assumptions non-disabled people made about his ability to contribute and how he challenged those assumptions in an often humorous way – my particular favourite instance being someone shouting at him loudly and slowly instead of talking to him as they were to everyone else in the room, for his response to be, “I’m not deaf you know?”

At this point I identified myself as being a non-disabled disability researcher; therefore, my approach to conducting research was largely influenced by this position as discussed below.

> *'Disability studies calls for at least a reflexive (if not a disabled) researcher, one who considers how perspective and privilege affect knowledge'*
> (Rinaldi, 2013, unpaged).

At the beginning of the process, there was a level of dissonance between how I thought about my own health conditions and that of my interviewees. Therefore, it was important to ensure that although I had not knowingly experienced disabling barriers myself, I fully considered how they would impact on those who were engaged in the research.

This section has presented my position at the outset of the research process. The following section considers the epistemological principles which shaped my approach to the research, which linked largely to my position as a non-disabled, disability researcher.

## 4.3 Approach to the Research

> *'Scientific research can never be wholly neutral, disinterested, or value-free because the process of knowing always begins in concrete contexts and material conditions of people's lives, together with the standpoints, perspectives or understandings of the knower'* (Henwood, 1993, p.5).

My approach to research was largely influenced by my background in disability studies. Coming from a social model of disability standpoint (Oliver, 1990), which focused on the societal barriers disabled people faced in a disabling society, I was aware that I had an epistemological preference that would shape my choices of research design and guide the research process. I needed to take data at face value as I chose to develop my findings from the ground up and this often proved difficult when having preconceived notions of social model definitions of disability, which often did not always align with all those who were being interviewed. For example, some interviewee's perspectives would view disability as an 'individual problem' which was a stance that challenged my own epistemological position.

I was committed to enabling participants to have power over the direction of the interviews and I encouraged participatory elements, in line with the principles of 'Nothing about us, without us' and the social model of disability (Oliver, 1990). This was a direct challenge to adopting a more positivist and scientific approach to research and other qualitative approaches to research which fail to meaningfully include disabled people's voices in the research process. Therefore, it was important that the participants were considered as experts rather than 'subjects' of the research. A further consideration was the importance of 'doing no harm', which has been a significant issue to disabled people traditionally deeming research as being unhelpful in meeting their needs (Oliver, 1992). Therefore, the research was focused on a topic that was of 'practical relevance of her/his research to the lives of research participants' (Stone and Priestley, 1996, p.703).

The appropriateness and ethicality of non-disabled researchers' involvement in investigating the lives of disabled people has often been contested (Oliver, 1992; Branfield, 1998; Stone and Priestley, 1996; Hunt, 1981). Therefore, as initially viewing myself as a non-disabled researcher, I was conscious of this perspective from the offset. The following section considers this perspective and how it has developed over time.

Traditionally disability research has been largely perceived as unhelpful in the advancement of disabled people's rights, as Oliver (1992) argues, research has often contributed to the exclusion and oppression of disabled people as opposed to addressing issues of inequality. Oliver (1992) states that:

> *'As disabled people have increasingly analysed their segregation, inequality and poverty in terms of discrimination and oppression, research has been seen as part of the problem rather than part of the solution . . . Disabled people have come to see research as a violation of their experiences, as irrelevant to their needs and as failing to improve their material circumstances and quality of life'* (Oliver, 1992, p.106).

Stone and Priestley (1996, p.701) reinforce this belief when stating that 'decades of 'scientific' research have perpetuated the marginalization of disabled people'. This poses questions as to whether non-disabled researchers should be involved in the generation of knowledge about disablement. Branfield (1998) posed one of the most striking arguments in opposition to non-disabled people being involved in disability research. Branfield stated that:

> *'The disability movement is our movement, where our voices and our actions determine the changes and redefinitions we want'* (Branfield, 1998, p.143).

However, Duckett (1998) argued that the binary between disabled people and non-disabled people is unhelpful when considering who should conduct 'disability research', stating that; 'clear-cut and unproblematised distinctions between disabled and non-disabled people are too simplistic to take us far in our understanding of the field' (Duckett, 1998, p.626). This was my own experience as a researcher, with ambivalence about my own mental health condition that meant sometimes identifying as 'disabled' and at other times identifying as 'non-disabled' which is reflected on below.

In more recent years, new values and principles have been developed about doing disability research by moving away from positivist approaches and developing participatory and emancipatory methods. These methods involve disabled people throughout the research process and aim to counteract the power dynamics which often place disabled people as the research 'subject'.

As discussed in chapter three, another significant aspect of my research approach centred on the importance of lived experience. Boylorn (2008, p.490) states that lived experience includes:

> *'[the] representation and understanding of a researcher or research subject's human experiences, choices, and options and how those factors influence one's perception of knowledge'*.

This suggests that the world should be explored within the context of how it is lived and provides a useful way of ensuring people's subjective experiences of welfare policy are at the forefront of this study (see chapter three).

The focus on lived experience can be perceived as at odds with the social model perspective as it challenges dualist notions and in essence, the social model is based on dualist notions of 'disability' and 'impairment'. However, this notion is also one of the key criticisms of the social model's theoretical understanding of disability. Shakespeare and Watson's (2002) critique of the social model reflects this when arguing that there is an 'unsustainable distinction' between 'impairment' and 'disability' and suggest that an embodied ontology would offer the best solution to developing a more suitable theoretical understanding of disability. Within this study, it is important to note that aspects of both social model thinking and an awareness of the complexity of disabled peoples lived experiences are deemed as appropriate. They are utilised to understand how disabled people's experiences are felt within the context of a disabling society.

As discussed in chapter three, Goffman (1968) identifies three types of identity and distinguishes between the 'personal identity', the 'social identity' and the 'ego identity', the latter which refers to how people feel about themselves. This is a useful tool for understanding how welfare reform has impacted on the identities and identification of those in receipt of benefits. Therefore, the awareness that there are multiple layers of identity was also important to the methodological approach. Therefore, when carrying out the interviews I as exploring people's naturally occurring descriptions of identity, from an awareness that there are multiple layers of identity.

This section has considered my approach to 'doing disability research' and explored some of the implications that arise from this. By understanding how research has traditionally been deemed as oppressive and inappropriate to the needs of disabled people, it provides an understanding of what not to do when researching alongside disabled people. By exploring the principles of doing good disability research, I was able to include disabled people's voices in a meaningful way and ensure that the research process itself was a positive one. It has also considered how the concepts of lived experience and identity are utilised within this study and the tensions this raises when utilising a social model approach to disability. The following section describes the methods employed for data collection.

## 4.4 Methods

In-depth, semi-structured, qualitative interviews were conducted using a loose interview schema that allowed participants to lead the conversation (see Appendix I). Powney and Watts (1987) consider qualitative research interviews as either 'respondent interviews', whereby the interviewer primarily leads the process or 'informant interviews' whereby the interviewer takes a less directive approach. Using this distinction, the interviews conducted were largely 'informant interviews', in which 'the prime concern is for the interviewee's perceptions within a particular situation or context' (Robson, 2002, p.272).

Questions changed responsively as participants brought up new issues, progressively developing through the interests of the interviewees. This approach therefore incorporated elements of an inductive, abductive approach. Themes were developed through a comparative approach and using these themes to develop new questions throughout the data collection process (Mason, 2002). This enabled interviewees to lead the direction of the process. As the interviews were semi-structured, they mainly consisted of open questions which were clarified by relaying my interpretation and asking participants if this was a correct interpretation of what they had said.

Most interviews were face-to-face encounters, with the exception of a minority that were conducted via telephone instead. This was due to the distance of location and/or the mobility and preference of participants. Interviews took place at a time and place of the participant's choosing. This was largely within disability organisations that they were engaged with or in local community centres and libraries, in order to provide a familiar and easily accessed environment.

The interview process was effective in meeting the aims of this study, however also very time consuming because of the planning, organisation and inevitable cancellations of interview slots, meaning that often several hours went into completing one interview. Robson (2002) states this as a key disadvantage to interviews as a method of data collection. Nonetheless, interviews still provided the most appropriate means to gather data by being adaptable and providing the opportunity to build rapport to ensure disabled people's voices and lived experiences were at the heart of the research findings.

This section has described how my research data was collected and why this was the most appropriate way to meet the objectives of this study. The following section focuses on who the research involved.

## 4.5 Sample

A purposive sample group was accessed, as the study was interested in exploring the lived experiences of a specific group of people. Patton (2014) states that purposive sampling involves:

> *‘Strategically selecting information-rich cases to study, cases that by their nature and substance will illuminate the inquiry question being investigated’* (Patton, 2014, p.245).

Snowball sampling (Mason, 2002) was also utilised, as often people would recommend a peer who might want to get involved following their own interview.

Five KIs (including welfare advisors and voluntary sector staff) and 36 ESA participants were interviewed. These were largely from North East England but also a minority were from across England and Scotland in order to try and gather experiences of various ESA categories such as, the SG, WRAG and those who had now been declared as FfW.

Of the 36 benefit claimants in total, 24 were male and 12 were female. Therefore, data was skewed towards males, with two-thirds of the claimants being male. This is in line with the ratio of the population claiming ESA with the August 2017 ‘Time series related to Out of work benefits’ Office for National Statistics showing a significantly larger population of males claiming ESA rather than females (ONS, 2017a)·

The interviewees were of a range of ages and had a range of impairments and long-term health conditions (this included individuals with fibromyalgia, visual impairments, learning difficulties, MS and limited mobility). Mental health was a common issue, with 20 of the 36 people interviewed stating poor mental health as the main condition impacting them and a number more stating this as a secondary difficulty impacting their life.

The research was not impairment-specific but sought to include a range of disabling experiences and included key groups such as people with learning difficulties and mental health conditions, which impacted on the overall methodological approach. Stalker (1998) provides useful methodological steps that aided the inclusion and involvement of people with learning difficulties and informed the research process. These steps include taking time to 'get to know' the participant before conducting interviews and to avoid simply 'coming in and out of their lives'. Additional means of giving informed consent, such as providing verbal consent was often beneficial when including individuals with learning difficulties.

As the sample included people at a range of points in their claimant journey, people had varying experiences of the process and had often transitioned between benefit statuses during the experiences they described. Twenty-two people had experienced being in the ESA SG, nine had experienced being in the ESA WRAG (this was often for a short period before appealing the decision) and six had been declared as FfW. Three interviewees also described experiences of being sanctioned and eight described having to engage with the appeals process. Although the sample was recruited based on the criteria of a working-age adult who had an impairment and experienced claiming ESA, not all participants who responded aligned with these criteria, therefore eight of the interviewees were not currently claiming ESA or were awaiting an assessment for their eligibility.

The following table presents the experiences of ESA each interviewee described, this reflects both their current and previous status and other significant processes they encountered e.g. an appeal. The table demonstrates ‘experience of’ rather than current claimant status as this was largely not a static position (Table 3.1):

| **Participant:** | **Gender:** | **Experience of:** | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | Support group | Work-Related Activity Group | Fit for work | Appealing | Sanctioning | Awaiting WCA | Not currently claiming ESA |
| Sally | F | 🟦 | | | | | | |
| Jack | M | 🟦 | | | | | | |
| Steve | M | 🟦 | | | | | | |
| Alex | M | | | | | | | Over 65 years old |
| Julia | F | 🟦 | | | | | | |
| James | M | 🟦 | | | | | | |
| Richard | M | | | | | | | DLA |
| Will | M | | | | | | 🟦 | |
| Emma | F | 🟦 | | | | | | |
| George | M | 🟦 | | | | | | |
| Amy | F | | | | | | | Undisclosed |
| Connor | M | | | 🟦 | 🟦 | | | |
| Robert | M | 🟦 | | | | | | |
| Lewis | M | 🟦 | | | | | | |
| Joe | M | 🟦 | | 🟦 | 🟦 | | | |
| Liam | M | 🟦 | 🟦 | | | | | |
| Beth | F | 🟦 | | | | | | |
| Katie | F | 🟦 | | | 🟦 | | | |
| Maria | F | | | 🟦 | 🟦 | | | |
| Josh | M | | | | | | 🟦 | |
| John | M | | | 🟦 | | | | |
| Alice | F | | | | | | 🟦 | |
| Fred | M | 🟦 | | | | | | |
| Ruth | F | 🟦 | 🟦 | | | | | |
| Max | M | 🟦 | | | | | | |
| Mike | M | 🟦 | | | | | | |
| Andy | M | 🟦 | 🟦 | | 🟦 | 🟦 | | |
| Luke | M | 🟦 | 🟦 | | 🟦 | 🟦 | | |
| Jake | M | | 🟦 | | | 🟦 | | |
| Carl | M | | | | | | | Carers Allowance |
| Barbara | F | | | | | | | Lost DLA |
| Keith | M | | | | | | | DLA |
| Lewis | M | 🟦 | 🟦 | 🟦 | | | | |
| Tracy | F | 🟦 | 🟦 | | 🟦 | | | |
| Steph | F | 🟦 | 🟦 | | 🟦 | | | |
| Kieran | M | | 🟦 | 🟦 | 🟦 | | | |

The main difficulty when recruiting and interviewing people about their experiences of conditionality was a reluctance of those in the WRAG to participate as these were potentially those who were most impacted by welfare conditionality and sanctions. Understandably, people were often fearful of discussing their benefit status at a time when there were increased fears around sanctioning and being reassessed as FfW. Similarly, people were often concerned about my agenda as a researcher and whether I had links to the DWP. This meant that the data was skewed towards those who were mainly in the ESA SG and faced limited conditionality, rather than the highly conditional WRAG. Due to the sensitive nature of the research topic, this also impacted upon interviewee participation. For example, one potential participant had recently been sanctioned and was too emotional to participate in an interview. As often those who were facing direct conditionality were difficult to access, a more nuanced perception of conditionality was gauged, as it often was a complex and dynamic process.

Even though the sampling process was legitimate and inclusive of a wide range of perspectives, the experiences people described were largely negative. The recruiting of participants from political groups (i.e. DPAC forum[6]) was not purposeful, however, it did mean that a percentage of the participants were politically engaged. The main limitation of my sample was that those benefit recipients who had fallen out of the system and were not engaged or able to engage with any local groups or charities were not largely covered through my methods of recruiting. There is a need for further research into those who disengage with services, which is explored further in my findings, as often they may face increasing poverty and social exclusion.

This section has considered the strengths and limitations of my sample. It has described the interviewees' characteristics such as gender, impairment and benefit status and why these were relevant to meeting the objectives of the research. The following section explores how interviewees were recruited and accessed.

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[6] Disabled People Against Cuts (DPAC) is a UK-based, group of disabled people and their allies who engage in political activism about austerity and its impact on disabled people.

## 4.6 Access

Participants were recruited through a variety of means to gather a range of experiences and ensure the opportunity to participate was largely accessible. My existing networks within the local voluntary sector meant that access was initially very easy to establish. Participants were accessed through a range of gatekeepers and methods including:

- Disability and Mental Health Charities
- Disabled people's groups and organisations
- Online forums, Twitter and Facebook
- Drop-in sessions at advocacy services

Attending drop-in sessions at advocacy services and going to local disability groups meetings was largely beneficial to not only improving my understanding of the issues around claiming disability-related benefits but also for recruiting participants. However, this did not come without its challenges: due to the nature of my research, potential participants were often wary of discussing issues around work and benefits. A minority of service users were even suspicious of my role and assumed that I was linked to the DWP or Jobcentre Plus (JCP), demonstrating just how prominent levels of fear impacted claimants and a climate of surveillance (Manji, 2017).

This section has discussed issues around accessing participants. The following section now explains how interviewees' experiences were recorded and how this data was transcribed for analysis.

## 4.7 Recording Data

As the majority of interviewees were interviewed face-to-face, they were recorded using a Dictaphone and notes were taken sparingly. Telephone interviews were recorded similarly; however, there was often less clarity in the recording, so transcription took longer in these cases. Interviews were transcribed fully using intelligent verbatim (recorded speech into text with the omission of fillers and repetitions), to ensure detail but also to manage time effectively. Approximately half of the interviews I transcribed and half were through a professional transcription service, making sure that any identifying details were anonymised during this process. The ethics around recording and storing data is considered below.

Rich data was collected from the interviews but unfortunately, I missed a lot of interesting experiences that I captured whilst in my volunteering role. This was due to issues around informed consent and my ethical approval only including interviews as a data collection method. However, the day-to-day occurrences of issues around assessments, poverty and signposting to other organisations e.g. the local food bank reinforced just how hard disabled people were hit by the political situation at the time.

This section has addressed how the interviews were recorded and transcribed. The following section considers how the data collected was consequently analysed.

## 4.8 Analysis

As my objectives and approach to research were grounded in people's lived experiences, data was analysed and coded by drawing on the key themes that emerged from the data. This approach follows the principles of thematic analysis (Silverman, 2014; Boyatzis,1998) and elements of a grounded theory approach (Glaser and Strauss, 1967) to analysis.

> *'Coding is an almost universal process in qualitative research; it is a fundamental aspect of the analytical process and the ways in which researchers break down their data to make something new'* (Elliott, 2018. P.2850).

As Elliott (2018) notes, coding is a significant element of any qualitative research approach and can be used to effectively 'segment and reassemble the data' (Boeije, 2010, p.89). The process of coding for this study was broken down into a number of key steps:

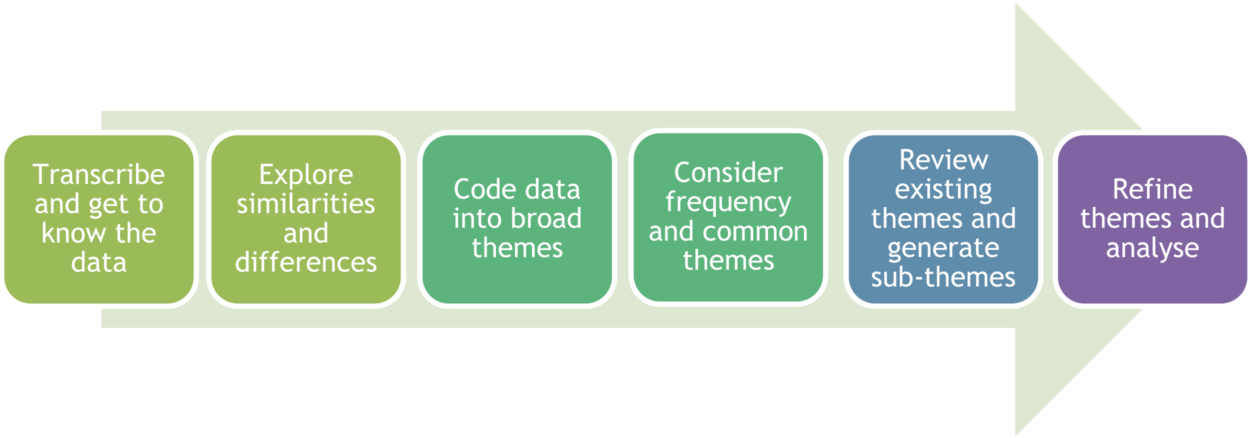

Fig. 4.1

NVivo software was utilised in order to manage and work efficiently with a large amount of qualitative data. Nodes (see Appendix VI for coding framework) were therefore developed in line with emerging themes from interviews and partially from themes emerging in the initial literature review stage. As questions were left intentionally broad, to capture what disabled benefit recipients deemed most important to them, this was a lengthy process but enabled me to reinforce my understanding of the key issues interviewees raised. There was not a pre-determined coding framework or ‘a priori codes’ (Creswell, 2013) therefore this meant that often nodes emerged and continued to emerge throughout the analysis process. This also meant that the analysis process overlapped with the data collection phase of the research as illustrated in Mays and Pope’s (1995) model of the qualitative research process:

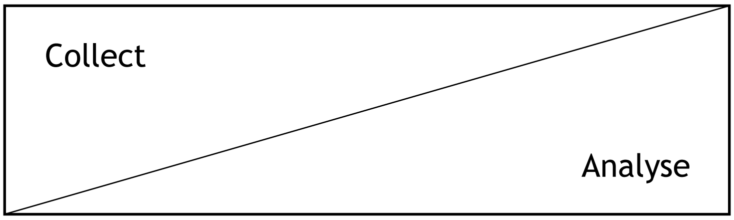

Fig 4.2

An example of the codes developed using NVivo software is shown below (for full coding framework see Appendix VI):

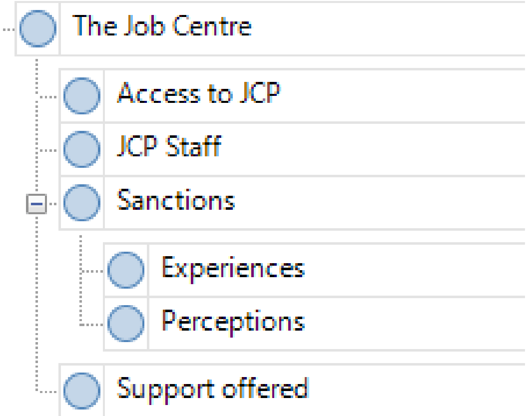

Fig 4.3

In this instance the nodes related to experiences of a part of the system that interviewees engaged with. The child nodes beneath this related to certain aspects of the system, this was then broken down further to categorise interviewees experiences of 'sanctions' and their views on 'sanctions' as a policy approach.

This section has focused on how the recorded data was understood and analysed to develop this study's findings. The following section focuses on the ethical considerations throughout the research process.

## 4.9 Ethics

In order to conduct my research ethically I employed several steps to the process; firstly, gaining ethical approval through the University of Glasgow (see Appendix V). During the research itself, considerations were made around working with 'vulnerable' adults, informed consent, anonymity and confidentiality and my own safety and wellbeing as a researcher.

### 4.9.1 Power

> *'Locating oneself within the research often has the potential to combat power issues in the research'* (Woodword, 2000, p.37).

A key element of doing disability research is a rebalance of traditional research power relations, as Barnes and Mercer (2004) argue that an:

> *'Asymmetrical relationship between researcher and researched in mainstream social research was identified as major reason for the alienation of disabled people from the research process'* (Barnes and Mercer, 2004, p.9).

Therefore, I spent time building a rapport with participants and ensuring that they were comfortable in my presence before beginning the interviews. I often disclosed my own experiences of having a mental health condition during this process, which often helped to decrease the power imbalance in the interviewing situation.

### 4.9.2 Consent and Safeguarding

Informed consent was ensured by adapting the methods of explaining and providing consent based on individual need. This was specifically important for people with learning difficulties in which information was often read out by the researcher in an accessible way (Stalker, 1998). Consent forms (see Appendix III) and clear participant information sheets were produced in accessible language and read aloud if participants had difficulty reading or a visual impairment.

Further means of safeguarding were applied due to the sensitive nature of the issues discussed. Participants were given the option of a third party (i.e. a carer for participants with mental health difficulties or learning difficulties) to accompany them for the duration of the interview. The presence of a familiar third party sometimes facilitated the process when informing the participant of what the study entailed, for the participant to give full informed consent. Participants were clearly made aware of their right to withdraw or refrain from answering any questions they might have felt uncomfortable with.

As the participants had often experienced negative aspects of conditionality, had been subject to benefit sanctions or experienced poverty, the Plain Language Statement included a list of support contacts in case of any distress following the interviews and the researcher ensured interviewees were fully debriefed before exiting the interview process.

### 4.9.3 Data Protection

The interviews were then recorded and transcribed, omitting any identifiable information and anonymising participant's names by using alphabetised letters and then pseudonyms within the findings to reflect the human narratives. Consent forms and contact data were stored in a locked cabinet in line with ethical guidelines and data protection and only accessed via the researcher.

### 4.9.4 Researcher Safety

To ensure researcher safety, interviews were conducted in a private space within a public location and a named contact was in place if the researcher failed to return in the assigned amount of time. It was not solely the physical safety of the researcher that was considered as due to the nature of the research their psychological wellbeing was a key consideration. This was addressed with supervisions so that the researcher had an outlet to discuss any distressing interview experiences or emotive issues raised. Researcher safety and the importance of debriefing are addressed within the ESRC Safety Protocol (see Appendix IV) which was referred to in order to maintain safety throughout the fieldwork process.

This section has considered the ethical implications which arose from the research and how they were explored and overcome in order to ensure my research was conducted ethically. The following section considers my position as a researcher and reflect upon the research process and how this impacted on the way I negotiated my own identities.

## 4.10 Reflexivity

> *'Nobody told me that a PhD was a trial by assertiveness'*
> (Academics Anonymous, 2017).

Through reflecting on the research process, I began to notice a change in my position as I explored this in relation to my role as a disability researcher, a volunteer and a PhD student.

Initially, my primary concern was being mindful of my position as a non-disabled researcher conducting disability research. However, throughout the research process, it became evident that it was not only the identities of those who were being interviewed that were fluid throughout the process, but also my own as I grappled with my underlying assumptions of self.

As someone with a mental health condition, but who had previously not acknowledged themselves as a disabled person, I began to challenge my own identities and how I perceived what it meant to be a ‘disabled person’. Interestingly, I would openly consider and discuss the benefits of disclosing as a disabled person to combat the stigma attached to this, often challenging the stigma around hidden impairments. However, in retrospect, I did not follow my own guidance and although being happy to disclose myself as someone who had a long-term mental health condition, the ‘disabled identity’ was something I often had subconsciously disassociated myself from. My disassociation with how I perceived myself or my ‘ego identity’ (Goffman, 1968) was complex and changed. Drawing on Goffman’s work, discussed in chapter three, the concealment of my mental health condition can be perceived as a way of hiding my ‘spoiled identity’ or ‘discreditable attributes’ (Goffman, 1968). Through this experience, I have now begun to identify as a disabled person, as someone with a hidden impairment and someone who experiences ‘impairment effects’ which have significantly impacted my confidence and progress as a PhD student.

Similarly, I had also not formally considered myself as someone who fitted the category of a ‘disabled person’. However, the parallels between each journey were evident. This was reflected in the assessment process I undertook to fulfil the administrative category as a ‘disabled student’ to receive the support I needed for my studies which I did not seek until much later in my study as a begun to challenge my own disabled identity.

In hindsight, my own experience of my own mental health issues and negotiating my own identities has been extremely insightful. Through my shared experiences, this gave me an existing understanding of the local organisations and the barriers people with mental health difficulties often face. This also enabled me to easily develop a rapport with a number of interviewees; it seemed that having shared experience went some way to rebalancing the traditional researcher-participant power relationship. However, it is important to consider the differences too such as not claiming disability-related benefits as my interviewees mostly had and that there was often a large difference in age between myself and those I engaged with.

Another dynamic which impacted my research process was my role as a volunteer at a local mental health charity with which some of my participants engaged. This was largely beneficial in initially recruiting participants. However, it did not come without its challenges. Organisationally, the charity had expectations of what information could be shared from the data collection, which was resolved by agreeing to present findings back on the submission of my thesis. On an individual level, there was some confusion around my role, and when interviewing participants, they sometimes assumed existing knowledge, which would have been useful to have recorded. In relation to working alongside people, Caetano (2015) states that 'reflexive deliberation requires a clear separation between subject and object so that their interplay can be analysed'. However, this clear separation was not always possible within this role (especially considering I also met the criteria of being a service user – 'someone who has or is at risk of a mental health condition') and presented as far more complex than a level of separation and reflection. Therefore there was an unusual dynamic of me as both an insider and outsider. I often felt more at ease as a volunteer (having worked as a support worker previously for a number of years and struggling to see myself in a somewhat more 'professional' role) rather than as an academic social researcher. Overall, being involved on the ground level over a period of time strengthened my understanding of people's lived experience and helped my knowledge around the process of claiming ESA.

A passion for helping disabled people to be heard had driven me to embark upon the research, but I had never considered to what extent these attributes would impact me as a researcher and therefore the research itself. This relationship was often challenging as throughout my studies, I struggled to identify myself as a PhD student, largely due to my underlying assumptions about what it meant to be a PhD student – my background and social-economic status were key factors that meant progressing onto doctoral studies seemed an almost impossible scenario for me to be living. This often meant I struggled to take the lead on large research design decisions and deliberated a great deal more than was useful. However, throughout the process I came to develop an awareness that, similarly to there being not only one type of identity, there was not only one neatly formed ‘ideal type’ of PhD student and our personal lived experience bring their own strengths and weaknesses to the process, each coming from a truly unique perspective.

## 4.11 Conclusion

This chapter has considered how my findings were generated, specifically in relation to why decisions around the research design and process were derived. It began by exploring the key research questions that this research aimed to answer. It then presented a reflective account of my role as a PhD researcher within the context of this study and demonstrated the challenges I personally faced whilst negotiating my identities as a disabled PhD student. It described the process of gathering and analysing data which hoped to highlight participants’ lived experiences of welfare conditionality.

The following chapters present the findings from interviewee’s experiences in relation to three key themes identified when coding the data. The first chapter considers the impact of engaging with the punitive welfare system, including experiences of the WCA, appeals process and experiences of support and sanctioning. The second chapter considers how interviewees perceived and experienced their access to rights and their mutual relationship to responsibilities and reciprocity, drawing upon the citizenship debates discussed in chapter two. The final findings chapter considers how disabled ESA claimants negotiated and maintained their identities, in the context of a disabling society which imposes a stigma on those in receipt of disability-related benefits.

# Chapter Five: The Lived Experience of the ESA Claiming Process: The Era of Punitive Welfare

## 5.1 Introduction

This chapter considers claimants' experiences of the process of claiming ESA. It illustrates how the return of punitive conditional welfare arrangements are enacted in a way which systematically punishes claimants and deteriorates their self-determination, citizenship and both physical and mental wellbeing. It draws upon the key issues interviewees identified when attempting to claim ESA such as; attending the WCA, which was often described as a 'traumatic' 'attack' on claimants and the lack of appropriate and accessible support delivered through back-to-work organisations. It also draws upon interviewees lived experiences of being in the SG, both thoughts on the 'unsupportive support group' and conversely on being 'one of the lucky ones' who do not experience the conditional elements of claiming ESA. It then explores how the process of claiming ESA has the potential to dehumanise claimants and consider the roles people feel they need to 'act out' to achieve an appropriate assessment outcome. This chapter draws upon interviews with both welfare claimants and KIs to fully understand the lived experience of the claiming process from the offset.

## 5.2 A Process of Punishment?

As discussed in chapter three, recent critiques of welfare policy have conceptualised the application and operation of policy as violent (Pring, 2017; Mills, 2018; Cooper and Whyte, 2017). This section presents empirical evidence which substantiates such arguments. Overall, claimants lived experiences of going through the process of claiming ESA were largely understood within a system of punishment.

> *'It's an interrogation now. It's not an assessment because the agenda is to fail you the minute…They just attack, attack, attack, attack. And on*

> *one assessment they said to me, I couldn't be feeling suicidal 'cause I didn't action it'* (Ruth).

> *'I would not have believed before that, that disabled people or people with chronic sicknesses would be the people that would be in the firing line. It just seems bizarre'* (Josh).

Unprompted, several claimants discussed being acutely aware of a level of systematic hostility and commented on the damaging government rhetoric surrounding reforms of the time.

> *'At the end of the day these people need help is what they need and the government is not giving them the help, they're just throwing a little bit of money at them and just saying go and get your beer, go and get your drugs, you know, hopefully, you might die and there will be one less person in society to have to pay out for'* (Katie).

> *'the victim is always everyone that's on the bottom, the working class, the physically and mentally ill, you know. I remember there was a demonstration for the disabled a couple of years ago in town, and the dole had taken photos of people…the walkers as they were walking and stuff like this'* (Liam).

The narratives in this chapter provide an empirical basis for understanding concepts of 'institutional violence' (Cooper and Whyte, 2017; 2018). More so, they illustrate that claimants were actively interpreting the process of scrutinising and punishing disabled people with dramatic consequences. Two claimants expressed even more concerning interpretations of the current treatment of disabled ESA claimants when linking recent governmental policies and their outcomes to eugenics.

> *'When Government policies are having that kind of impact, there's something severely wrong with what. It's almost like eugenics are being practise*d' (Josh).

> *'Propaganda to the public about disabled people about how we waste resources if you like and you know, I was actually really struck that there were similarities in the rhetoric between those early Nazi propaganda items and actually the Ian Duncan Smith rhetoric and I was blown away by what'* (Tracy).

This section introduced how claimants broadly experienced engaging with the welfare system in relation to punishment. The main body of this chapter considers specific aspects of the process and how notions of punishment and violence are embedded and perpetuated throughout. When considering the process of welfare conditionality, the role of sanctioning is recognised as a way that claimants experience social harm through the system (Wright *et al.*, 2020). The following section discusses interviewees' experiences of those who were unable to meet the conditions imposed upon their ESA receipt and the role of sanctioning. Claimants often linked sanctioning to notions of punishment, this was particularly evident in their narratives of being a 'victim' of sanctioning or 'suffering' a sanction.

## 5.3 '*Failing*' to Meet Demands: The Role of Sanctioning

This section considers interviewees experiences and thoughts on sanctioning. Due to the limited sample of WRAG respondents, only a minority[7] of those claimants interviewed had actually incurred a sanction, those who had not were asked about their thoughts on the effectiveness or appropriateness of sanctioning, with a majority of interviewees mentioning that they knew someone who had been sanctioned. Sanctions were imposed as a form of conditioning and penalising those claimants who failed to meet work-related requirements such as, attending the WP and applying for the required amount of jobs per fortnight.

The majority of interviewees, including claimants and KI's, felt that sanctioning was an inappropriate way of 'punishing' those who failed to meet the imposed conditions. However, many interviewees also suggested it was necessary for those who were deemed as 'serial offenders':

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[7] 3 interviewees discussed personally being sanctioned.

> *'I think it's necessary, but I don't think it's helpful and this goes back to what I was saying about that there will always be those people who want to progress and those people who will work the system, there will always be. That's just life isn't it?'* (Service User Involvement Officer).

This reflects the notion that sanctioning is a 'necessary evil', however, also indicates that it is not effective in moving people closer to employment. As discussed in chapter two, the notion that sanctioning is counterproductive to the aim of activating people into employment has been evidenced widely (Dwyer *et al.,* 2018). A Specialist Welfare Officer reinforced the issue of poor effectiveness in terms of securing employment but argued it was effective in the context of saving money:

> *'I think it's very effective in terms of Jobcentre Plus because they're saving heaps of money, obviously, for people who are a victim of a sanction, it's horrendous because how are you gunna sustain that? How are you gunna feed yourself? How are you gunna pay for your bills? However, I think the ethos for sanctioning people who are perpetual offenders for want of a better phrase, people who just aren't you know, we all know they're there, people who just aren't interested in looking for work, they're only signing on for money erm I think there's a case that this needs to happen'* (Specialist Welfare Officer).

People were often described as 'victims' of sanctioning which reinforces the notions of punishment discussed earlier. Although it was widely acknowledged that sanctioning has a detrimental effect on people, there was still a significant consensus that it was 'necessary' for some who were perceived as uninterested in looking for employment. Most claimants suggested that being sanctioned was becoming increasingly more common and described the potential impact this had to their day to day lives:

> *'if you get sanctioned and it is very easy to get sanctioned now. I was sanctioned once for forgetting to fill in an application form which I lost but if you get sanctioned you very much depend on things like food banks because it's either food or heating, especially in the winter times'* (Joe).

Claimants reiterated the point made by all KIs that sanctioning had a detrimental impact and, converse to its intended purpose, potentially hindered their ability to apply for jobs:

> *'when I got sanctioned it was more frustration, it was like what can I do? Sanction is like a punishment, it's like what does punishment to do me to make it any better for us? If you sanction us, I've just go no money now'* (Will).
>
> *'you can't help it if you can't find a job, you can't find a job. So taking your money away from you is just going to make it more difficult because then you can't get to interviews, you can't apply for jobs and things and you can't pay your bills'* (Alice).

It was not only the appropriateness of sanctioning that was questioned but also the fairness of reason to impose a sanction through the discretion of JCP staff. As noted by Joe when mentioning 'it's very easy to get sanctioned now' often the reason for the sanction was a factor in whether interviewees deemed them as fair, this linked back to ideas of genuine deservingness and what are perceived as appropriate behaviours for claimants.

The result of sanctioning or being left without income for periods of time (due to cuts to benefit entitlement or inaccurate rates through assessment) often meant those who experienced sanctions were impoverished and in turn, moved further away from the labour market. In particular, some claimants noted a deterioration of health due to lack of income to support health or disability-related needs. John, who was declared as FfW although experiencing multiple chronic conditions discussed this. He discussed how the reduced rate of benefit meant that he was unable to hoover and clean his linen as regularly to deal with his chronic allergies and eczema, substantially increasing his risks of anaphylactic shock. Narratives such as John's identify that instead of sanctions 'nudging' those who did not meet the claimant requirements, as recent government rhetoric suggests they intend to do, it potentially had the opposite effect for ESA claimants who had to focus on ensuring they could fulfil their day to day needs, rather than considering their progression into employment.

Sanctions were therefore experienced as counterproductive to moving people into employment but also could lead to significant worsening in people's mental and physical health. Sanctions also posed a clear barrier to people's self-determination, whereby, the lack of fairness felt about the sanctioning reason led to increased frustration, however, claimants often did not want to challenge decisions due to the fear of future repercussions.

The following section begins to explore interviewee's experiences of the WCA. It considers issues of accessibility, the physical and mental impact the process has and the significance of the relationship between the claimant and the assessor, it also identifies the process as a key site of institutional violence (Cooper and Whyte, 2017; 2018).

## 5.4 The Work Capability Assessment: Delegitimising and Dehumanising the Claimant

> *'It's a barbaric way of assessing it'* (George).

As discussed in chapter two, the WCA has been largely criticised throughout academic literature (Barr *et.al*, 2016), by disability activist groups (such as DPAC and The Black Triangle) and the mainstream media (Ryan, 2017; Ryan, 2018a; Ryan, 2018b). Despite this, since its implementation in 2008, it has continued to be a dominant part of the process disabled people encounter when claiming ESA and most recently UC.

The process of claiming ESA initially began with claimants being called upon for a WCA, the receipt of ESA was therefore often conditional on the attendance of this assessment. Almost half of the welfare claimants interviewed had experienced a face-to-face WCA, as not all those interviewed were required to attend a formal face-to-face assessment following their initial paper application[8] (see chapter four). The following sections present the process of the assessment, initially beginning with the application, the build-up to the assessment and

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[8] 16 claimant interviewees had experienced a WCA; 2 interviewees were awaiting a WCA; 7 interviewees had not had a WCA following their paper assessment; 6 interviewees were not sure, or it was not clear as to if they had a WCA; 5 interviewees had not had a WCA as they had not attempted to claim ESA.

finally exploring interviewees' experiences of the WCA itself as a site of institutional violence.

### 5.4.1 The Paper Assessment

The paper application (ESA50 Form) was a key concern for those interviewed, the majority of KIs highlighted the increased pressure on themselves and voluntary sector groups who offered support to people with completing the application. For example, a specialist welfare officer found the form to be confusing and difficult to complete:

> *'people get it [the form] and a lot of people will sit and look at it and the way it's written, the way the terminology is used, they've redesigned it loads of times but it's still completely inaccessible to a lot of people and if people come in and see me, I actually think they've got a far, far better chance of actually qualifying if an advisor fills in the form, it shouldn't be like that, it should just be their condition'* (Specialist Welfare Officer).

Claimants similarly found the form hard to follow and often needed support in doing so, meaning the demand for support services (or family and friends support) was increasing and therefore spread thinly for those who were supported. This indicates that those who are isolated or unable to access support with this process would be at an even greater disadvantage when completing the initial ESA50 form. This reflected Andy's experience, who had been sanctioned for 7 months before going to see a Specialist Welfare Officer at a local charity who helped him understand the process and requirements:

> *'he's [the welfare officer] telling us how to go and what forms to fill in, go to my doctors and sort the stuff out with the doctor and everything…And then [he] just got all my paperwork and started to sort it out for us and eventually, it did, it did happen'* (Andy).

Following this Andy was moved into the SG; however, it was evident that if this additional support with the process was not accessed, he may have still been experiencing long-term sanctions due to not being able to complete the initial form in a way which fully addressed his condition and needs. This demonstrates an experience of positive support received; however, this support was delivered through the voluntary sector and often only available after a long wait due to the number of people awaiting similar support.

It was not just the inaccessible language that was raised as an issue when completing the form but access to forms in different formats. Julia, who had a visual impairment, discussed how she struggled to access an appropriate, large print form after she was told what forms to get by an advisor. She described initially finding them herself online and receiving them in small print, before telephoning for a large print version:

> *'Then you would do that [telephone] and they'd say, oh I've never had to send them in large print before and then that would take a few weeks…It looked like someone had enlarged them on a photocopier and it would come in line a big massive piece folded over in a big envelope and they would be like all grey, light grey and you could hardly read them…you'd be laboriously filling them in and it would be really, really difficult'* (Julia).

The issues of both language and format inaccessibility illustrate the barriers that exist for disabled people interacting with the welfare system from the offset. Julia noted that this process had led her to rely on a family member for support when filling in the forms, therefore, limiting her ability to exercise self-determination (Morris, 2005).

### 5.4.2 Awaiting the WCA

Some claimants were awaiting their face to face assessment or reassessment, with many complaining of long delays which in turn emphasised fears surrounding the assessment process and subsequent outcome:

> '*the number of people whose levels of anxiety have gone through the roof waiting for the brown envelope to come through the door etc. And*

> *the distress which people get with both with being confused with the system and then the stress of waiting for their assessment'* (Service User Involvement Officer).

The notion of 'waiting for the brown envelope' draws parallels with previous studies that explore long-term sickness benefits who outline the increased anxiety around awaiting the WCA (Garthwaite, 2014; de Wolfe, 2012). This was reinforced by the majority of the KIs interviewed who highlighted the stressful impact that awaiting the assessment had on those they worked alongside:

> *'in most cases, the face to face assessment completely freaks people out duly and to be fair I think they've got good reason to be freaked out'* (Specialist Welfare Officer).

Both the initial paper and face-to-face assessment were the first conditional element of claiming ESA that claimants were required to engage in, with the majority of people interviewed describing the WCA as problematic on a number of levels.

The claimants emphasised the anxieties noted by the Specialist Welfare Officer and often discussed the potential impact this fear had on both their mental and physical health. Tracy, who was initially placed in the WRAG prior to appealing and being moved into the SG, discussed her fears of awaiting reassessment:

> *'I'm sort of dreading them coming back to me for a reassessment cos I know they will throw me out again and I know I will become more mentally ill and er all that again you know? I was so depressed I lost two stone in weight during that waiting for that tribunal'* (Tracy).

Ruth similarly described the impact that waiting for an assessment had on her emotionally and physically:

> *'The whole time you're going through this system, you're up, you're down, you're up, you're down, you're up, you're down. Then you're attacked, so then the anger levels, the stress levels, the can't sleep, the depression, everything exacerbates'* (Ruth).

The association between awaiting assessment or reassessment and the deterioration of claimants' mental health conditions was a common theme when discussing the build-up to the WCA. It was evident that the uncertainty and ever-changing nature of benefit status often left claimants feeling fearful and expecting to have their ESA entitlement withdrawn upon assessment, even though they expressed that they still felt unable to enter back into employment. Therefore, even the initial stages of the process had the potential to exasperate people's existing conditions and move people even further away from participating in the labour market, where appropriate. As discussed in chapter three, the deterioration of people's mental health conditions is particularly concerning when investigating the rise in 'austerity suicides' (Mills, 2018) and clearly demonstrates that people feel the impact of the punitive welfare system even before they attend their WCA.

### 5.4.3 Attending the WCA

A key site of where institutional violence is enacted is evidenced within the WCA itself. The WCA was described as 'barbaric' and unfit for purpose; hence it was understandable as to why a significant number of people were fearful in the lead-up. Claimants often noted that they knew people who had experienced the assessment prior who had found the experience 'traumatic' and the outcome inappropriate to their needs. A particularly problematic assessment was described by Katie, who was placed in the SG following an appeal, after an initial unsuccessful assessment. Katie had previously been in employment for several years before she began to struggle with her mental health. She described her experience of the assessment as 'horrific' and began crying when asked about the assessment stating:

> *'I'll be a little bit vague because for a few reasons but one because it's so traumatic, you kind of block it out quite a lot'* (Katie).

A significant issue to do with the assessment she explained was in relation to the dynamic between the assessor and the claimant. Generally, claimants described the assessors as highly impersonal and used terms such as 'like a robot' to describe them. Often assessors' actions had the potential to reinforce the dehumanisation of claimants and directly contradicted the key practices set out by the DWP guidelines for the WCA. Katie reinforced this idea when describing her experience:

> *'[He] came into the room, sat at his computer; there was barely even any eye contact. He was very cold, yeah, complete lack of empathy, lack of sympathy, anything, just, you know, like this, you know, I just don't even know, like this robot or something, you know, like, yeah, you've got a job to do but at the end of the day this is a person sitting in front of you, a person who is in pain, a person who is suffering, you know'* (Katie).

Her emotional response to the assessment and how this was invoked through retelling this experience showed the extent of the longer-term impact of the behaviours of the assessor can have on someone going through the process. Furthermore, Katie went on to indicate further issues with the assessment, such as inappropriate questioning in relation to self-harm and inaccurate reporting back:

> *'I sat there feeling about that big. I was just, like, excuse me, he was like 'can I seen them?' [the self-harm scars] so, you know, kind of, basically, like, you're telling the truth and I was mortified. I was sitting there thinking, oh, I feel so uncomfortable, this is like, I don't know, going to jail, asking me to drop your pants, and then as if that's not bad enough, they send you through the decision and they give you the paperwork that the interview is done…It said does the patient have any signs of self-harming, no, and I had like, you know, shown him my arm and it said no and I just thought are you actually kidding me, so you did that, made me feel just awful and then you've got no signs of self-harming'* (Katie).

Katie felt immensely humiliated by this part of the assessment and the idea that the assessor deemed this an appropriate question to ask someone reflects the dehumanising nature of the assessment and additionally, demonstrates how the legitimacy of the claimants' answers are consistently put into question. This humiliating experience or 'hostile environment' (Mills, 2018) was also evidenced by Marks *et al.* (2017) who discussed how claimants having to justify their condition to a stranger, whilst simultaneously experiencing the condition was very destructive to participants. Katie's experience clearly illustrates how austerity measures are part of a 'system designed to humiliate and intimidate' (Laverty, 2016, p.3). Further frustrations arose when Katie then found that the assessor had not taken this into account after she had complied with his requests. The negative nature of the interaction between the assessor and claimant was common amongst those interviewed and compounded the anxieties claimants faced in the lead up to assessments.

Both Katie and Ruth discussed how assessors failed to recognise the complexities of mental health conditions with blanketed statements regarding proof of self-harm or the belief that a person was not suicidal if they had not actioned this. The idea that hidden impairments, particularly mental health conditions, were perceived as less genuine was a common trend not just amongst assessors' perceptions, but when claimants discussed public perceptions of disability and the increased stigma attached to hidden impairments. As discussed in chapter three, Goffman's notion of 'discrediting' and 'discreditable' attributes support the understanding of the difference between attributes that are clearly visible or 'discrediting' and those that can be concealed. In this instance, both Katie and Ruth had to clearly 'prove' their hidden impairment or 'discreditable attribute' to the assessor, this flaw in the assessment signifies repercussions for people experiencing hidden impairments.

The appropriateness of the questions asked during the assessment was also an issue for claimants. Several claimants felt that the questions failed to cover issues significant to their impairment. Additionally, questions were open to interpretation and this led to confusion, specifically for those claimants with learning difficulties. This was evidenced by an advocate at a local charity who described their experience of advocating an assessment:

> *'one person was asked if he could eat a balanced meal and he said 'yeah I can eat a balanced meal' and I knew he couldn't so I says to him 'what is a balanced meal?', he says 'you carry it on a tray and you don't drop it'*

> *but the assessor had already ticked the box 'can eat a balanced meal'* (Volunteer Advocate).

### 5.4.4 Assessing Mental Health

As noted, interviewees discussed the lack of consideration for mental health conditions during the WCA as a massive issue with the way the assessment was conducted:

> *'When I was unwell I remember my assessment had nothing, no questions, nothing, about my mental ill-health it was all about whether I could stand up, sit down, lift a weight, squeeze my fist, absolutely nothing about it and I remember saying I'm not here about my physical health, I'm here about my mental health'* (Service User Involvement Officer).

Across the board, mental health was recognised by interviewees as under-acknowledged by WCA assessors and JCP staff. It was also often noted as a condition that was most likely to deteriorate due to the increased stress and anxiety caused by the system through sanctions, assessments and negative interactions.

More generally both KIs and claimants discussed the need for a more holistic approach to the assessment when discussing the descriptor system as unsuitable:

> *'literally, all we've got is a standard format, a ticky-box exercise on a computer screen where the assessors don't know what they are ticking or not ticking whereas a decision maker will know how that will fit within the criteria'* (Specialist Welfare Officer).

> *'[The assessment] is a bit of a farce, because it's not taking into account the whole person. It just seems to be a method of, let's say, see how many people they can all look at and then sort of say is fit for work. You know?'* (Robert).

The issues surrounding appropriate ways of accessing mental health needs and the simultaneous experience of the exacerbation of mental health conditions due to the WCA is a complex relationship. Research using population data has demonstrated that the WCA ‘was independently associated with an increase in suicides, self-reported mental health problems and antidepressant prescribing’ (Barr *et al.*, 2016). Therefore, the WCA is a tool which simultaneously worsens mental health conditions but when enacted fails to recognise mental health in an appropriate way. This highlights a further barrier for disabled people accessing ESA and especially puts people with mental health conditions or learning difficulties at a further disadvantage.

### 5.4.5 Understanding the WCA Outcome: An Inappropriate or Insidious Tool?

As evidenced by Robert, the idea that the purpose of the WCA was primarily to take people off ESA and reduce eligibility was a common theme among claimants. This was often due to experiences of being awarded zero points and/or inaccurate reporting of information following the assessment, leading to perceived unfair outcomes. There was a consensus that the assessment criterion was becoming harder to fulfil, which was reinforced by the Conservative government’s agenda to significantly reduce the number of people claiming ESA. Therefore, a number of people mentioned that it was getting harder to be eligible and made reference to the government’s agenda to move people into employment or onto mainstream out of work benefits.

A key theme was the expectation of ‘failure’. Many claimants discussed how they would expect to fail, with a number suggesting that there was an assumption that you would score zero to minimal points and would almost certainly need to appeal in order to be placed in the correct group.

> *‘It’s known that you’re going to fail’* (Katie).

> ‘*It was zero. Everybody gets zero practically* (Maria).

> *‘It’s expected that you will fail when you go to Atos, absolutely. So, you know that you just put straight in for appeal and you wait for that’* (Katie).

In three of the interviews, KIs from the third sector, discussed a significant success rate when they helped people to appeal, which also questions the accuracy of the initial assessment process. The notion that the WCA was not just flawed, but also was designed to remove people's entitlement to ESA, demonstrates a process embedded within a context of 'social violence' (Grover, 2018). It is not a surprising observation that most people felt the system was designed to make people 'fail', as according to DWP (2014) outcomes data from this period almost 40% of ESA claimants who had appealed against the initial assessment decision have had this decision overturned.

The idea that information recorded from the assessment was sometimes inaccurate was also discussed by a Specialist Welfare Officer from a disability charity, who dealt daily with ESA claims and tribunals, he suggested that there were:

> *'Just massive inconsistencies and people routinely tell me 'but I didn't say that', that's an assumption at best, downright lie at worst. So I dunno why or how it falls down, I dunno if it's in interpretation of what's been written when they have the assessment or it's the decision maker's assumptions'* (Specialist Welfare Officer).

Additionally, a number of claimants discussed that prior to the assessment they knew they were going to fail due to these inconsistencies in information, not just the tightened criteria, but due to previous experiences of inaccurate assessment outcomes:

> *'The Atos descriptors, [are] very good at making up fairy tales. Yes, a lot of what was in, well, yes, both reports I've experienced since 2013 they're just full of lies basically'* (John).

> *'It took me three months chasing DWP and Atos to actually get a copy of that so at least I can prove that what he's written in the report is false…everybody I know that's been for a Work Capability Assessment have said that when they've got the report it's full of lies. That's the general consensus'* (Josh).

It was noted that assessors would frequently 'lie' on the reporting of assessments by both the claimants and a Volunteer Advocate. This was a powerful accusation to make and was commonplace for a number of interviewees who indicated a level of acceptance that they would have to go through the appeal process before they had even attended the initial assessment. This understanding of the process contrasts with ideas of passive welfare recipients and also illustrates how people can feel powerless within a system that is set up to achieve what they perceive as a pre-determined outcome.

There was a common understanding amongst interviewees that the WCA is a rigid tool which was inappropriate when addressing and evaluating people's needs. The tool itself and the way it was implemented by assessors was deemed as unfair. Assessors were seen as implementing it in an automated way, this meant the process was seen as not only unsuitable, but also, made people question the underlying intentions and purpose of the assessment. These concerns were amplified when claimants experienced inconsistencies in the reporting back of assessment details and the outcome. This resonates with findings from the Welfare Conditionality project (2018) which found the WCA was 'intrusive, insensitively administered and regularly leads to inappropriate outcomes' (Dwyer *et al.*, 2018, p.2). However, it is particularly interesting that this was internalised by several claimants who felt that the WCA was mostly concerned with removing benefit entitlement and that appealing the decision was often a necessary part of the process to accessing ESA.

This section has discussed claimants lived experiences of the WCA, particularly the issues interviewees felt most important when engaging with this element of the claiming process or for KI's supporting people to do so. There are key issues identified around access requirements and the importance of support to complete the paper application. The wait for the assessment often led to a deterioration in claimants mental and physical health. The need for a more person-centred approach to the assessment was evident throughout these narratives, particularly with regards to effectively assessing people's mental health needs. The relationship between the claimant and assessor often served to dehumanise the claimant and inconsistencies in the process influenced how claimants and interviewees from voluntary organisations viewed the purpose of the assessment. However, the overarching narratives raised more insidious issues around not solely the flaws in the WCA but also, the underlying function of the assessment as a tool for removing entitlement and 'punishing' claimants. This problematic practice was not just experienced when undergoing assessments, but also reflects issues claimants raised when engaging with back-to-work support. This is the focus of the following section.

## 5.5 Inappropriate and Inaccessible Support: Disengaging with Back-to-Work Services

> *'Anything ESA related you were just handed a sheet with telephone numbers on or told to use the phones when they were there. The Jobcentre staff weren't interested'* (John).

This section considers interviewees' thoughts on the help available through back to work support, specifically in relation to those who were engaged with The JCP and The Work Programme (WP). A number of claimants had not been engaged with these services as they had been placed in the SG for a period of time and were unable to consider employment as an option or hoped to but felt that support was not forthcoming; this is discussed in more depth in the following section. Those who had engaged with the JCP noted issues to do with the lack of appropriate and accessible support available to them. This was often in relation to the one size fits all approach that was largely adopted and members of staff being unable to offer suitable support, particularly for those claimants who were educated to a degree level or higher. A number of interviewees also noted that similarly to assessors, members of staff were sometimes impersonal; however, this was not always the case.

One example of the support available was explained by Steve, who had been previously employed and was educated to degree level before becoming visually impaired. Steve described his experience when attending a meeting with his adviser at JCP. He felt that although his adviser listened and aimed to provide support, they had neither the qualifications nor the resources available to give the appropriate help. Steve was only offered training such as attending a CV writing class and therefore chose to seek employment independently:

> *‘Well I stopped going after the last time I was there, the employment adviser said that I probably know more about disability employment advice than they did… so I thought well there’s no point in going back there’* (Steve).

The idea that advisers are willing to help, but are limited in the level of control and availability of resources for claimants who are hoping to get back into employment, was echoed by Jack:

> *‘Generally whatever I asked for she [the JCP adviser] would try and do as much as she could you know’* (Jack).

Narratives such as these illustrate the lack of appropriate support available to help ESA recipients who want to enter employment. In some cases, it means claimants even disengage with JCP as a way of getting back-to-work support in favour of independent job search strategies. It is evident that there are two elements at play: the staff attitudes and the discretion they have over allocating limited resources and training, as suggested below:

> *‘[On JCP staff] …they are usually quite helpful or as helpful as they can be. I feel in some cases I’ve gotta be honest I feel for the people who are on the front line because they can only tell you what’s written on the screen and if the information, they’ve got in front of them is poor… I do sometimes feel sorry for the staff I do but I do think that some of the attitude is absolutely appalling’* (Specialist Welfare Officer).

This dual dynamic of staff attitudes towards those claiming benefits and the inability to provide adequate support for job seekers can mean often support was both inappropriate and inaccessible to those engaging with the JCP or WP. Claimants discussed the hardening of JCP staff attitudes and their existing judgements of claimants often leaving people feeling like they needed to defend themselves when engaging with the JCP:

> *'Jobcentre is a joke; it's an absolute joke and it really pisses us off. The woman that I dealt with was really patronising. I mean there was a huge distrust in me like I was doing everything that I was asked, I was filling out the booklet, I was applying for jobs and, you know, but to be honest I don't think it has anything to do with the individual, I think it's the system'* (James).

James also discussed how, following being upset in the JCP, a member of staff had told him to calm down or she would have to call security. This raises questions around the changing roles of JCP staff which has increasingly become more concerned with enforcing conditions and ensuring claimants are meeting the jobseeker contractual obligations rather than supporting people to enter the labour market. The presence of security guards within the building, although only noted by two interviewees, also reflects a shift in the way the JCP administers the service and can reinforce the feelings of mistrust claimants already describe as so detrimental. This links to the criminalisation of claimants and reflects ideas of deviant behaviour associated with claiming benefits (Fletcher and Wright, 2018) and can feed into the environment which is more concerned with punishing claimants as discussed earlier.

It was evident that there was a divide in thinking around staff being constrained by the system and choosing to act based on underlying assumptions, and it can be argued that both these elements come into play when delivering back to work support for ESA claimants. One KI also suggested that there was a divide in the way claimants and non-claimants were treated by JCP staff when describing attending an appointment with a service user:

> *'…It was pretty bad though cos I actually went with [Carl] to the Jobcentre and I stood back and the way they treat [Carl] was appalling, really bad and when I stepped forward, they changed the attitude'* (Volunteer Advocate speaking about the experience of attending the JCP with Carl).

This narrative portrays the stark distinction in the way that JCP staff treated those who were attempting to claim ESA and those who are not. If this attitudinal divide holds true, this could infer that there is a significant level of personal or institutional discrimination that impacts the way back to work support is delivered.

Experiences of inflexibility in the system continued in relation to the level of support offered by the WP, with those who had engaged with the WP suggesting that the support was often unsuitable for their needs:

> *'they give one size fits all training, so I've got people who've got a degree and post-graduate qualifications have been oh 'Do you know what a CV is?'* (Team Leader).

The lack of training within the WP for people who were educated to a degree level or higher and had previously been engaged in employment was reflected by Tracy. She was initially placed in the WRAG and describes being left to it due to lack of suitable resources for her skill level:

> *'In the end the man at [WP Provider] actually said to me that he trusted me to look for work erm and that he didn't think he could help me anymore and that he would just leave me to it, he was perfectly happy to do that and that was probably not really entirely legal but he said he would sign for the fact that I was coming often so it was a bit dodgy you know?'* (Tracy).

Tracy's experience highlights how WP staff can use discretion to alleviate conditions placed on claimants by the system. In this instance, the removal of the condition meant she was able to self-determine her own work-related activity. However, this was not a common occurrence amongst claimants and this was based on judgements linked specifically to Tracy's education and work background.

In contrast, another claimant noted that being engaged in the WP actually erected further barriers to employment. He discussed experiences of having to turn down independently sought out employment opportunities in order to comply with mandatory training through the WP. He chose to do this, although feeling that the mandatory training was at an inappropriate level, in order to avoid sanctioning. On one occasion he described being engaged in a Citizens Advice training course, which had the potential to progress into a paid role. However, due to WP obligations, he had to disengage with this before gaining the intended qualification. By engaging with the WP, he, therefore, was moved further away from employment and disengaged with meaningful, work focused experience. This is a clear example of counterproductive compliance (Dwyer *et al.*, 2018) and also demonstrates how certain elements of the system significantly erodes claimant's ability to exercise self-determination.

Another reason that claimants disengaged with the JCP was when they were unable to comply with the imposed requirements. Andy disengaged with the JCP following being re-assessed and moved into the WRAG. When discussing receiving several phone calls from the JCP that he was too ill at the time to deal with, he described the impact that this had on his mental health:

> *'Massive, massive, [impact] honestly, I'm not joking, it sounds really, really, bad and you're only a young lass like but I could have topped myself easy'* (Andy).

The section has considered the main issues identified by claimants about the level of back to work support they experienced. Claimants described either disengaging with support in favour of independent job search strategies or being constrained by the WP, therefore contradicting its aim of helping people back into the labour market. The level of support was particularly inappropriate for claimants who had previously been employed or had a high level of education. The following section specifically considers the experience of those placed in the SG who were not required to engage with back-to-work support or work-related activity.

## 5.6 The Unsupportive Support Group: Thoughts on Being 'left on the shelf'

> *'They definitely did listen, but they just couldn't really offer much support'* (Steve).

As previously discussed, the back to work support was often minimal but particularly for those placed in what I would argue is the ironically labelled Support Group, who had a desire to take steps back into employment. A number of claimants described this support as non-existent or equally unsuitable for individuals who had existing qualifications and work experience. Returning to Morris' (2005) tenants of citizenship, she importantly outlines how steps should be made in order to support people to achieve self-determination, participation and contribution. The omission of optional employment support for people who are placed into the SG demonstrates a shift in the way welfare provision is administered. This shift is characterised by an increased focus on the role of sanctioning and punishing those who are perceived as 'shirking' rather than supporting those who want to enter employment to do so.

One example of this was described by Sally who had a degree and previously worked as a teacher before becoming disabled. She was offered only inappropriate literacy and numeracy training by JCP, which was significantly below her existing skill level. Sally's experience was that despite being encouraged to find work (including being encouraged to apply for retail jobs), there was minimal support on offer to help her get back into employment. Sally, therefore, lost faith in JCP as a service to help her re-enter employment:

> *'She [the JCP adviser] said you know we need to maybe think about training and stuff. I said right well what training could you offer, and she went well literacy and numeracy level two. I said I've got a degree and I've got a PGCE…so I've clearly got literacy and numeracy skills which is GSCE level…. And then they went oh well we can't offer you anything'* (Sally).

Julia, another claimant, discussed her desire to get back into work, but felt that being placed in the SG had meant that she was 'kind of left on the shelf':

> *'[on being placed in the SG] it might as well have said, don't worry, we are not going to bother you anymore, you're a lost cause in so many words. Sorry, like, but yeah you're right, you are incapable and we are not going to bother you anymore and there is nothing more we can do for*

> *you and this is how much you are going to get, so bye bye, we'll not bother you for another 100 years – that's what it felt like anyway'*(Julia).

Many claimants who were placed in the SG also discussed desires to enter employment but felt there was limited assistance to do so. This idea links back to debates on the 'creaming and parking' (Carter and Whitworth, 2015) of those who are deemed as easier or harder to support back into employment, meaning often those who needed the support most were unable to access it. Additionally, claimants discussed worries around seeking and completing independent work-related activities due to the fear of this impacting on their current or future eligibility. One claimant discussed wishing to volunteer and develop her skills but felt unable to do so as she was concerned it would impact the outcome of her next WCA. This is considered further in a subsequent section.

The deficiency of support in this group meant that some claimants found work independently. As considered further in the following section, the lack of conditionality and persistent nudging towards employment, meant people had time to gradually improve their health and manage to get back into some form of paid work, particularly those with mental health conditions.

## 5.7 On Being One of the '*Lucky Ones*'

> *'Cos I know people that you know had to go to the Jobcentre every week and all these job searches. …I'm lucky that I've not had to do that really'* (Sally).

This section considers another common theme raised by those in the SG. Claimants referenced being 'lucky' with regards to being placed in the SG. This was not in relation to the higher levels of financial assistance but in relation to not having to meet the obligations placed upon WRAG claimants:

> *'The full support group, yeah, which means you don't get bothered at all by the Jobcentre, you don't have to go for meaningless job interviews or meaningless coaching for, you know, to help you write your cv, I think my cv is perfectly good'* (Joe).

Although Sally had previously discussed the issue of lack of appropriate support for her through the JCP, she also made numerous references to ‘being lucky’ that support was not compulsory for her. Sally had recently successfully applied for a job and talked about how the lack of conditions in the SG gave her time to improve her mental health and gradually return to employment. In this instance, the lack of conditions imposed on her benefit receipt meant she was able to exercise self-determination and contribute in a way that was appropriate to her needs.

The claimants placed in the SG made numerous references to being one of the lucky ones by ‘being left alone’ and not having to engage with JCP and WP. This demonstrates the alternative positive side of being in the ‘unsupportive support group’ discussed in the previous section. This also evidences that the lack of conditionality enabled the improvement of health conditions and greater autonomy for claimants getting back into employment. This presents a further example of how inadequate claimants feel the support available is when they feel that they would rather disengage with it completely and that would put them in a ‘luckier’ position.

Claimants demonstrated a significant conflict in their views of the SG. Although most valued the lack of conditions placed on their benefit status, a number still felt that they would have preferred to have gradual support into achieving a suitable level of employment. Therefore, the importance of support being available to those who are in the SG is key. However, claimants noted that this would only be available to them in conjunction with conditions which they would not be able to meet. For claimants, back-to-work support and conditions are experienced mutually, as is lack of support and lack of conditions. However, for many claimants, they perceived access to back-to-work support and lack of conditions as the most appropriate and helpful way to progress into work, which is not how the welfare system currently works. ‘Being lucky’ can be seen as a way of distancing claimants from the conditional state, those who are perceived as ‘unlucky’ (WRAG) are given back-to-work support (carrot) which is embedded within a system of punishment (stick). For those who identify as ‘lucky’, they have an awareness that the minimal presence of the ‘carrot’ is significantly outweighed by the substantial ‘stick’. The following section begins to explore how claimants engage with the claiming process by taking on ‘roles’ to maintain their benefit status or access benefits for their needs and secure their position as one of the ‘lucky ones’.

## 5.8 Resisting the Role of The Victim: Having to Present Yourself as ‘*Needy*’

This section considers how although claimants were genuinely claiming ESA, they still felt that they needed to, and were encouraged to, ‘act out’ certain roles whilst progressing through the claims process. As discussed, access to support was often limited in both the financial sense and the practical support offered by the JCP and WP. Claimants were aware of a change in the system and often felt pressure to behave in a certain way to ensure they met the tightened criteria of eligibility.

Issues arose not only through the way in which people were treated through the welfare process but also, the way in which claimants feel they had to portray themselves and roles they have to take on in order to be deemed ‘deserving’. This was particularly problematic during the assessment phase but also throughout claiming in order to continue receiving the existing level of support. Claimants and KI’s often discussed presenting yourselves as at your worst for the assessment and worried when engaging with activities following an assessment in fear of being perceived as more ‘able’ than they were.

Those claimants who weren’t perceived to act out this role often felt this was detrimental to their assessment as they weren’t deemed as ‘disabled enough’. These perceptions link back to assessors’ subjective views of disability. For example, interviewees discussed ideas of points not being awarded due to reasons such as being well enough to dress yourself or even the ability to attend the assessment independently. Therefore, suggesting preconceived notions and assumptions of what is judged to be a ‘deserving’ or ‘genuine’ level of disability.

> *‘But because of me being independent, don't need sheltered housing…think of all the tick boxes, I would lose points like needles off a Christmas tree’* (Amy).

> *‘They’ve given us no points on any mental or emotional or social problems because for example, ‘he appeared intelligent and loud and has never been in trouble with the police’* (Luke).

Luke’s experience not only indicates judgements around disability but also displays a highly problematic association between mental health and criminal activity linking to a stigmatised perception of what it means to have a mental health condition.

WCA assessors using physical observations and assumptions as a way of completing the assessment was commented on by claimants frequently. A Service User Involvement Officer, who had previously claimed disability benefits due to a mental health condition, discussed how he made an effort to attend the assessment and this meant his impairment was deemed as less genuine:

> *‘I wasn’t supposed to be driving but I drove and because and I hadn’t been showering and at the time shaving, and I remember making a real effort this day and I put nice jeans on, nice jumper and I looked quite smart compared to how I would normally dress and it went completely against me’* (Service User Involvement Officer).

In this instance, the Service User Involvement Officer resists the ‘victim role’ by ‘making a real effort’ when attending his WCA. However, although the system encourages claimants to self-improve in order to move closer to employment – this demonstrates that claimants must also embrace the ‘victim role’ at the time of assessment to be deemed as eligible for benefits. This binary approach to work and welfare meant that the Service User Involvement Officer felt he had to ‘act out’ a role which was counterintuitive to the main objective of entering employment.

It is important to note that whereas some claimants felt the need to present themselves at their worst, a number also rejected the ‘victim’ role and downplayed impairment effects in the WCA which risked them receiving inaccurate outcomes. A Volunteer Advocate who often attended assessments with claimants mentioned this in relation to claimants with learning difficulties.

She described how the service users she worked with often memorised the correct answers to assessment questions due to worries about answering questions ‘wrongly’. The standard descriptor format does not allow for much discretion by assessors in situations similar to this and can be especially problematic when assessors have little understanding of specific conditions, such as learning difficulties in this scenario. Both of these instances demonstrate how claimants felt they needed to alter their behaviour in order to either present at their worse or best during the WCA.

Following the WCA, claimants often still felt they needed to behave a certain way. Josh described how he felt benefit status was increasingly determined on fulfilling specific roles:

> *‘So the whole reform about what this is supposed to be about has become disabled and sick people presenting themselves at their worst so that they can get onto a benefit, not get sanctioned and get better in their own time if they can’* (Josh).

This idea that disabled claimants have to behave in a certain way in order to be deemed ‘deserving’ is problematic on a number of levels and again has the potential to move individuals further away from entering employment. One example of this was when claimants suggested that they felt fearful when engaging in activities such as volunteering in case this resulted in being deemed as FfW at the next assessment, although they expressed an interest in doing so to gradually build up to paid employment. This can be seen as a further underlying punishment, that once claimants are within the conditional state, they have to limit their engagement with further opportunities for fear of being stripped of entitlement. This fear also demonstrates how claimant’s self-determination and participation within the wider community is restricted through complying with the system.

Playing roles has the potential to affect individuals constructed identities’, with a specific issue arising when focusing on just impairment effects. Particularly when the assessment’s focus, has a significant emphasis on functional limitations, despite being aimed to focus on ‘what people can do’. This, in turn, affects claimants' abilities to enter employment post-assessment. As discussed earlier, the assessment negatively impacted peoples mental health but often playing this role also perpetuated existing health conditions, particularly mental health conditions.

> *'You don't really want to think of your worst day, this is how you've been. You want to think of the days that you've had good and have been a normal person as such. So I do feel a bit sometimes like I have to defend myself'* (Fred).

On a broader level, this directly opposes the move towards a more barriers focused approach discussed in chapter two that has been evolving in the years preceding the welfare reforms and conversely places emphasis on disabled people as 'needy'.

This section has considered how interviewees' feel they need to 'act out' certain roles in order to be perceived as 'deserving'. This notion is explored further in chapter seven when exploring the way in which interviewees negotiated their identities in relation to *being* a disabled ESA claimant.

## 5.9 Conclusion

As presented in chapter three, useful arguments have been developed concerning the process and environment of a conditional welfare state and its detrimental impact on those claiming welfare support. However, this chapter demonstrates the 'structural violence' of austerity grounded in the qualitative narratives of those who experience it. Punishment was something that claimants were explicitly aware of, as illustrated in the way people described their experiences as 'barbaric' or adversely 'being one of the lucky ones'.

The chapter mapped out the journey claimants experienced through applying, receiving and losing ESA entitlement – to understand their shared lived experiences throughout the process from the offset. Through exploring the key issues claimants and staff from the voluntary sector who supported claimants identified, it has begun to explore how conditionality affects ESA claimants' experiences of the WCA and both successfully and unsuccessfully engaging with back to work support. It has identified the often detrimental impact of the WCA both through the assessment itself and the outcomes. It has also considered both the suitability and effectiveness of the support available for those attempting to enter employment. There is a significant need for a move towards a more individualised approach, specifically with regards to the understanding of impairment effects, this was even more apparent when talking to interviewees experiencing mental health conditions. Additionally, adequate support for those who had been educated to a degree level or previously worked before claiming ESA was a particularly problematic area in need of improvement. However, these narratives do not solely demonstrate a fundamentally flawed process but highlight a more insidious concern that the process was not just inappropriate, but also designed and enacted with the intention to punish those who engage with the system.

By understanding the lived experience of the process and exploring how welfare policy is enacted in practice, this demonstrates the disparity between intended policy outcomes and the reality of disabled people living within and (often) without the conditional welfare system. This chapter links to key theoretical concepts that are used when interpreting interviewees’ experiences such as dehumanisation and violence. It considered how peoples’ lived experiences are embedded within a context of ‘institutional violence’. It also illustrates how the process presents barriers to self-determination, participation and contribution (Morris, 2005).

# Chapter Six: On Citizenship:
# Rights, Responsibilities and Contribution

## 6.1 Introduction

The previous chapter considered how interviewees experienced the process of claiming ESA and the impact of engaging with the conditional elements of the system. This chapter now draws upon citizenship debates to explore how interviewees perceived and experienced their access to rights and their mutual relationship to responsibilities and notions of reciprocity. It also explores how often reciprocity is denied to disabled people through barriers to employment and the inaccessible nature of the labour market, which often fails to accommodate for impairment effects (Thomas, 1999). It finally examines how claimants were able to access or were denied a good standard of living whilst being in receipt of ESA, which contributes to wider debates about deservingness.

This chapter draws upon interviews with ESA claimants, in receipt of varying levels of support[9], and interviews with KIs[10]. It begins by drawing upon ideas of 'deservingness' which impacted the way individuals framed citizenship, before looking more closely at the importance of reciprocity. It considers the significance of rights being tied to responsibilities and the barriers to both fulfilling these responsibilities and accessing equal rights.

The following section explores how interviewees emphasised the need for fulfilling responsibilities and specifically the notion of 'giving back' to society in order to feel deserving of social rights in relation to the right of claiming ESA.

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[9] Support Levels included: ESA Support Group; ESA Work-Related Activity Group and Fit for Work or not currently in receipt of ESA.

[10] Key Informants included in this chapter: a Service User Involvement Officer at a local mental health charity; a Volunteer Advocate at a learning difficulties charity; an Information Officer (specialising in welfare advice) at a disability charity and a Welfare Officer Specialist for the local council.

## 6.2 Deserving Citizens? The Importance of '*Giving Back'*

As discussed in chapter two, citizenship debates can be defined and conceptualised using various models, which are often dependent on overlying philosophical dispositions (Dwyer, 2004). Two significant models of citizenship are the liberal and civic republican models which emphasise the importance of rights being tied to the fulfilment of responsibilities. Both models are evident in recent policy trends which are in favour of increasingly conditional welfare arrangements and associate the receipt of out of work benefits with actively seeking employment. This shift was notably evidenced by the introduction of ESA in 2008 which further promoted the importance of job-seeking efforts for disabled benefit claimants. The increasing focus on citizenship being linked to paid employment can be problematic for a multitude of reasons (see chapter two). Morris' (2005) citizenship approach outlines how disabled people's citizenship can be understood through self-determination, participation and contribution. This section discusses how ESA claimants emphasised the importance of contribution or 'giving back'; with a number of interviewees reinforcing the idea that 'if you can work, you should work', it was evident that perceived economic contributions were a significant factor on whether claimants were deemed to be 'deserving' or not of benefit entitlement:

> *'I've always been if you could work you should work. If you can't work, you need this, then welfares there for you, until there becomes a time when you're able to work. However, there are always certain people that will never be able to work, unfortunately. They should be looked after'* (Maria).

As described by Maria, paid employment for those 'who can' was seen as a key citizenship obligation, reflecting traditional notions of contribution. Interestingly, Maria was declared as FfW and in turn needed to actively seek employment herself, although she felt this was something that she was unable to achieve. This raises questions about the accuracy of ESA entitlement as explored in chapter five.

Maria described a binary distinction between those who were deemed as being able to work and those who will ‘never be able to work’. This notion failed to take into account the fluctuating nature of some impairments and the need for some people to supplement income with additional in-work benefits. It also reinforced the perception that contribution is considered specifically in relation to paid employment. This idea was reiterated further by Sally:

> *‘I think for people who need it, which is what it was originally set up for people that need it, I do believe in that because I believe in a society where you know, you should take care of people that have a disability or someone who can’t achieve to the level someone else does. I think that society’s you know that’s our responsibility to make sure that everyone’s you know taken care of in a way’* (Sally).

Sally noted the importance of a societal obligation to make sure those who are unable to work are ‘taken care of’ on the basis of their level of perceived ‘need’. The distinction between the ‘needy’ and those who are able to enter employment, meant that often those who didn’t perceive themselves as ‘needy enough’ felt additional pressures to find employment:

> *‘I kind of feel, I dunno if everyone feels the same, I think I kind of feel like I’m obliged to look long term and think that one day to work full time and if I can you know? If I’m stable enough, if I remain stable enough. And of course, then pay your taxes and look after people who are in the same boat’* (Jack).

This further evidenced how deservingness was often framed by interviewees in relation to an individual’s motivations and behaviours to seek employment. Jack reinforced this when stating that he felt pressure to fulfil responsibilities such as looking for work in order to deem himself as deserving of his benefit entitlement. This reinforced the contractual nature of benefit receipt, Handler (2003) suggests that as benefits have become increasing conditional, social citizenship has changed from status to contract. Thus, citizenship rights are only accessible for those who meet their contractual obligations. The pressure to meet such obligations was evident from the majority of claimants who were interviewed.

The pressure to be ‘doing’ or to be in work, meant that some people continued to work for long periods of times, despite being unwell, demonstrating that the importance of ‘doing’ acted as a deterrent to people who became unable to work. Roger described how he felt pressures to be ‘doing’ before eventually coming to terms with claiming benefits and not being able to work:

> *‘It took us about a year of me stress post quitting the job to really allow myself to be ill and be okay with that. Not beating meself up and thinking you should be out there doing…I like to think phrases like economically inactive, I find that so offensive, every penny I have ever had on benefits has gone back into businesses, shops you know? I’ve not been able to hoard or save any, yet I’m called as economically inactive because you’re not on the paper like’* (Roger).

Roger challenges traditional notions of contribution when critiquing the use of the term ‘economically inactive’ but expresses that it took a while before he could ‘be okay with that’. This indicates how the pressure disabled people put on themselves had the potential to cause further mental distress. As interviewees themselves emphasised the importance of rights being tied to fulfilling responsibilities, this reinforced political rhetoric and reflected neoliberalist thinking around ‘no rights without responsibilities’ (Giddens, 1998, p.65). This idea is reinforced within the increasingly conditional nature of welfare receipt for claimants with impairments and health conditions. As discussed in chapter two, the contractualist element of welfare receipt has been increasingly evident within government thinking, specifically since New Labour and its predecessors (Patrick and Fenney, 2015). Morris’ (2015) tenants of citizenship provide a more inclusive way of understanding ‘contribution’, however within this study, the focus for a majority of claimants was solely considered in relation to paid employment.

Beth noted that the responsibility to work should be encouraged:

> *'it would be nice to be able to work and feel like you're giving back to society…there was definitely a period in time when there was no way I should be working, and so it definitely shouldn't be forced on to you, but I think it should be encouraged'* (Beth).

Beth indicated the potential benefit to the individual, rather than the need to give back in this instance, but it was not clear how much the benefit to the individual was framed by an underlying pressure for reciprocity to be fulfilled. There was an area of contention as to what was deemed as fair responsibilities connected to the right of receiving welfare support. This was often linked to the idea that the conditions imposed by the DWP were seen as unfair or unachievable for claimants:

> *'I have got to go once a week to the work provider now, cos once you've been on Jobseekers for a year, you got to go to Work Programme. So part of that is like you do two hours of job search a week. So, because I'm in ill health I'm looking for part-time and you've got to apply for five jobs, and I know very well I can't do it. I wish I could, but I can't do it'* (Maria).

The experiences of attending the JCP and WP are explored comprehensively in the previous chapter. However, it is important to note from this that generally, the responsibilities people considered were to do with being engaged in employment or seeking employment in order to have the right to welfare. This contractual idea that receiving welfare is only determined by an individual's motivations to find paid work is problematic; however, it does find common favour with all mainstream political parties. This supports the policy focus on contractualist welfare support discussed earlier and places emphasis solely on individual actions of the claimants, as highlighted in one of the interviews with a Service User Involvement Officer:

> *'I don't think we should just give money out willy-nilly cos I don't think that helps anybody. It doesn't help the government, it doesn't help the financial crisis that's happening around us and it doesn't help the individual if you're not asking them to do something, to take responsibility for their own'* (Service User Involvement Officer).

This reinforces the idea that those who are unable to fulfil responsibilities are 'not helping' the situation and therefore deemed as lesser deserving of citizenship status. Citizenship status has increasingly become synonymous with the ability to partake in paid work (Roulstone, 2015), specifically this has been more prominent since the New Labour administration (1997-2010) and its successors. This work focused approach is steadily more evident due to a growing 'moral panic' around fraudulent benefit claimants (Briant *et al.*, 2013).

Interestingly, the rhetoric behind conditional welfare arrangements that places increasing emphasis on fulfilling responsibilities is underpinned by the idea that the government is supporting those who were left without the appropriate support back into employment by previous administrations in order to help those who are able and want to work. A key issue that the Disabled People's Movement have been concerned with is securing equal access to employment, so on the surface, this move could be perceived as positive. However, the conditionality regime that has been used to enforce this has been argued as ineffective in helping disabled people get back to work (Patrick, 2017). Although the priority remains on 'supporting' disabled people into employment, the policy focus continues to concentrate on 'individual deficit' rather than tackling the broader structural inequalities that prevent disabled people from entering the labour market, such as discrimination, lack of training opportunities and poverty. The presence of significant demand-side barriers to employment is reinforced by Patrick and Fenney (2015) as one of the factors which problematize the use of conditionality for disabled benefit recipients. The policy development of individualised, supply focused approaches to welfare support is explored in chapter two.

Since its emergence under the Labour Government (1997-2010) and subsequent Conservative-led administrations the notion of active citizenship has a been central to work-focused policy. ESA claimants reinforced the idea that 'active citizenship' was an important element of their perceived 'deservingness' of claiming ESA. Dwyer (2010) argues that historically, the 'inactivity' of disabled people and claim to welfare support was supported by both citizens and governments for two reasons: '[They] meet commonly held views about legitimate need for the provision' and because 'the cause of inactivity is perceived as beyond their control. (Dwyer, 2010, p. 136). This clearly links back to medical model thinking when considering that people are unable to work due to their impairment or condition. However, interviewees explained thoughts that contrasted with this when feeling that the 'inactivity' was not always seen as a justifiable response to impairment. This was evidenced in the focus of responsibilities that interviewees discussed earlier in this section.

The idea that people need a nudge into becoming 'active citizens' was reflected by a Service User Involvement Officer at a local voluntary sector organisation:

> *'I don't agree with people being wrapped up in cotton wool and given the lifestyle that they had when they were working, I think people should be supported but I think people should also be given, I dunno how you would do it but people who just need that gentle nudge to start rebuilding their lives need that. Rather than, just sitting back and expecting other people to do it for them'* (Service User Involvement Officer).

This highlights a link in favour of conditionality for disabled benefit recipients, reflecting the need for soft nudges to fulfilling individual responsibilities. This idea was not widely supported by the KIs interviewed; it is important to note that this KI was also the only professional not to be directly engaged in disability and health-related benefits advice or services.

This section has considered the importance of reciprocity and the increasing pressure to fulfil certain responsibilities as emphasised by those interviewed. The following section further considers interviewees thoughts on contractual citizenship (Handler, 2003), specifically in relation to social rights.

## 6.3 Feeling like a *'Second-Class Citizen'*

This section explores how interviewees identified themselves as feeling like 'second class citizens', as they often emphasised the importance of reciprocity. This, in turn, impacted those who were unable to 'give back'. This discussion, therefore, considers how social rights are not experienced without the focus on responsibilities.

Those who placed less importance on ‘giving back’ argued for a more universalistic approach to defining and attaining citizenship. Additionally, interviewees often expressed the need for a consideration of roles such as caregiving and volunteering as forms of contribution, linking back to Morris’ (2005) more inclusive conceptualisation of contribution. Sally, who was previously a teacher, discussed this when mentioning the contribution she made by regularly volunteering at a local charity:

> *‘I’m not working but I do a lot, like I do a lot here and I run a couple of sessions and there was a couple of weeks where I wasn’t very well and it wasn’t on and people were really upset that you know and they sent me a lovely little card and things but I give back into the community cos I feel like I’ve had a lot so I do, I give back what I can’* (Sally).

Sally therefore still highlighted the desire to ‘give something back’ but argues that there are alternative forms of doing so other than paid work. This idea of other means of contribution is often absent from government discourses around welfare which are often largely concerned with paid work as the best form of contribution. Barnes and Roulstone (2005) argue that there needs to be an understanding of work that ‘goes beyond the rigid confines of paid employment’ (p.322); and therefore ‘goes well beyond economic production and wage work’ (Grover and Piggott, 2015, p.249).

However, not all interviewees felt comfortable claiming benefits whilst being unable to work. A number noted that they felt ‘undeserving’ of certain items if they were not deemed as essential due to their benefit status, this links to experiences of self-stigma (see chapter seven). This, in turn, meant that claimants often denied themselves a good standard of living (this was not always possible due to the level of benefit available) as they deemed themselves undeserving of anything deemed as non-essential to day to day life:

> *‘I felt that when I was on benefits, I didn’t have a right because I was living on other people’s money, so its self-stigma. I didn’t believe that I had a right to have nice clothes when I felt well enough to go out for a*

> *meal'* (Service User Involvement Officer [discussing his prior experience of claiming benefits]).

This Service User Involvement Officer had previously been employed in a 'well-paid job' for a number of years before leaving due to a mental health condition. He also discussed how he began to withdraw from his social groups, as he did not feel deserving of partaking in the same social activities. As a result, he isolated himself further because of his self-stigma over his benefit status. This, therefore, reinforces the notion that benefit claimants are lesser or 'undeserving' of the same quality of life as those who are in paid work. This self-stigma he describes linked back to the feelings of shame which are discussed in the following chapter.

The idea that claimants had unequal access, or denied themselves, the same rights as others was reinforced by how they described their citizenship status. This was reflected directly by two interviewees when they referred to feeling like 'second-class citizens'.

> *'You tend to be like sort of classed as a second-class citizen'* (Robert).

> *'Everyone's got something to give and I think that a lot of time when you're in mental health services or you're on benefits, people think you're a second-class citizen'* (Sally).

It was not clear whether this was felt in relation to benefit status and/or being disabled, although this inequality between those who were in employment and not in employment was reflected further by Ruth:

> *'It's just a culture. I am working so I've got rights. I'm better than you. I'm the taxpayer… once they're given State money, it ain't free. They're going to have to pay a price for it and that isn't an easy price'* (Ruth).

The synonymous link between work and access to rights is especially evident here. It is particularly interesting that Ruth talks of the 'price to pay' in order to receive benefits, expressing the negative impact claiming benefits can also have on claimants citizenship rights. Generally, the rights referred to by claimants would fall under the category of social rights (Marshall, 1950) – as discussed in chapter three - which include access to basic welfare provision such as health and education and full or equal participation within society. However, access to social rights also has the potential to impact on access to other rights. Lister (2003) reinforces this idea when stating that ‘without social rights, gross inequalities would undermine the equality of political and civil status inherent in the idea of citizenship’ (Lister, 2003, p.17). Marshall’s framework of citizenship stressed the importance of providing at least a ‘modicum of economic welfare and security’ (Marshall, 1950, p 8). However, the Conservative government (2015-) and its predecessors over the past 30 years, have increasingly made access to social rights conditional on fulfilling certain duties. This, in turn, has the potential to jeopardise benefit claimants political and legal rights. This interdependence is also reflected when considering how claimants’ ability to self-determine, participate and contribute (Morris, 2005) are impacted by welfare policy.

The link between rights and responsibilities meant that people experienced negative connotations around not fulfilling the responsibilities, as noted by Luke:

> *‘Degrading, the way they make you feel as if you’re wanting something for nowt’* (Luke).

The notion that people were more valued if they are working is problematic when disabled people are consistently excluded from equal participation in the mainstream labour market (Roulstone and Prideaux, 2012; Berthoud, 2011). This is the focus of the following section. This section has considered claimants access to equal rights and how this impacts their citizenship status. Claimants also continued to stress the importance of ‘giving back’ as a way of achieving social rights and feeling less like a ‘second-class citizen’. The following section specifically explores some of the barriers to employment, which was one of the key determinants of citizenship that interviewees identified, and links back to the underlying ethos behind welfare conditionality.

## 6.4 Barriers to Equal Participation in the Labour Market

This section explores the difficulties interviewees experienced when attempting to enter back into employment. Despite populist rhetoric suggesting that a significant number of people simply lack the motivation to work, twenty-eight out of the thirty-six claimants interviewed in this study expressed a desire to regain employment in some form[11] but set out a number of barriers that prevented them from doing so. One of the most common related to lack of appropriate JCP and WP support (as discussed in chapter five). This chapter now draws its focus to the additional barriers discussed to participation and contribution (Morris, 2005), such as the lack of accessible jobs and the presence of discriminatory attitudes towards disabled jobseekers.

> *'They want something to do with their time because they want to feel like a member of society again, because they want routine in their life, because they want a boost to their self-confidence and their self-esteem and, you know, not just be looked down on as if you are the dredges of society because you're not working, you know, you're sitting on your arse all day doing nothing, what do you want us to do'* (Katie).

It is evident from this narrative that work is seen as beneficial to an individual's wellbeing. This idea has been reflected in policy trends and several government agendas that express the positive impact work has (see chapter two). Notably, the Biopsychosocial Model of Health (Waddell and Burton, 2006) which significantly influenced policy around the WCA and the limiting of ESA eligibility, has received much criticism from disability academics and activists (Shakespeare *et al.*, 2016; Jolly, 2012).

> *'This would be the last thing I would wanna be doing, I wish I was normal. I wish I could just go and put me coat on and gan for a pint, gan to work, you know what I mean? But it's just impossible at the minute and like I say I cannot see it changing cos the older I'm getting the worse I'm getting you know'* (Luke).

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[11] This included part-time, voluntary and self-employed work.

> *'Well, obviously I've received welfare because I haven't been able to work, but I would also like the right to work'* (Richard).

These quotes highlight both the need for a right to welfare support and a right to work. However, interviewees faced multiple barriers to both seeking and maintaining employment. Often it was noted that full-time mainstream employment would be unsuitable and not inclusive, particularly in relation to supporting claimants' impairment effects (Thomas, 1999). Additionally, fitting around unsuitable job requirements had the potential to be detrimental to existing conditions, even more so in those claimants with mental health conditions:

> *'I'm having to get low paid jobs and things like that and that's not good for my mental health. I've tried my best to do them'* (Will).

This raises several issues around the nature of work and how this is possible for disabled jobseekers with additional needs. The post-industrial labour market, with a significant emphasis on productive value, means that often work is highly demanding and regulated by employers (Roulstone, 2012). Consequently, jobseekers coping with health and impairment-related effects often felt that full-time mainstream employment would be unsuitable or inaccessible for them. Seven out of nine claimants interviewed expressed interest in working part-time, but the complications of permitted earnings caused reluctance and 'the benefits trap' meant that often people would not earn enough to make up to benefit entitlement and therefore would be left unable to support any additional needs they may have. The lack of flexibility within the system therefore clearly undermines people's ability to exercise self-determination and contribute in a way deemed appropriate for their own needs.

A number of interviewees said that due to their current level of impairment, work would not be an option. The impact of the benefits trap and impairment effects overlapped to make the nature of full-time employment inaccessible for those with particular conditions and therefore being on ESA was the only way people felt able to financially support their needs:

> *'Health-wise I physically couldn't do enough hours to cover what I get on benefit. I know probably a lot of people do say that, but I physically just couldn't'* (Fred).

> *'…not just to push people into any job they can get because that's just so unhealthy, it's going to make your mental health worse, you know. So why not try and get people that are interested or passionate or have skills in certain areas to work in those certain areas, that would make more sense, you know'*(Katie).

Furthermore, as historically disabled people have lesser access to education and training opportunities, issues surrounding quality of jobs and pay (underemployment) were consistent (Roulstone, 2012). A Volunteer Advocate gave a stark example of the type of role an adult with learning difficulties had recently been given:

> *'One of them got a job in McDonald's grating cheese all day every day, got to the point where he won't even look at a McDonalds, he can't face cheese, he left and he's worse off now than he was at the beginning, not financially, but emotionally because he feels he's failed so I don't think you should just push them anywhere, I think it needs to be something that they can get a bit of…satisfaction, and be proud of what they've done'* (Volunteer Advocate).

Another claimant discussed his desire to work, but reflected the importance of work being appropriate to their expertise and interest:

> *'I think at this stage I'm quite disillusioned with society, with employment, I would quite like to be a self-employed designer and consultant, design consultant maybe business development manager, however, there is very little support financially and both practically for me to achieve that. There is just this external pressure of being a willing minion, work in a factory job or cleaning or with absolutely no consideration for the person and what it is they would like and what they are actually good at'* (James).

It was not only the quality of the jobs available to disabled people that was discussed but also issues raised in relation to applying for positions. One of the issues identified by an Information Officer, who provided information and advice to people going through the claims process, was the expectation of those people who had been long-term unemployed to now be expected to seek work:

> *'Somebody who has been a long-term benefit claimant now it's there's huge barriers around confidence, skills you know? And a lot of people that you see have kind of like quite chronic mental health issues so the support's not there to help people step-by-step towards employment'* (Information Officer).

This is significant as recently it has been argued that 'the disability category' (Roulstone, 2012, 2015) has been shifted meaning some claimants who have been deemed unfit for work for a number of years are now deemed fit and therefore lose their benefit entitlement. Roulstone (2012) discusses the idea of 'political footballing' as a method of reframing the benefit category to meet government agendas. Peck (2001) further suggests that the boundaries between work and welfare are often 'constructed and reconstructed'. The reconstruction of welfare entitlement also, in turn, redefines what it means to be 'disabled'. This is especially problematic for those who have been excluded from the labour market who are now encouraged to re-enter, without addressing any of the external barriers to equal participation. This links back to the claimant narratives discussed earlier of 'if you can work you should work', raising issues for those who have consistently been labelled as unable to until the tightening of assessment criteria.

Another barrier to employment as identified by the interviewees was the disclosure of impairments and health conditions. Disclosure was evidenced as a significant issue for those applying for jobs, even though recent steps have been made to promote equal opportunities employed for disabled people in legislation such as The DDA (1995) and The Equality Act (2010) (see chapter two). It was clear from interviews with claimants and with the KIs working in disability organisations that this is something that still needs to be addressed further:

> *‘I reckon that they would of just looked at it, googled the meds and seen it’s for schizophrenia mainly and then thought you know we can’t take him on’* (Jack).

> *‘I mean I wouldn’t disclose anything until I’ve got a job and stuff anyway because I don’t think, you know, I don’t want anything to count against me at an interview’* (Alice).

> *‘Disclosure is a massive one, erm there’s a huge barrier, stigma around their diagnoses and disclosure is a huge one. Certainly, in dealing with employers, it’s about when I’m at the point of being employed, how much information do I need to give to employers, that’s always an issue’* (Welfare Officer Specialist).

The discriminatory and stigmatising attitudes of employers meant often claimants felt unable to disclose, with a number perceiving their disclosure of conditions as a key reason for their failed employment status. However, interviewees also mentioned the pressure to disclose early due to fears of employers finding out at a later stage, once employment was obtained, and causing potential dismissal. The level of disclosure was based on individual discretion and varied from person to person, although the anxiety over discriminatory attitudes of employers was evident. This was illustrated by Max, who had been diagnosed with Multiple Sclerosis:

> *‘If I go into an interview in a wheelchair, and they say, well, we don’t really want somebody in a wheelchair because that office isn’t really wheelchair…well, they wouldn’t say that, but they could run through and they find one thing to not hire me. It won’t be my wheelchair of course but that would be the underlying cause that they won’t specifically say, and there’s nothing you can do there’* (Max).

> *‘You do feel disheartened by the way people treat you I think because you feel as though you've not been given a fair chance. I only want…being visually impaired or, you know, whatever condition you have you just want to have a level playing field and you don't have it’* (Richard).

The idea of not being given equal treatment to others, particularly when engaging in the labour market was notable throughout the interviews. This highlighted that despite the presence of anti-discrimination legislation, in practice this was not often applied and left disabled people at a further disadvantage when engaging with the welfare system and the labour market.

When considering rights for ESA claimants, the balance between promoting equal rights to employment whilst also noting that it is ‘okay’ for some claimants not to work is vital. Narratives illustrated that the welfare policy at the time of interviewing allowed some claimants to fall in between the categories of being ‘not disabled enough’ to receive state welfare but also ‘disabled enough’ to be unable to enter employment. The persistence of employment barriers for disabled people means it will be more difficult for this group to enter employment and this needs to be considered when designing welfare policy. It is important to note that the majority of those interviewed wanted to work and referenced the detrimental impact not engaging in employment has on their quality of life and citizenship status. Therefore, the balance between the right to work and the right to not work is a complex area for consideration:

> *‘The two main things that are human life and human living is your productivity and your output of useful work that is useful to society, doing things that are helpful for others. The other thing is, is the social side of your life, being fitting in as an equal, being able to interact and participate socially on a social side in life. If one of those things in your life is ruined, you can't work but you can still have friends and still socialise it's not so bad. But if you can't make friends, you're socially isolated, but you can absorb yourself in some kind of activity or work it's not so bad’* (Amy).

The relationship between the right to work and the right not to work is explored thoroughly by Grover and Piggott (2015) who argue that, in relation to the social model, if disabled people are to be treated equally in terms of labour market participation then there should be an acknowledgement of the right to work but also the right not to work. Claimant narratives reflected this perception, however, often in contradiction, reinforced the firm focus on economic contribution.

This section has considered the barriers that are faced by disabled people hoping to enter employment as an alternative to claiming ESA or as a conditional requirement for their ESA receipt. Although the barriers to employment is not a significant focus of this study, it is an important consideration in the development of welfare policies which place a firm focus on the importance of work. The desire to work which was articulated by the majority of interviewees is also significant when considering welfare policies which are underpinned by the assumptions that people need motivating to enter employment (see chapter two). The following section considers the impact of claiming ESA on an individual's standard of living, both financially and socially to explore how engaging with the welfare system clearly links to a deterioration of citizenship rights.

## 6.5 The Right to a Good Standard of Living

Earlier in this chapter, the discussion focused on how often claimants denied themselves anything that was not seen as essential through self-stigmatising perceptions of deservingness, thus impacting their standard of living. This section builds upon this idea and considers how being on ESA directly affected a claimant's quality of life and citizenship. It explores interviewees' perceptions of the financial support available on ESA and how this impacts their standard of living. It also draws upon what is deemed as 'responsible' use of ESA entitlement.

The interconnected issues of both poverty and social isolation were evident outcomes of benefit status. This is particularly concerning when both are already significant issues for disabled people, who have a much higher potential for living in poverty and being socially excluded and isolated (Parckar, 2008). The impact of limited financial support has direct consequences for the social inclusion and participation of claimants:

> *‘Some people can't even buy a couple of drinks once a week and when you go out socially people...I mean you can't expect other people to buy your drinks for you. You end up becoming socially isolated. Your life gets more depressed and if everything so tight you can't have a treat, you can't...you've got only existence money, enough money to exist, not to live’* (George).

> *‘So it becomes a vicious, vicious circle. You know, you can’t afford to go out anywhere to do anything. It’s all very well and good, saying go for a walk, that’s free but, you know, at the end of the day how many walks are your friends going to go with you for, you know, and it’s hard dragging yourself out because you have mental illness’* (Katie).

As indicated by Katie, the lack of financial support can potentially exacerbate existing impairments and therefore claimants’ overall quality of life. This idea is reiterated:

> *‘It actually physically costs me financially more to take preventative measures and look after my eczema. I’m sleeping on blood-stained sheets. I have been for the last year or so. I just simply can’t afford to get any’* (John).

> *‘It does mean your quality of life is very much affected. You exist I think rather than, well you can pay for your bare essentials’* (Joe).

> *‘…the idea of expecting everybody to live in a box with only just enough you need. It's like because you are on benefits you're not allowed much in life. I think that is wrong. That is totally wrong’* (Amy).

The association between social exclusion and mental health is already largely evidenced by the literature (Payne, 2011). As my interviews drew upon a large number of interviews with claimants who experienced mental health conditions, this link was clearly evident. A stark example was provided by Katie, who had a mental health condition. Katie went into further depth about the day to day implications of living off her ESA amount:

> *‘You can’t have any quality of life, you can’t, you know. Most of the time you’re deciding between bread or milk. Walking, again even though you’re exhausted…to save that £2 that you’d spend on the bus so that you can treat yourself to a can of pop and a bar of chocolate’* (Katie).

> *‘You can’t even afford to live you know what I mean?... we got no food in and that’s gunna be another two weeks before we get money do you know what I mean? So we’ve got nowt in to eat’* (Barbara).

> *‘Well food prices and everything is going up and obviously, living prices are going up and then obviously you’re getting less money, how’s that work?’* (Karl).

> *‘So financially it was really tight, very tight indeed you know with food and stuff we were having to get all the stickered items and I don’t mind that really, but we had to do it and that’s a bit different’* (Tracy).

These narratives depict just how difficult it is for ESA claimants and disabled people to even maintain a very basic standard of living and be able to meet their basic needs. This is especially worrying when a number of claimants needed additional money to assist them in coping and managing their impairment. These narratives reflect the trends in increasing food bank usage for people to support their basic needs (Garthwaite, 2016). Often interviewees talked about how they ‘got by’ with the limited money and one of the coping strategies was related to budgeting their money (Patrick, 2017).

The importance of budgeting effectively to meet their needs was reiterated by a number of claimants:

> *‘I’m really good at budgeting. Because I’ve literally lived on nothing. I’ve had to get by with no food in the cupboard and no money’* (Ruth).

It is important to note that a minority of claimants said that they did not struggle with the amount of benefit awarded. This often varied based on many factors such as living arrangements and previous employment status:

> *‘I live comfortably. I can manage to drive and run a car, at the minute I’m obviously at the house with my partner and we don’t struggle, we’ve got plenty of stuff. We don’t have a lot of luxuries, but we manage’* (Fred).

> *‘We don’t struggle by any means, and I think that’s primarily because we don’t have the outlay of kids to look after, we don’t have a car, et cetera’* (Max).

Both Fred and Max experienced long-term physical health conditions which meant they received the highest level of ESA entitlement. Fred still noted that he didn’t have ‘a lot of luxuries’ but this was not discussed as a problem; this may be linked to underlying assumptions that being on benefits should only entitle you to an adequate standard of living or the basics.

Another interviewee, Sally, mentioned being placed in the SG with access to ESA assisted in her recovery and regaining a good quality of life. Sally discussed this in terms of the benefit helping her during her recovery from a mental health condition:

> *‘I’ve got quite a good life now and I’m just lucky that the support and the benefits I’ve had have enabled me to get back to a point where I am ready to get back into society and start giving back again…I haven’t got any dreams anymore they’ve all gone because of you know doesn't mean to say I can’t have a good quality of life again but. So, for me, it’s been really, really helpful to get me back onto a-to lead a fulfilling life and that’s what the money’s helped me…not just exist but I’ve got a good quality of life now and yeah I’m grateful for that’* (Sally).

This contrasted with the majority of interviewees’ narratives which focused on the issue of financial hardship, poverty and therefore the social exclusion that faced people due to the insufficient ESA amount. It is important to note that this has the potential to move people further away from the labour market, as outlined in chapter five when claimants were restricted or unable to cope with impairment effects whilst receiving ESA and this impacted their existing health conditions.

### 6.5.1 Appropriate Spending

Interviewees' reluctance to use their benefits for anything deemed as non-essential means that they denied themselves opportunities to improve their quality of life. For example, one interviewee noted the reluctance to attend mindfulness classes due to fears of spending benefit entitlement. Another interviewee discussed ideas of spending responsibly; linking back to debates of what is deemed as 'appropriate' behaviour for claimants:

> *'I don't go out and buy fags and drink and drugs and I won't got out partying. I actually invest it. The way I look at it is that I've invested it in my home, so I've got a prettier environment to be depressed in. That's my saying. I've just got a prettier environment to be depressed in'* (Ruth).

The idea of spending ESA financial support 'responsibly' or acting as 'responsible citizens' links with debates around 'shirkers and scroungers' (Garthwaite, 2011). This was noted by Ruth when rejecting ideas around irresponsible behaviours of benefit claimants. This, therefore, raises questions around what is deemed as responsible behaviours and how this varies between those who are employed or receiving welfare support. As discussed earlier, the element of reciprocity impacts this distinction. Those who are perceived to contribute have the ability to increase their standard of living, whereas numerous factors influence the standard of life for those who are reliant on ESA. This is also influenced by government rhetoric which indicates that benefit claimants 'choose' to not seek employment, and claiming benefits is instead considered as a 'lifestyle choice'. This has contributed towards the hardening of attitudes towards those in receipt of welfare support and is discussed in further detail in the following chapter.

Steve, who had a visual impairment and was placed in the ESA SG, discussed this idea in an example from one of his friends who felt like he was unable to go on a holiday:

> *‘…He missed one of the things; he missed it because he went on holiday abroad, so he told them why he missed it. And they told him you’re not allowed to go abroad when you’re on benefits and so they stopped his benefit because of that. So basically if you’re on benefits you can’t go on holiday’* (Steve).

The idea that you are a more valued citizen if you contribute economically through paid work again risks the citizenship status and equal access to rights of disabled benefit recipients, therefore meaning being unable to be employed not only affects poverty and social exclusion but the ability to engage as a ‘valued citizen’ on the whole.

This section has considered the tensions between claimants’ perceptions of contribution and being responsible citizens. This clearly influenced how claimants felt about themselves and the standard of living they should be entitled to. It was evident that a significant amount of those interviewed felt that the benefit amount was not enough to maintain a good standard of living, minus a few examples where people had described the role that benefits had in supporting a good standard of living. It is important to note that these opinions were exclusive to those who were placed in the ESA SG which offers the highest level of financial support, rather than the lower level given on the WRAG or through mainstream JSA. There was a stark contrast of opinions and experiences on living standards as they were largely dependent on personal situation. It is important to note that often claimants relied on family members for additional financial support which presented another disadvantage for people without family or community networks to support them.

## 6.6 Conclusion

This chapter has considered interviewees’ perceptions of the rights and responsibilities associated with claiming ESA. It has explored the clear association between citizenship status and contribution, and the difficulties this entails for those who are excluded or unable to enter the labour market. Additionally, it considered the barriers to employment that claimants identified as most significant when exploring job seeking and the impact being on out of work benefits had on claimants' standard of living. Issues around disclosure and unequal availability of opportunities were key issues for those interviewed despite significant legislation to combat this, such as DDA (1995) and The Equality Act (2010) (see chapter two). There is a clear need for citizenship debates to take into consideration varying means of contribution for those who are unable to enter employment, such as Morris' (2005) approach, which extends beyond formal paid work. The need to fulfil responsibilities in order to be entitled to claim ESA is a distinct area of contention for claimants who reinforce the need of 'giving back' but are not always able to do so, consequently meaning that the recent increase in conditional welfare arrangements for ESA claimants has the potential to be largely problematic for many disabled people.

The following chapter explores further narratives from claimants with a particular focus on the stigma attached to being in receipt of ESA and its impact on people's identities.

# Chapter Seven: A Disabled ESA Claimant? Constructing and Negotiating Identities

## 7.1 Introduction

The first findings chapter illustrated interviewee's lived experiences of experiencing the claims process. It explored how their experiences shaped the way people interacted with the welfare system and began to consider how people negotiate their identities as disabled ESA claimants. The second findings chapter explored claimants' perceptions of citizenship by considering how interviewees perceived and experienced their access to rights and their mutual relationship to responsibilities. Contribution was identified as a significant element of a claimant's perceived 'deservingness'.

This chapter now draws upon experiences from both claimant and KI interviews to explore how claimants constructed and negotiated their identities as a disabled person and an ESA claimant. It specifically utilises Goffman's (1968) concept of 'spoiled identity' and 'discrediting' and 'discreditable' attributes. It begins by considering broadly how people constructed their identities in relation to their disability and claimant status. A key theme emerged when considering people's acceptance or rejection of identities in relation to their levels of political engagement. I present a typology which is informed by the relationship between political engagement and identities as a tool for exploring this concept.

The following sections then consider how people continued to negotiate their identities. They explore the role of stigma and shame and, explore how processes of 'othering', normalising impairment effects and avoiding disclosure of claimant status all served as a way that people negotiated their identities. The following section begins to explore how interviewees initially identified themselves and the reasoning behind their constructed identities.

## 7.2 Disabled Person and Welfare Claimant: Mutual Identities or a Dichotomy of Difference?

> Interviewer: *…how did you feel about disclosing the fact you were on benefits?*
>
> KI: *I found that harder than telling people I had mental ill-health* (Service User Involvement Officer discussing his prior experience of claiming ESA).

The majority of interviewees reflected this feeling of unease in relation to identifying as a claimant, with a minority, such as the KI above, directly stating that identifying as a disabled person was personally easier than disclosing their benefit status. Interestingly, existing literature (Riddell and Watson, 2003) has evidenced a reluctance to identify as disabled due to the perceived stigma. Therefore, this indicates that the stigma attached to claiming welfare support is greater than that of the stigma surrounding disability.

Goffman's (1968) exploration of discrediting and discreditable attributes is relevant here. Based on Goffman's definition, claiming benefits would be identified as a discreditable attribute which can be concealed by the individual. The concealment of benefit receipt as a 'discreditable attribute' led to various mechanisms that disabled claimants took on. The following sections consider the processes that claimants experienced when negotiating both their claimant and disabled identities.

### 7.2.1 Identities and Disability

Seventeen interviewees discussed their identities as a disabled person. This included interviewees who had a range of impairments including sensory impairments, mental health conditions and learning difficulties. Only seven people discussed choosing to openly identify as a disabled person, however, this was often linked to administrative tasks such as, filling in forms or disclosing their impairment to employers rather than it being an active part of their identities.

> *‘Yeah, if I fill out the forms or something, I’ll tick the box that says so, but not in everyday life, like, form filling it comes to things like that definitely, but I don’t, it’s not in my mind, I can go weeks without mentioning it to someone?’* (Steve).

Conversely, nine interviewees discussed not identifying as a disabled person. For a minority of interviewees, this was in relation to the stigma attached to identifying as disabled.

> *‘…for a long time, I didn't like to admit that I was disabled because it was like a pride thing’* (Julia).

On the other hand, a considerable number of interviewees did not identify as disabled due to the perception that disability did not resonate or apply to their experiences.

> *‘I wouldn’t call myself disabled just, I guess, just have a long term illness, I guess’* (Alice).

> *‘I wouldn’t class meself as disabled. I mean I walk about with a walking stick, but I wouldn’t say I was disabled* (Luke).

It was evident that there was a disparity between what people perceived disability to mean and how their condition related to their perceived understandings.

However, as discussed in chapter three, the construction of identities in relation to disability was very rarely a clear binary between identifying as disabled or not. A clear example of this was when Luke initially stated that he did not class himself as disabled, but then shifted this view later in the interview, when he started to challenge his own assumptions of the meaning of the term.

> *‘I would class disabled as like people with a wheelchair and that but that’s the way I think disabled people are you know what I mean… I suppose I have got a disability cos if you’re frightened to come out the house then, so it is a bit of a disability I suppose you know?’* (Luke).

The way in which people identified was therefore shaped by the person's unique perception of disability. It could be argued that this simply in relation to challenging the negative 'spoiled identity' (Goffman, 1968) associated with identifying as disabled as discussed in chapter three. Although, this alludes to a more complex process of how people understand disability and how this reflects their own view of self. In this case, it linked back to traditional views of what disability means, such as having a physical impairment, when Luke described 'being in a wheelchair' which was underpinned by a medical understanding of disability. This perception was not unique to Luke, as several people reinforced this perception of disability. Additionally, people often used physical impairments as a comparator to their personal experiences when describing disablity.

> *'I have got friends who are actually physically disabled'* (Beth).
>
> *'I've got learning difficulties, but I don't feel I'm a lot disabled than others'* (Emma).

Several interviewees implied that they also consciously made the decision to avoid identifying as a disabled person in the hope of achieving a level of 'normality'.

> *'Well I'm blind and registered disabled, but I wouldn't like to be classed as disabled anyway, try and fit in with everybody else and I can't'* (Richard).
>
> *'I think it was because I just wanted to have a bit of normality. I don't want to be defined as the person with the problem, I want to just be a normal well now 27 year old who's just, you know, well like I say just a normal person rather than being defined as a disease… Yes and no. I don't, I do class myself as disabled because it does help but I don't want other people to class me as that. It's that trying to balance between judgement and being judged'* (Fred).

These narratives show how some people actively chose not to identify as a disabled person, which has the potential to reinforce ‘disablist practices’ (Watson, 2002). This also caused increased pressure on people trying to meet ‘normalised’ expectations. Richard noted the challenge of trying to ‘fit in’ but being unable to do so, implying that to him the disabled identity was an indicator of difference. Richards’ identities were constructed around the desire for a sense of belonging that being ‘normal’ would achieve. Fred also felt conflict when considering his disability status. He rejected the labels associated with having a ‘problem’ or disease as a strategy for becoming perceived as ‘normal’ whilst noting that he is happy to identify himself as disabled but not for others to share in that judgement, in turn taking active ownership over his own identities.

These quotes begin to explore how people denied being disabled to normalise their identities. However, by doing so this has the potential to reinforce medicalised viewpoints of disability by positioning the disabled identity as a negative attribute to be disassociated with, and therefore distancing themselves from other disabled people who self-identify as such. This also links to the reproduction and reinforcement of ‘disablist practices’ discussed by Watson (2002).

The reluctance by claimants to consider impairment as a part of their identities reflected findings from Watson’s (2002) study, whereby three out of the twenty-eight participants interviewed incorporated disability within their identity, without denying the presence of their impairment, their sense of self was not determined by this characteristic. However, this study found a much more varied response, with four interviewees actively identifying and a further three stating that they did not know whether they identified as disabled or not, illustrating a much more complex picture.

### 7.2.2 Identities and Claimant Status

Through this initial exploration of interviewees’ narratives on identities, it was evident that perceptions of being disabled and claiming welfare support were intertwined. When discussing perceptions of disability, conversations most frequently led to perceptions of genuineness, especially in relation to hidden impairments, as illustrated by Sally below.

> *'I felt a little bit ashamed telling people. Cos then they wanna know why you're claiming benefits, cos I look fine like you don't look like you've got a disability'* (Sally).

The way in which interviewees constructed and negotiated their identities is explored in further sections in relation to stigma and discrediting attributes (see section 7.5; 7.6; 7.7).

When considering the factors that meant people engaged or disassociated with either disabled or claimant identities it was interesting to observe that often the interviewees' level of political interest appeared to affect the way interviewees chose to identify. The following section explores this further and presents a typology which provides a useful framework for understanding how people interacted and negotiated with both the claimant and disabled identity.

## 7.3 Political Engagement and Constructed Identities

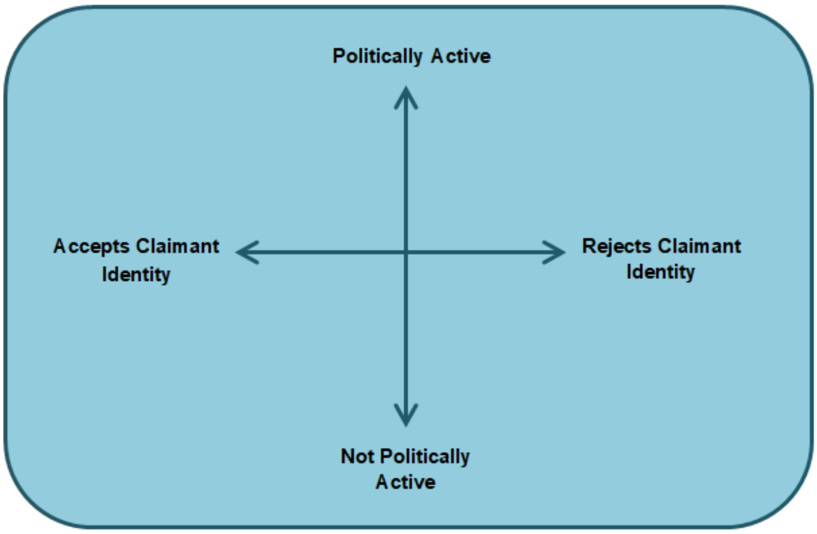
When mapping out claimants' levels of acceptance or resistance towards identifying as either a disabled person or an ESA claimant, a significant theme that emerged was the link between how politically engaged the interviewees were and their identities. There was a general correlation between the most politically engaged interviewees being the most accepting of both their disability and claimant identities. However, this was not always the case. This section explores this relationship further as a means of understanding this relationship and present a typology.

### 7.3.1 The Typology – Political Engagement and Identities

Whereas literature (Edmiston and Humpage, 2018) has previously explored how welfare claimants exercise political engagement in terms of promoting citizenship and social rights, this section instead looks closer at the relationship between identities and political engagement. Limited research has explored the relationship between political engagement and identity in relation to disabled benefit claimants. However, it has been evidenced that claimants sometimes separate themselves from a stigmatising identity and protect themselves from ‘self-blame’ by acknowledging the role of the Government in reducing eligibility and becoming a political activist (Saffer *et al.*, 2018).

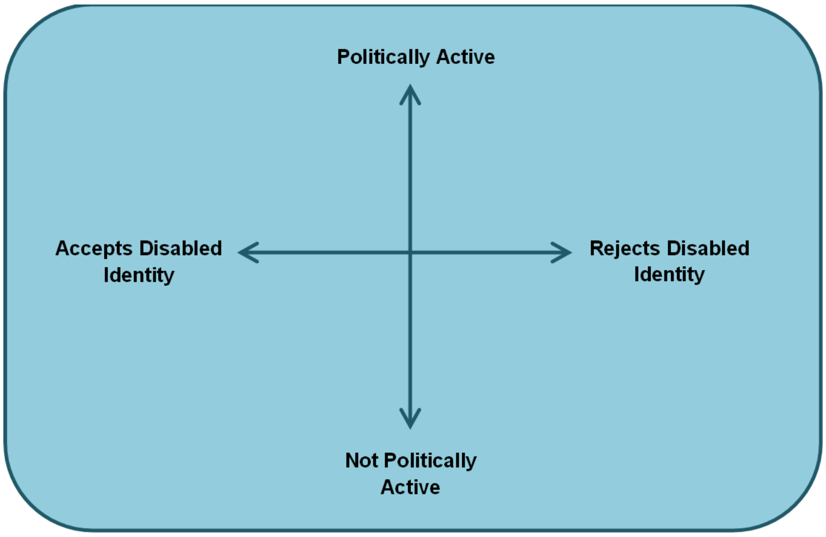
This typology has been developed to illustrate a framework for exploring the relationship between political engagement, the ‘claimant identity’ and the ‘disabled identity’ based on empirical evidence from this thesis. In the context of this framework, political engagement has been characterised by interviewees discussing activities such as being involved in political activism, a noted interest in politics or involvement in disabled people’s groups. However, it is important to note that many interviewees had a level of political understanding in relation to current affairs and welfare agenda, this potentially was influenced by recruitment methods (see chapter four). Both disability and claimant identities are considered separately in relation to interviewee’s political engagement as often one identity would be accepted and another rejected, rather than the acceptance of one identity meaning the another was accepted simultaneously.

**Fig. 1 Political Engagement and Claimant Identity:**



Acceptance of the claimant identity included those interviewees who generally felt ‘okay’ about claiming benefits or felt this was an entitlement as opposed to rejecting the identity and disassociating themselves from the claimant identity.

**Fig. 2 Political Engagement and Disabled Identity:**



Accepting the disabled identity linked to interviewee’s view of themselves as a disabled person and interviewees who did not deem themselves as disabled therefore rejected this identity.

### 7.3.2 Identities as a Spectrum

This typology, therefore, presents a spectrum of possible identities, which consider the correlation between political engagement and identities. When utilising this typology, most claimants who were identified as ‘politically active’, also identified as a disabled person. When exploring this in terms of claimant identity this was much less consistent. The majority of claimants rejected the claimant identity and distanced themselves from this identity through a variety of processes (see sections 7.8; 7.9; 7.10).

The following section illustrates various positions on the spectrum through case studies of interviewees.

## 7.4 Case Studies:

As mentioned, an indicator of whether an interviewee would identity as both disabled and an ESA claimant linked to their increased levels of political engagement. Therefore, this first case study presented a claimant who embraced both identities and was highly politically active.

### 7.4.1 Jack

> *Jack, who was currently in the ESA Support Group whilst volunteering part-time at a local charity, was one of the most significantly politically engaged participants interviewed. He was an active member of the Labour Party and had previously ran for a role in local office. He was educated to degree standard and had studied Disability Studies at University.*
>
> *Jack had experience of claiming Jobseekers Allowance prior to his mental health diagnoses, before being moved onto Incapacity Benefit and finally transitioning onto ESA. When considering his identity as a claimant he stated 'I don't have a problem with it' in reference to his personal feelings about claiming ESA and suggested that he was generally happy to disclose this to others. He acknowledged that there were negative connotations associated with claiming welfare support, although suggested that this was largely due to the government scapegoating a group in a time of economic hardship.*
>
> *He also considered himself as a disabled person and therefore embraced the 'disabled identity', however, preferred the term 'people with mental health diagnoses'. He was happy to disclose his mental health diagnoses of schizophrenia although did mention an occasion when applying for a job where he felt that the disclosure of this was of detriment to him getting the job.*

In contrast to Jack, not all interviewees who were politically engaged chose to identify with both identities. The following case considers an interviewee who, although engaged with disability activism, chose to reject the disabled identity.

### 7.4.2 Richard

> *Richard, who was registered blind, also engaged in politics. He was involved in political activism surrounding cuts to the public sector and involved in a disability activist group. Although Richard did not currently claim ESA, he had experienced receiving various other disability-related benefits throughout his life. He discussed many years of work experience and his desire to enter full time paid employment but felt the support to do so was 'not forthcoming'. He had experienced a work-focused program several years prior and stated that this was not a useful process for him and that nothing employment-related came from it. When considering the way in which Richard identified, he focused mainly on the stigma surrounding disability, making note of the negative connotations of claiming benefits but primarily in relation to fraudulently presenting as disabled. He also rejected his own disabled identity when stating that 'Well I'm blind and registered disabled, but I wouldn't like to be classed as disabled anyway, try and fit in with everybody else and I can't'. He, therefore, avoided association with the disabled identity, due to his desire to 'fit in with everybody else', which was problematic as he felt unable to do so.*

Richard's narratives show how disabled people's identities have become interlinked with claimant identities which question the genuineness of claimant's impairments. When exploring the way in which non-politically engaged interviewees constructed their identities, it was often not as clear cut as those who were politically engaged. Although, it is important to note that levels of political engagement are also linked to interviewees' social class, educational background, ethnicity and gender (Henn and Foard, 2013) which is not within the scope of this study, but presents questions for future research (see chapter eight).

The following case study considers an interviewee who had minimal political engagement and resisted both identities.

### 7.4.3 Luke

> *Luke was originally placed in the WRAG when first assessed for ESA. He was unable to meet the requirements placed upon him for several months before seeking help through a local charity. He had assistance to appeal the decision and was successfully transitioned onto the Support Group. The disclosure of his claimant status was a significant issue for him, stating that: 'if I could live somewhere without having to claim any money which I cannot cos my sister cannot look after us, I wouldn't, I wouldn't claim at all. Nah, I wouldn't go through all the hassle that you gan through for the pittance that you get you know?'. His perception of disability was different to how he viewed himself.*

The above case studies demonstrate the interviewees that fit most clearly into the quadrants of the above typology. However, it is important to note that the majority of people were much less neatly placed and that the fluidity of identities (Jenkins, 2014) means that peoples position on the spectrum would likely be open to continuous change. Initial empirical evidence from this study demonstrates that people experienced varying degrees of stigma associated with 'discrediting attributes' and, that levels of political engagement often mean that the discrediting attributes associated with the claimant and disabled identity are resisted and rejected.

This section has considered how people's identities were impacted by their levels of political engagement. The following section considers how interviewees' lived experiences of stigma also influenced how they perceived themselves.

## 7.5 '*You feel sort of like* an outcast': Lived Experiences of Stigma

This section presents data portraying disabled benefit recipients lived experiences of stigma. It initially considers the stigma associated with claiming benefits and consequently the negative stereotypes linked to being in receipt of ESA. It, therefore, draws primarily on interviews with claimants in relation to their perceptions of stigmatisation and stereotyping, a key element of the stigmatisation process (Link and Phelan, 2001). Taylor-Gooby (2013) notes that there is a ‘growing stigmatisation of poverty among people of working age’ (Taylor-Gooby, 2013, p.36). This can be increasingly evidenced since the late 1990s where coverage has progressively perpetuated negative stereotypes towards those who are perceived as ‘economically inactive’ (Baumberg *et al.*, 2012). The increasing levels of stigma interviewees discussed also alludes to the context of institutional violence (see chapter five) which punishes disabled people when interacting with the state.

Sally, who was placed in the ESA SG due to a mental health condition, had previously worked as a teacher for several years. However, she explained that she felt that she was able to give more back to society whilst on ESA through her role as a volunteer at a local charity. She described the dual stigmatisation she felt around her impairment and unemployment status:

> *‘…I just think you know I’m not working but I do a lot…I think people think we are scroungers and that we are lazy…mental health has got that whole other stigma, so you’re smelly you’re dirty, you’re not very bright, you’re unsafe like around people’s kids’* (Sally).

Sally first identified the stigma around receiving benefits when relating to ‘scroungers’ and being ‘lazy’, ideas which are largely reflected in government discourses of the time and the rhetoric of ‘shirkers and scroungers’ (Garthwaite, 2011). Interestingly, this stereotype could easily apply to non-disabled benefit recipients, highlighting that the primary stigma was attached to the concept of ‘worklessness’ and not in relation to impairment. Sally reinforced this idea when stating that ‘I do a lot’ therefore noting the personal importance of reciprocity and giving something back to society. This links to the debates around societal contribution and citizenship status discussed in chapter six.

Sally also identified the stigma relating to her mental health condition as secondary. This was in line with the majority of interviewees discussed the stigma around claiming benefits rather than the stigma attached to being disabled. Many interviewees noted the presence of dual stigmas as an important aspect of their experiences. However, Steve, who was in the SG and had a visual impairment, reinforced the idea that impairment status often failed to affect the stereotypes attached to benefit receipt when stating that:

> *'I mean it comes under the same bracket, I mean welfare, I don't think it matters whether they are disabled people or non-disabled people it's still viewed in the same way'* (Steve).

The idea that impairment did not affect public perceptions links to the increasingly work focused policy arena (see chapter two) and the increasing rhetoric surrounding fraudulent claimants which put into question the genuineness and legitimacy of ESA recipients (Briant *et al.*, 2011). As a group of people who were traditionally perceived as 'deserving' of benefits, ESA claimants have increasingly become combined with the rhetoric linked to 'shirkers and scroungers' (Garthwaite, 2011).

This was reflected when interviewees were asked about public perceptions of disabled benefit recipients. The majority identified stereotypes which questioned genuineness discussing labels such as 'fraudsters' or 'spongers'. This indicates how the disabled identity has become synonymous with the claimant identity which is characterised by suspicions over genuineness. Connor, who was declared FfW following his WCA, portrayed this notion when stating that:

> *'A lot of the public just think people are spongers and just think they're putting it on'* (Connor).

Additionally, the idea of 'putting it on' extended from notions of genuineness to debates around visible and hidden impairments, with interviewees suggesting hidden impairments often made it harder to 'prove' you are 'disabled':

> *'people can see very clearly a physical disability but with a mental one, you can't see it. They might think, oh he's putting it on'* (George).

Interviewees suggested that the idea that some impairments were favoured as more deserving than others was problematic; often due to people with mental health conditions feeling a heightened level of stigmatisation. Beth discussed this in terms of her own mental health condition as she perceived that she would need to ‘look like you’re disabled’ to be taken seriously:

> *‘It’s that whole invisible illness like you’re in a wheelchair therefore obviously you need benefits because you’re clearly disabled… it’s like you have to look like you’re disabled for people to take you seriously’* (Beth).

Interviewees reinforced this idea of feeling like they were having their genuineness questioned because they had a hidden impairment, or discreditable attribute, such as a mental health condition rather than a visible impairment or discrediting attribute. This was both in relation to the process of claiming ESA and more broadly in relation to wider societal perceptions.

Finally, the issues arising from the stereotypes attached to ‘worklessness’ and claimant status linked back to how interviewees constructed and shaped their identities. In consideration of ‘deviations’ and ‘norms’ (Goffman, 1968), interviewees desire to be ‘normal’ was linked to the participation in meaningful employment. As all those interviewed had ‘deviated’ from this perceived ‘norm’, this impacted the formation of their identity.

> *‘…the job becomes the thing you are and people are more looked upon as the value of their work and if you haven't got that label cleaner or shop worker or manager, a job description title next to your name that's part of your identity and that is your identify, if you haven't got that then you’re nothing’* (Amy).

Amy noted how she struggled to navigate her own identity due to not having an employment status, highlighting that she felt employment was a significant element of establishing a positive identity as a working-age adult. Therefore, not having a job was detrimental to her personal identity formation. This linked back to claimants underpinning the significance of reciprocity (see chapter six) but also raises questions around the challenges when constructing positive identities in the absence of employment.

This stigma surrounding benefit claimants, particularly the rhetoric surrounding fraudulent claimants (Garthwaite, 2011) can evoke a range of emotions, particularly the idea that claiming benefits is increasingly shameful (Baumberg *et al.*, 2012). Shame can be defined as 'a negative assessment of the self-made with reference to one's own aspirations and the perceived expectations of others' (Chase and Walker, 2012, p.739). Walker (2014) also suggests that 'shame and stigma are intricately connected to the point whereby they can be treated as being almost synonymous' (Walker, 2014, p.50). Therefore, it is important to consider how stigma may be internalised by recipients and how this reinforces feelings of shame. The following section considers this response to benefits stigma.

## 7.6 '*Am I just making this up? Am I really depressed?*': Internalised Stigma

> *'I'm eligible, yes, eligible for claiming the benefits, so I'm able to get them, that's not the issue, but I found that I felt awful for claiming them. I made myself feel like a scrounger. It wasn't other people; it was my perception of myself and what other people thought of me'* (Max).

Max, who had Multiple Sclerosis (MS), discussed how his view of self was tainted by how he perceived his benefit status rather than the perceptions of others, linking clearly to Goffman's (1968) notion of 'self-stigma'. However, when noting that he made himself 'feel like a scrounger', this aligned his mainstream narratives which stigmatise benefit claimants. This demonstrates how stigma is internalised and reflected in his perception of self.

When discussing claimant status, Max demonstrated how the collective context links the social to the shared understandings of the personal. Therefore, in relation to disability, it is imperative to consider how people are influenced by the societal values and norms placed upon them and thus 'self-image is thus dominated by the non-disabled world's reaction to us' (Morris, 1991, p.28). From a social model perspective, it can, therefore, be argued that disability lies not with the impairment but 'more importantly, in the area of our relationship with 'normal' people' (Hunt, 1966, p.146).

The relationship between the personal and the social can also be considered in terms of benefit status. Freire (1972) states that:

> *`Self-depreciation is another characteristic of the oppressed, which derives from their internalisation of the opinion the oppressors hold of them. So often do they hear that they are good for nothing, know nothing, and are incapable of learning anything - that they are sick, lazy and unproductive - that in the end they become convinced of their own unfitness'* (Freire, 1972, p.38).

As the public reaction to benefit claimants is often negative then claimant's own self-image is potentially constructed and reinforced in the reflection of this view. As discussed in chapter two, since the post-2010 reform of welfare benefits, public perceptions of disabled benefit recipients have increasingly questioned the legitimacy and genuineness of claimants (Garthwaite, 2011).

Will, who was awaiting his ESA assessment and experienced a mental health condition, noted how he began to question his own legitimacy, illustrating the internalisation of 'the opinion oppressors hold':

> *'You're like oh well can I do it and then it just becomes like a confusion for you and you're like well what do I do? I'm not going to be able to cope with work and then you start like doubting yourself and you think am I just making this up? Am I really depressed? Am I just making this up?'* (Will).

In this case, the stigma surrounding 'fraudulent' claimants was so great, Will began to question the legitimacy of his own impairment. This was despite him noting throughout the interview, how much his mental health condition had affected his ability to carry out a range of day-to-day tasks. Therefore, demonstrating the considerable impact societal reactions can have on one's own sense of self and construction of identities. Additionally, how a stigmatised person can often 'buy into' the stigma.

## 7.7 ‘*You feel sort of guilty*’: Claimants Internalisation of Shame

The previous section explored recipients lived experiences of the internalisation of the stigma attached to claiming ESA. This section considers how interviewees continued to internalise this stigma and expressed feelings of shame regarding benefit receipt. In this context, shame can be defined as: ‘the range of emotions to do with feeling foolish, stupid, ridiculous, inadequate, defective, incompetent, awkward, exposed, vulnerable and insecure’ (Wilkinson and Pickett, 2009, p.41). This section draws upon narratives of claimant interviews throughout. Peacock *et al.* (2014) state that:

> *‘The working class are not passive recipients of shame, that they attempt to protect themselves and resist, is of course well documented in the sociological literature on health and inequality’* (Peacock *et al.*, 2014, p.9).

Therefore, this section considers to what extent that those interviewed experience, resist, and engage with feelings of shame, when not passive recipients of its influence. Furthermore, as the emotion of shame has deep-rooted relations to the process of stigmatisation, it is important to consider shame as a process that involves being shamed and shaming of oneself.

Will, who was in the process of being assessed for ESA due to a mental health condition, explained how he felt about claiming benefits:

> *‘You feel sort of guilty and then you hear all these comments about people saying, oh people scrounging off benefits and things like that and it does sort of stick in the back of your mind and you feel like sort of, I don’t know if alienate is the right word, but you feel sort of like an outcast. You feel sort of not inclusive with the rest of society’* (Will).

It was evident that Will felt negative associations about receiving ESA, which affected his view of self and feeling of belonging within society. The connotations of feeling like ‘an outcast’ and ‘not inclusive’ are also significant when disabled people are often already at risk of social exclusion (Heslop, 2013). The emotions such as shame and guilt were a common theme among many other interviewees, often linking back to ideas around ‘deservingness’. This was reflected by Sally who also discussed the feelings of shame:

> *‘I felt a little bit ashamed telling people. Cos then they wanna know why you’re claiming benefits, cos you look fine like you don’t look like you’ve got a disability’* (Sally).

Sally expressed feelings of being ashamed about disclosing she was claiming ESA, specifically as this often led to questions about her impairment. She highlighted the issues again surrounding the questioning of genuineness around identifying as disabled when having a hidden impairment or condition. The notion that people in receipt of ESA were expected to answer questions about their impairment or reason why they were claiming ESA was common. It illustrated societal obligations placed on individuals to ‘prove’ their entitlement, which was particularly difficult for those who did not want to disclose this information. This alludes to larger issues around how disabled people are obligated to share personal information both within the claiming process (see chapter five) but also within a wider society that divides people based on perceived contribution and ‘deservingness’. Reflecting on Goffman’s (1968) exploration of ‘discrediting’ and ‘discreditable’ attributes, claimants often faced an obligation to disclose their discreditable attributes to prove their genuineness as a welfare claimant.

Often the level of shame claimants experienced was linked to how much an individual perceived the stigma attached to being in receipt of benefits. Also, levels of shame were sometimes dependant on if an interviewee had engaged in work before claiming ESA, linking back to the notions of reciprocity explored in chapter six.

> *‘I’m quite happy that I’m getting money and to be comfortable and not having to force myself to work, but then at the same time I’ll have days where I feel really guilty, but it’s like I’m not even doing anything and I’m getting all this money and my friends who have only got part-time*

> *jobs, they're not getting as much money and they deserve all this money because they're working so hard, and oh, this is horrible'* (Beth).

Beth felt conflicted when asked about her personal feelings on claiming ESA. There was a distinction between the importance of claiming benefits being both beneficial, but at the same time detrimental to her sense of self. The sense of shame was emphasised when comparing herself to her peers who were engaged in employment, therefore emphasising her deviation from the perceived 'norm' and feeling shame herself for not meeting this.

Beth's feelings of shame illustrate a process of shame co-production. Chase and Walker (2012) discuss this idea in relation to individuals both being shamed and feeling shamed, linking back to the notion that people are not solely passive recipients of shame, but they have the potential to reinforce and resist. This idea of feeling shame is reinforced by Max:

> *'I just thought it was quite interesting that actually, I felt more pressure on myself about claiming them than anyone else'* (Max).

Both Max and Beth did not seem to engage in attempts 'to protect themselves and resist' shame as active agents as Peacock *et al.* (2014) stated. This may have been due to the stigma of the claimant status or Beth and Max's underlying personal beliefs about the importance of work and reciprocity impacting their self-judgement.

Finally, it is important to note that the interviewees who took part in this study actively chose to do so. Therefore, it could be hypothesised that those who felt the most 'shame' in relation to benefit status would not actively choose to engage with the study and therefore levels of internalised shame may generally be even higher than portrayed in these narratives.

This section has considered interviewees' experiences of shame. It can be argued (Chase and Walker, 2012) that one way people manage the feeling of shame, is by engaging in the process of 'othering'. This phenomenon was highly evident in the discourses from those claimants interviewed and is the focus of the following section.

## 7.8 ‘*We get trapped in that same bracket as just people that refuse to work’*: The distinction between ‘*us*’ and ‘*them*’

The previous section explored how interviewees personally experienced stigma and how this, in turn, caused feelings of shame surrounding ESA receipt. This section explores another common response to the stigma which involved the process of ‘othering’ (Lister, 2004) by drawing on a number of claimant interviews. Within mainstream media and political rhetoric, disabled benefit recipients are often portrayed as the ‘other’ in relation to those who are ‘economically active’. However, the claimants interviewed in this study often applied othering in a different sense, the ‘other’ being those perceived as undeserving or those who drew parallels to the undesirable stigma surrounding ‘fraudulent’ claimants. Interviewees often resisted the stigma attached to claiming ESA by distancing themselves from these negative stereotypes discussed earlier and reinforcing the identities of ‘us’ – the genuine claimant and ‘them’ – the fraudulent claimant. This process of ‘othering’ those based on similar characteristics was highlighted in Patrick’s (2015) study whereby ‘those who were themselves disabled were particularly likely to talk of undeserving disability benefit claimants who were not *really* disabled’ (p.229).

As discussed in chapter three, the concept of ‘othering’ is interconnected with notions of stigma. Othering can be described as an ongoing process which has the ability to distinguish and maintain a distance between the more and less powerful members of society (Lister, 2004). Lister (2004) argues that other social processes such as stigmatization and stereotyping can impact and support the process of othering. Thomas (1999) states that:

> ‘...*to maintain a sense of ‘who I am’ one has to participate constantly in the process of constructing and reconstructing the boundaries of the self*

> *through an ongoing process of differentiating oneself from 'the Other''* (Thomas, 1999, p.114).

Therefore, when considering how claimants constructed their identities, it is important to note that interviewees attempted to challenge the 'spoiled identity' (Goffman, 1968) in relation to disability and benefit status by differentiating themselves from the perceived 'other'.

When further exploring the relationship between stigma and othering Goffman (1968) implies that a 'person with stigma is not quite human' (Goffman, 1968, p.15) (see chapter three). Therefore, in terms of the process of othering, the individuals who are perceived as less powerful or seen to be deviating from the norm may be recognized as less than human. This can simultaneously reinforce and maintain the process of 'othering'. The idea that claimants were perceived as 'less than human' was a significant theme discussed when exploring how the process of claiming ESA potentially dehumanised and reinforced the practice of stigmatisation (see chapter five).

Populist rhetoric that welfare claimants lacked the motivation to enter employment was not just apparent within the perceived public perceptions but was also often upheld by the interviewee's discourses when identifying that there were people who were not perceived as genuinely deserving of their ESA entitlement.

> *'…I think they are some people like that who just don't wanna work but then there are genuine people who really need it and wanna make an effort to give back to society'* (Sally).

The distinction between those who did not want to work and those who want to 'give back' was a clear illustration of 'othering'. Interviewees would often reinforce the negative stereotypes attached to claiming ESA but then distance themselves from those who were perceived as the fraudulent claimants, rejecting the perceived 'spoiled identity' (Goffman, 1968). This not just reinforced negative claimant stereotypes which justify paternalist approaches to welfare policy but also can reinforce disablist practices (Watson, 2002). This notion was reinforced by Connor, who was deemed FfW, following his remission from cancer and an ongoing mental health condition.

> *'I know people who do pull the ropes on the benefits system and I think that spoils it for a lot of people…I do know that there are people that do spoil it for everybody else…fair enough a lot of people do discriminate the system but there are people that are genuinely ill and they have to suffer, as well'* (Connor).

Connor identified fraudulent claimants impacting the perceptions of genuine recipients, illustrating a clear binary between those deemed as genuine and the 'other'. Over half of the interviewees supported this idea and resisted the stigma attached by arguing against being perceived by others in the same way:

> *'you're now tarring me with the same brush'* (Sally).

> *'the genuine ones are tarred with the same brush'* (Steve).

Shildrick and MacDonald's (2013) study evidenced a similar distinction when 'research participants constructed a self-identity in contrast to a (usually) nameless mass of 'Others' who were believed, variously, to be work-shy, to claim benefits illegitimately and to be unable to 'manage' and to engage in blameworthy consumption habits' (Shildrick and Macdonald, 2013, p.291).

Richard, directly mentioned levels of perceived 'genuineness':

> *'You hear a lot of disabled people being called scroungers, but it depends how genuine their disability is – that's what people have got to think'* (Richard).

The disassociation away from those claimants who were fraudulent can be linked to 'practices of disidentification' (Skeggs, 1997). These practices of disidentification can be as influential as practices of identification in the establishment of an individual's identity (Holt, 2012; Skeggs 1997). Therefore, people identify themselves in relation to what they are not. This is reflected in those interviewee's perceptions of the 'other'. Generally, claimants talked increasingly more about what they were not i.e. the undeserving ‘other’, rather than how they identified themselves, thus showing that it was often easier to resist association with the ‘other’ than to identify oneself. Most interviewees rejected being defined by their impairment or benefit status but also discussed a struggle to formulate identities, especially with the absence of a ‘job title’ which was previously noted as an important issue when formulating interviewees’ identities.

This idea draws parallels to Holt’s (2010) study of parents’ experiences of compulsory support programmes whereby often parents would identify the ‘other’ (in this case the ‘bad parent’) as a method of managing parents own ‘spoiled identities’ (Goffman, 1968). This notion of good and bad was reinforced by Richard when stating

> *‘…there are that many people who say they need it, there is nothing wrong with them. How do you judge the bad out from the good if you like?’* (Richard).

This also draws parallels to literature which considers the process of othering in relation to poverty and social classes. Shildrick and MacDonald’s (2013) study of deprived communities found that participants produced ‘phantom others’ to identify with ‘the ordinary’ and disidentify with ‘the undeserving’ who were perceived as financially, culturally, socially and morally below them (Shildrick and MacDonald, 2013, p.299; Garthwaite, 2015). Skeggs (1997) discusses this idea in relation to her study of women who made ‘disidentification from being positioned as working class’. In this study, those who did not identify with being working class also did not identify as taking on ‘the whole package of being middle class’ (Skeggs, 1997, p.93). Therefore, in relation to ESA claimants, it is important to consider the nuances between the identity’s interviewees chose to accept and reject.

In this thesis, the distinction between ‘us’ and ‘them’ is not only apparent when considering those who are in work and those who are not, but also when considering those who are deemed as ‘deserving’ or ‘undeserving’. Many interviewees often distanced themselves when discussing perceptions of claimants by discussing this in terms of ‘they’ – *‘they are perceived to be scumbags’* (James). As claiming benefits was identified as synonymous with ‘being lazy’ and the ‘scrounger’ rhetoric, claimants detached themselves from this by identifying these people as ‘other’ to themselves. James’ use of ‘they’ shows resistance and distances him from the ‘other’. This narrative reflected the idea of ‘them and us’ (Hills, 2015) which is arguably influenced by the myth that welfare provision excessively helps the minority of those who are ‘economically inactive’.

However, it is important to note that a number of interviewees also showed acceptance of collective identity or group when using ‘we’ to describe the stigma attached to benefit receipt:

> *‘we get trapped in that same bracket as just people that refuse to work so I don’t think there’s a positive view’* (Steve).

Although establishing a collective identity, Steve still acknowledged the ‘scrounger’ rhetoric when identifying those that refuse to work. This, therefore, reinforced and maintained the negative stereotypes attached to claiming ESA, by implying the presence of non-deserving recipients.

A significant example of this was when Maria, who was declared FfW following multiple assessments and appeals disclosed that she had ‘shopped’ someone who she had perceived as fraudulently claiming ESA. As evidenced in this interview extract:

> Maria: *Unfortunately that’s, for me that could be because some, many people are actually scroungers, they actually don’t work, they just claim benefits whether or not they are entitled to it and stuff like that and they tar everybody with the same brush. Just because somebody bad has done it doesn’t mean everybody else has.*
>
> Interviewer: *Do you think that there are many people who are actually legitimately sort of ‘playing the system’?*
>
> Maria: *Yes, oh yeah, I shopped somebody the other week.*

> Interviewer: *Oh really?*
>
> Maria*: I did, nobody in here*
>
> Interviewer: *So you've encountered people who are?*
>
> Maria*: Yeah, I mean I don't begrudge anyone getting what they are entitled to but when a person gets it and they are not entitled to it whatsoever and I can't get nothing its…*
>
> Interviewer: *Frustrating?*
>
> Maria: *So I'm sorry but I kept me gob shut for a long time and I just enough is enough I've done it.*

Maria had also mentioned that she felt she had been unfairly treated when she was refused access to ESA and encouraged to instead apply for JSA. This potentially had been a contributing factor in her decision to 'shop' someone she perceived as undeserving. The significance of people claiming ESA fraudulently was internalised by Maria who made multiple references to the 'other'.

Another, characteristic which interviewees mentioned in relation to the perceived 'other' linked to the 'responsible' behaviour of claimants. This linked to ideas around behaviours such as alcohol and drug use and criminal behaviour, being characteristics of the 'bad' benefit claimant.

> *'there is a small minority who are happy to sit on their arse drinking their cans'* (Katie).
>
> *'there was a guy on that again one of those benefits programmes and he was smoking loads and he was drinking he was like yeah, yeah I'm not working cos I'm depressed and this that and other…and I just thought there's a lot of backlash with that and you're now tarring me with the same brush and I don't do that, I don't go rob people'* (Sally).

Both Katie and Sally noted these behaviours as being undesirable and dissociated themselves with the minorities who had been perceived as doing so. Katie also made reference to the stereotype relating to being ‘lazy’ and ‘feckless’, reflecting the negative rhetoric within the mainstream media (Briant *et al.*, 2011). Fred reinforced this idea of perceived irresponsible behaviour when comparing levels of benefit receipt:

> *‘Some of us are trying to get back to work and just survive and just live this normal life rather than spend money on drugs, alcohol and cigarettes… it’s just like well why don’t I get this extra money for I don’t know shopping and things like that? Why do they get it for their alcohol when they’re just destroying their insides and doing the drugs’* (Fred).

As discussed in chapter six, the tensions between what is perceived to be a legitimate use of benefit money or not can be associated with discussions around claimants’ right to a good standard of living.

The presence of ‘othering’ among benefit claimants was also evidenced by a number of the KI interviews, with each informant mentioning service users engaging in the process to varying extents. This was usually about a service user comparing their own situation to others that they had seen in the local neighbourhood or within social networks. One common example of this was described by an Information Officer at a disability charity:

> *‘what I always say to people because it happens a lot…People come in and they go ah there’s the alchy he’s at the bottom of the street and stuff and I always say to them yep you know it is really bad if that happens, apparently, it’s only 0.5% of people who are actually committing benefit fraud which isn’t widely known at all is it? But also, it’s when you don’t know what happens behind closed doors, you know you don’t know what a person’s situation is when you’re just seeing them in the street occasionally’* (Information Officer).

The Information Officer’s narrative depicted just how prevalent the process of othering is amongst disabled benefit recipients, which reflected and reinforced the negative stereotypes attached to the claimant identity surrounding ‘fecklessness’ and the ‘workshy’. By claimants distancing themselves from this identity this, in turn, reinforces the negative connotations associated with it, simultaneously rejecting and reinforcing the process of stigmatisation of disabled benefit recipients.

In addition, a minority of claimants discussed ‘the other’ when referring to other minority groups, specifically immigrants:

> *‘I mean when you get people quite often like abroad coming to this country, they seem to getting anything and everything they want’* (Richard).
>
> *‘Some people that come in from other countries they kind of expect it and they get it near enough straightaway’* (Fred).

However, this was not a common theme amongst those interviewed and this rhetoric was only evident in three of the thirty-six ESA claimant interviews.

It is important to note that not every claimant interviewed engaged in the process of ‘othering’ in relation to the distinction between ‘deserving’ and ‘undeserving’. A number also referred to the scapegoating of disabled people that focused on the small minority who were committing benefit fraud to influence political rhetoric and policies. These views were more prevalent from the interviewees who were currently politically active.

This section has considered how interviewees engage with the process of ‘othering’ in the aim of distancing themselves from those who are perceived as ‘undeserving’. It has explored how the tool of disidentification was used as a potential means of negotiating their ‘spoiled identity’ (Goffman, 1968) and constructing identities that distance themselves from the significant stigma attached to claiming disability and health-related out of work benefits such as ESA. Arguably, this has the potential to further reinforce the negative stigma attached to ESA receipt by acknowledging the importance of ‘deservingness’ and the presence of the ‘other’.

## 7.9 '*I give the perception that I'm* okay': Negotiating the '*Spoiled Identity'*

As evidenced by both Richard and Luke's case studies (See sections 7.4.2; 7.4.3), the desire to be identified as 'normal' meant that they often denied or downplayed their impairment and its effects. The process of adapting behaviour to conceal discreditable attributes and meet the perceived societal norms was also reflected by both Beth and Ruth when stating that:

> *'So you try and hide it as much as possible and then when you actually need to talk about it, it's like, oh no, everything's fine'* (Beth).
>
> *'But I give the perception that I'm okay because I laugh, and I joke and I'm fine and I won't put people out. I don't play the martyr card. I don't play, I've got an illness card'* (Ruth).

Ruth, who had multiple chronic conditions, identified this in the sense she did not want to 'play the martyr card' linking to disabled people being deemed as victims of circumstance (Marinelli and Dell Orto, 1999). She rejected the assumptions of the tragedy model and the way this could influence her perceived identities. This 'downplaying' of impairment effects reflects the 'adaptive techniques' (Goffman, 1968) that individuals use to divert attention from stigma. Therefore, it was evident that some interviewees would use these strategies to attempt to conceal their discreditable and discrediting attributes to disassociate from their 'spoiled identity' (Goffman, 1968).

This section has considered one way in which interviewees dealt with stigma through normalising. This is closely linked to disclosure, which is the focus of the next section.

## 7.10 '*You live a lie'*: Disclosing the Claimant Status

Similarly, to their disabled identities, several claimant interviewees were reluctant to disclose their benefit status to others:

> *‘it’s just my close friends and family who know I claim benefits… well there are people locally who disapprove of people who are on benefits, you know and they say quite nasty things but they’re not amongst my friends…they’re even a couple of members of my family who are, well they read Daily Mail you know erm and the telegraph who I’ve heard through other family members say awful things about people who get disability benefits’* (Tracy).

Tracy discussed personal challenges in revealing her ‘claimant status’. These tensions were reflected in both de Wolfes study (2012) and Garthwaite’s study (2015a) which both considered the stigma attached to both disability and benefit status. Garthwaite (2015a) argued that the reluctance to identifying with the ‘claimant identity’ was highly problematic for long term sickness benefit recipients as they faced increasing social exclusion and isolation.

It is important to consider the process of dual stigmatisation as often both benefit status and ‘disability’ status impact how interviewees self-identified. Goffman (1968) neglects to notably mention the influence this can have in shaping the identities of individuals with more than one ‘discrediting attribute’. However, his analysis can explain how both avoiding the disclosure of benefit status and concealing of impairment effects can be used as tools of ‘stigma management’ (Goffman, 1968).

The idea of hiding a claimant identity was also reflected by Ruth, who discussed the challenges around this:

> *‘You have to invent a life. You have to… I’ve learnt to be very good at switching the subject because I don’t want people… I don’t want to have to say, this is my life. I’m still not at that point where I can turn around and say, yeah, I do one day here and there. And I can’t say it anyway because there’s too many people out there waiting to look at me and say, well, there’s nothing wrong with you, you was here today, so, therefore, you must be a right scrounger, I’m gonna grass you up. So constantly, you live this life…you live a lie’* (Ruth).

Both rejecting and hiding the claimant identity can lead to the risk of social exclusion (Garthwaite, 2015). This is experienced not only through personally hiding information and disclosure to family and friends but additionally distancing themselves from other disabled people who chose to identify as such.

On a practical level, in relation to accessing welfare support, this raised issues in relation to the WCA where claimants felt pressures to ‘present at their worst’ to be awarded ESA (Garthwaite, 2014) (see chapter five). These strategies of negotiating their ‘spoiled identity’ (Goffman, 1968) and reframing how both themselves and others perceived them act as mechanisms to reject stigma. This was in relation to the stigma of either claiming benefits, being disabled or, more often, a combination of both these characteristics which were perceived as discrediting.

## 7.11 Conclusion

This chapter has explored claimants lived experiences of the stigma attached to claiming ESA and how claimants negotiate their ‘spoiled identities’. It has considered the processes disabled claimants go through to navigate their identities.

Claimants went through a myriad of processes when constructing and negotiating their own identities. This process was often negotiated in a way that aimed to reduce the perceived stigma and therefore challenge the ‘spoiled identity’ or distance themselves from ‘discrediting attributes’. Stigma was still a significant issue in relation to both disability status and benefit status, leading to increasing levels of internalised shame and even in some cases questioning of one’s own legitimacy, through the co-production of being shamed and feeling shamed. Claimants challenged and resisted the perceived stigma, most notably through denial of disability status and normalisation of impairment effects. However, this often reinforced the medicalised view of disability by positioning it as a negative attribute to be disassociated with.

A key consideration of this chapter was the exploration of how stigmatisation is experienced and the notion of the ‘spoiled identity’ (Goffman, 1968). Claimants attempted to conceal their claimant identity in order to move away from the ‘spoiled identity’ (Goffman, 1968) by rejecting or hiding discrediting attributes such as claimant and disability status. Additionally, claimants often delegitimised the ‘other’ which was identified as claimants deemed less ‘deserving’ of their ESA entitlement. The acceptance or rejection of either identity often reflected a claimant’s level of political engagement. A typology is presented which is a useful tool for understanding the way in which interviewees constructed their own identities in relation to their understandings of what it meant to be both an ESA claimant and a disabled person.

Interviewees often rejected the mainstream stereotypes attached to claiming benefits but also significantly constructed them as the ‘other’ and agreed that there are some people who are ‘fraudulent’ and therefore often felt the need to distance themselves from the perceived other. Thus ‘othering’ did not just occur between those who are working and those who are not, but also on a subtler level. This level makes the distinction between the ‘deserving’ ESA recipients (those who are perceived to be genuinely disabled and unable to work) and the non-deserving (those who are thought to be ‘playing the system’ or ‘putting it on’). The presence of the ‘other’ allowed claimants to use the process of ‘disidentification’ to establish their own identities. This meant they often chose to construct their identities based on who they are not the perceived ‘other’.

# Chapter Eight: Discussion and Conclusion

## 8.1 Introduction

This chapter brings together the study by outlining the key findings from chapters 5-7. It first reviews the research objectives and provides a summary of the thesis chapters. It then presents a discussion of the primary findings, beginning with the findings which demonstrate a new and original contribution to existing academic debates around disabled people's experiences of engaging with the welfare system. This is explored in relation to three key aspects; the institutional violence that is enacted by the state, the impact welfare policies have on claimants' citizenship status and how the welfare system influences disabled ESA claimants' identities.

It then addresses each research question and then situates the findings within the broader literature base to then identify areas for future research. It outlines recommendations for the future research agenda and highlights important implications for future research.

Finally, it outlines key policy recommendations for the future of welfare provision for disabled people, crafted through listening to the direct experiences of those hardest hit by the flaws in the current system.

## 8.2 Review of Research Objectives

This study aimed to answer: 'What are the lived experiences of disabled ESA recipients?'. To achieve this aim, three research questions were identified (see chapter four):

1. What are the lived experiences of disabled people when encountering the conditional welfare system? [RQ1]

2. How does the process of engaging with this system impact disabled people's identities and wellbeing? [RQ2]

> 3. To what extent is there a gap between policy provision for disabled people, and the lived experience of *being* a disabled person within the conditional welfare state? [RQ3]

Lived experience was utilised in this research as a way of responding to ‘not only to people’s experiences but also to how people live through and respond to those experiences’ (Boylorn, 2008, p.490). The study’s focus was initially centred particularly on people’s experiences of welfare conditionality, however, when reflecting on the approach it felt impossible to isolate the research to focus to one particular aspect of the raft of changes that disabled people were experiencing. Although welfare conditionality is a theme of the findings, this needs to be understood in relation to the overall punitive system and the range of policies that are enacted and impact disabled people’s lives.

This section recapped the research objectives and outlined the shifts in focus that impacted on the initial approach. The next section presents an overview of each chapter, before discussing the key findings this study presents.

## 8.3 Summary of Chapters

Chapter one outlined the background and objectives of the study. It set the scene and identified the importance of this research. Chapter two then largely drew upon Drake’s (1999) approaches to disability policies. These approaches framed a chronological overview of welfare policies relating to disabled people in the UK. Chapter three presented the existing literature in the field and discussed the concepts of citizenship, identity and violence which are utilised in the findings to understand people’s lived experiences of the current system. It specifically drew upon Morris’ (2005) tenants of citizenship, Goffman’s (1968) conceptualisations of ‘spoiled identity’ and emerging literature which frames welfare policies within the context of violence (Cooper and Whyte, 2018). Chapter four then discussed the chosen methodology and provided a reflexive account of my experiences of being a disabled PhD student.

Chapters 5-7 presented this study’s research findings by focusing on three overarching issues. Chapter five presented interviewee’s narratives of their lived experiences of the claiming process. This largely focused on their experiences of engaging with the punitive system and how it was experienced as violent. It also reflected on the barriers to self-determination, participation and contribution which were clearly embedded within current approaches to social security. Chapter six drew upon the concept of citizenship and presented findings about interviewee's views of reciprocity and the challenges they face to citizenship as a disabled ESA claimant. Chapter seven then explored findings on how interviewees constructed and negotiated their identities, specifically in relation to managing their 'spoiled identity' and 'discrediting' and 'discreditable' attributes (Goffman, 1968). It then presented a typology for understanding the way political engagement interacts with acceptance or rejection of the 'claimant' and 'disabled' identities.

This section has presented an overview of the chapters within this thesis. The following section now provides a discussion of the key findings from this study. It demonstrates their contribution to the current field and addresses the main objectives of the research.

## 8.3 Discussion of Key Findings

When synthesising the research findings to address the key objectives of this study, it was apparent that the first two objectives: 'What are the lived experiences of disabled people when encountering the conditional welfare system?' [RQ1] and, 'How does the process of engaging with this system impact disabled people's identities and wellbeing?' [RQ2] are significantly interlinked. The findings clearly demonstrate how people's lived experiences are characterised by engaging with a punitive system that has significant adverse effects on their wellbeing (see chapter five). Therefore, the discussion of key findings below addresses both these objectives, before finally exploring the objective: 'To what extent is there a gap between policy provision for disabled people, and the lived experience of *being* a disabled person within the conditional welfare state?' [RQ3].

### 8.3.1 Evidencing the Violence of Welfare: Beyond Structural Violence

When exploring RQ1, it was clear that interviewees experiences were characterised by not simply engaging with a 'conditional' welfare system but a 'punitive' welfare system. This consequently had a significant impact on interviewees identities and wellbeing [RQ2]. Interviewees' narratives described 'feeling punished' and clearly demonstrated what Cooper and Whyte (2017) conceptualise as institutional violence. This was particularly pertinent when describing their experiences of attending the WCA and being sanctioned (see chapter five).

> *'It's an interrogation now. It's not an assessment because the agenda is to fail you the minute…They just attack, attack, attack, attack. And on one assessment they said to me, I couldn't be feeling suicidal 'cause I didn't action it'* (Ruth).

A key strength of this research is the contribution it makes to the growing empirical evidence base on the institutional violence (Cooper and Whyte, 2018) enacted on disabled people by the state. As discussed in chapter three, previous studies conducted by Garthwaite (2014); Patrick (2017) and Baumberg et al. (2012) have provided an insight into disabled people's experiences of being a 'welfare claimant'. Additionally, Cooper and Whyte (2017; 2018), Mills (2018) and Grover (2018) focused on the macro conceptualisations of institutional and structural violence. This study synthesises these bodies of work to draw the links between the narratives of disabled people and the conceptualisation of institutional violence. This thesis, therefore, emphasises the narratives of those experiencing such violence and illustrates how claimants articulated their awareness of this process occurring. I argue that disabled people have faced and continue to face institutional violence as the hands of the welfare system.

As discussed in chapter three, Cooper and Whyte (2018) use the term 'institutional violence' and argue that 'structural violence' does not fully explain a series of decisions made by actors that lead to violent outcomes. Using this as a theoretical lens, I argue that although structural violence has a significant impact on disabled people's lives; it fails to reflect the series of decisions made by the UK Government that have enacted violence on those requiring social security. Despite disabled people campaigning and lobbying for change; decisions have and continue to be made that enact violence against disabled people.

‘Decisions that result in violent outcomes’ (Cooper and Whyte, 2018, p.2) are illustrated in a number of policy decisions that impacted this study’s interviewees. Therefore, it is not one single act of violence, but a cumulative series of decisions that led to the deterioration of disabled people’s rights, wellbeing and identities. Key decision points where this can be clearly evidenced include; the implementation and outsourcing of a stricter WCA to private contractors, the increased levels of conditionality and, particularly the use of sanctioning for non-compliance with work-related activity.

> *'Institutional violence [is used] to identify precisely how particular public and private organisations have delivered acute physical and psychological harm, and have caused untold injury and death by administering austerity policies’* (Cooper and Whyte, 2018, p.2).

These decisions are made against the backdrop of divisive populist rhetoric (Briant *et al.*, 2011; Jensen and Tyler, 2015). This reinforces a climate of ‘othering’ and illustrates a veiled form of violence which promotes division between those identified as ‘deserving’ or ‘undeserving’. However, it is important to note that several interviewees were acutely aware of the ‘attack on disabled people’ (Pring, 2017) and could not be described as passive victims of such violence. Several interviewees also had complex and contradictory views on ‘deservingness’ which meant that often they would take on or deflect this violence too.

The empirical evidence in this study demonstrates how violence manifests at several levels. Firstly, it can be understood at a macro-level through the governance and policies that reflect the ‘control’ approach to disability policies, as described by Drake (1999) and enact punishment at an institutional level. Interviewees demonstrated how such governance was internalised, and then manifested in various self-governing behaviours. For example: interviewees who 'concealed' their claimant status, interviewees who played the role of 'needy' to ensure benefit entitlement and interviewees who enacted surveillance of those perceived as 'undeserving' (see chapter seven). This can be understood in terms of Wacquant's (2009) theory of 'lateral denigration' whereby they,

> *'demarcated themselves from their neighbours and reassigned onto them the degraded image that public discourse gives them'* (Wacquant, 2009b, p.117).

This manifested in a more nuanced level of violence whereby interviewees would reinforce popularist narratives and effectively 'turn on each other' to distance themselves from the perceived 'discrediting attributes' (Goffman, 1968). This reflects what Shildrick and MacDonald (2013) argue are 'discursive devices deployed to protect the self from social and psychic blame' (p.301).

However, several interviewees demonstrated active resistance to these behaviours, challenging the dominant narratives and engaging in political activism to oppose the violence of the system. Overall, this research illustrates how violence manifests in often complex and contradictory ways. This means that disabled people can mobilise, but also, turn on each other.

The importance of rejecting the identity of 'feckless' or 'workshy' was a significant element alluded to by interviewees when discussing stigma, as reinforced by Shildrick and Macdonald (2013). Rejecting this identity was greatly important to the majority of those interviewed, who continually emphasised the desire to work (see chapter six) and the impact of their impairment or health condition on their ability to do so. Consequently, they rejected the stigmatised claimant identity but also attempted to validate their 'deservingness' and thus the genuineness of their impairment. This links back to Goffman's (1968) 'undesired differentness' and the processes individuals go through to distance themselves from attributes perceived as 'discrediting' or 'discreditable' (see chapter seven).

The use of sanctions was perceived as a way of punishment and this study showed no examples where it was an effective mechanism of moving people into the labour market. The financial constraints of the system, including but not limited to sanctioning, evidenced the opposite impact whereby people were unable to meet their health-related needs moving them further away from employment. For example, John who was unable to hoover and clean his linen as regularly to deal with his chronic allergies and eczema, substantially increasing his risks of anaphylactic shock (see chapter six). Reflecting on [RQ2], this shows a clear example of how the financial impact of welfare policies impacted on a claimant's wellbeing and ability to manage their health conditions. This disconnect between policy approaches and the outcomes experienced by claimants is discussed further in a subsequent section.

This section has considered how the findings demonstrate the institutional violence against disabled people through reforms to social security in the UK. I argue that punitive welfare policies are not simply inappropriate but rather, an insidious tool seeking to reduce welfare expenditure at any cost. Politicians have utilised popularist rhetoric to reinforce welfare myths to both justify dramatic changes to social security and remove government culpability. As discussed in chapter five, this is not something people are passive victims to, but people are acutely aware of and take on various strategies to defend themselves against this process.

### 8.3.2 Barriers to Self-determination, Participation and Contribution

Although interviewees expressed the importance of 'giving back', experiences of the system implemented and reinforced contractualist notions of citizenship (see chapter three). Morris argues that 'full citizenship involves the exercise of autonomy' (Morris, 2005, p.6) and self-determination, participation and contribution are central to ensuring disabled people secure full citizenship. The narratives from disabled claimants in this thesis demonstrate several barriers the welfare system poses to exercising self-determination, participation and contribution.

The WCA, inappropriate employment support and fear of sanctions clearly reduced disabled people's ability to exercise self-determination. This was particularly challenging for those interviewees who perceived the removal of entitlement as the main policy goal of welfare reform, leaving them feeling powerless to pre-determined decisions. Self-determination was further limited when claimants had to stop engaging in individually sought out work-related activity to engage with inappropriate compulsory training for fear of sanctioning.

Claimants experienced barriers to meaningful participation within wider society due to the stigma attached to benefit receipt and the insufficient amount of ESA awarded. Interviewees emphasised the importance of contribution, however, noted that this should not be limited to economic activity and needs to be flexible and appropriate to the individual. Although the majority of claimants interviewed desired employment, the current system failed to provide appropriate, personalised employment support and suitable job opportunities.

Within the wider context of contribution, interviewees described disclosure of impairment and unequal availability of employment opportunities as a key issue when applying for jobs. As discussed in chapter two, despite significant legislation to combat this, such as the DDA (1995) and The Equality Act (2010), this demonstrates the need for stronger investment in the removal of disabling barriers to employment.

### 8.3.3 Negotiating Identities and Political Engagement

Chapter 3 demonstrated the complexity and fluidity of identities. Chapter seven presented empirical data that illustrated the range of ways in which interviewees managed and negotiated their identities as a disabled ESA claimant. An emerging theme which influenced how people identified was political engagement. This research shows that political engagement was a contributing factor when accepting the ‘claimant’ or ‘disabled’ identity. Those who identified as such often engaged in ways of challenging and resisting the ‘attack on disabled people’ (Pring, 2017).

This was an unexpected theme and not initially a key area of focus of this study. Participant’s narratives provided evidence that demonstrates the interconnection between political engagement and identity acceptance. As illustrated in chapter seven, the typology provides a practical tool for future understanding.

It was evident that even when disabled claimants tried to resist the punitive actions enacted on them and have a political voice, they were still subject to the constraints of disabled ‘performativity’ (Dorfman, 2016) - whereby if they do not engage in the ‘victim role’, they do not get any support. Interviewees noted that their experiences of the system were influenced by whether they had a hidden impairment, such as a mental health condition. In some instances, claimants with ‘discreditable’ attributes were obligated to expose this to justify their entitlement to welfare support, both in the welfare setting and publicly. Without a reconceptualization of disability that considers the temporal, cyclical and permanent issues of disability, pushing disabled people to the margins will continue.

This section has considered the relationship between political engagement and acceptance of identities. The following sections consider how the process of claiming welfare support was enacted at a ground level and experienced as violent.

### 8.3.4 The Inaccurate and Inappropriate WCA

Interviewees’ experiences were embedded within a society which devalues and delegitimises disabled welfare claimants. The process of the WCA itself was not only inappropriate in assessing need but the premise of assessing ‘work-readiness’ fails to address the complexity of people’s lived experiences of being disabled. Moreover, the WCA is based on a problematic assumption that people do not want to work which was not the case for the majority of interviewees. Interviewees discussed the experiences of several structural barriers to employment, which are not accounted for within the current assessment process. This study strongly reinforces arguments that conditionality is an inappropriate tool for disabled people (Patrick, 2011b).

Interviewees discussed the flaws within the current process and often demonstrated an acute awareness that its purpose was to remove entitlement. This increased claimants’ anxiety in the build-up to the assessment and added additional stress to the process which was lengthened through the appeals process.

A number of interviewees also questioned the accuracy of the assessment reports and outcome. Accounts showed that there was a disparity between the experiences of the WCA and what was reported back by the HAP. Although, this could have been dismissed as an administrative error, most claimants and KI's viewed this as a deliberate misrepresentation of the assessment.

Assessors carrying out the WCA were largely described as impersonal or resembling 'robots', their role could be viewed as administrative rather than to understand people's experiences of impairment or health conditions. As well as acting as a barrier or gatekeeper to welfare entitlements, it was commonplace for them to ask inappropriate and highly personal questions which often impacted claimants' health and wellbeing whilst awaiting, undergoing and following their WCA. The approach combined with such questions often made assessments feel dehumanising and a stage for defending, rather than explaining or understanding.

These findings add to existing academic debates (Barr *et al.*, 2015) about the harm of the WCA and highlight the need for a new approach to assessing entitlement, specifically in relation to claimants mental health and wellbeing. The devolved Scottish Government have terminated such assessments within the elements of social security they control (see chapter two). This provides useful learning for the rest of the UK to understand the wide-scale impact that this could have.

This section has discussed the findings around the claiming process which directly relate to [RQ1] and [RQ2]; the following section discusses the findings about the inappropriate support offered to those engaged with the JCP and the WP.

### 8.3.5 Experiences of Poor Work-Related Support

Interviewees described support as 'limited', 'inappropriate' and conditional. There was an evident trade-off between employment-related support only being made available to those who had imposed conditions attached to their benefit receipt (see chapter five). Those in the ESA SG, whereby conditionality was not present, were offered no support to engage with employment. This presented a conflicting view from interviewees, with some noting they felt lucky to be ‘left alone’ but others feeling ‘left on the shelf’.

When people engaged with work-related activity, this was only perceived as meeting work-related requirements if it was prescribed activity through the WP. This was despite WP activity often being deemed as inappropriate. A clear example of ‘counterproductive compliance’ (Dwyer *et al*. 2018) was given by an interviewee who had independently sought out his own work-related training and was forced to terminate this activity so that they could meet the requirements of the WP (see chapter five). This undermines claimants’ self-determination and contradicts policy goals, which aim to reduce ‘dependency’ culture and promote ‘individual responsibility’ (Cameron, 2011).

As discussed in chapter five, these findings clearly demonstrate that conditionality was present within interviewees’ experiences; however, interviewees experienced a binary trade-off between access to inappropriate support and mandatory conditions or zero support and no conditions.

### 8.3.6 The Disconnect between Policy Approaches and Lived Experience

The final research objective was: ‘To what extent is there a gap between policy provision for disabled people, and the lived experience of *being* a disabled person within the conditional welfare state?’ [RQ3]. This study’s empirical data clearly demonstrates a significant disparity between the articulated policy aims and how claimants experience the welfare state. This section illustrates the fundamental differences between what is outlined in Government and DWP policy documents and, the outcomes experienced by disabled welfare claimants. In this section, two significant policy documents, ‘Universal Credit: welfare that works’ (DWP, 2010) and ‘Improving Lives The Future of Work, Health and Disability’ (DWP, 2017b) have been drawn from to illustrate relevant policy approaches alongside narratives from those interviewed in this study to show how such policy approaches are experienced.

In relation to the WCA, DWP (2017b) state that:

> *‘We want the individual to experience a streamlined assessment process – enabled by secure, timely sharing of relevant data between benefits systems, an appropriate reassessment regime for those with severe conditions, and a personalised approach which helps people access the right support’* (p.21).

As discussed in chapter five, claimants often experienced a very different assessment process, which in contrast, featured long waiting times paired with increased anxiety. Claimants often feared the reassessment process and felt that the assessment was neither personalised nor appropriate to meet their needs, as portrayed in the narratives below.

> *‘[The assessment] is a bit of a farce because it’s not taking into account the whole person’* (Robert).

> *‘literally, all we’ve got is a standard format, a ticky-box exercise on a computer screen’* (Specialist Welfare Officer).

The DWP (2017b) subsequently stresses the importance of personalised employment support being available to those who require it, including those people who have fluctuating and complex conditions.

> *‘We want individuals to receive personalised employment support which is flexible to their needs and based on discussion and consideration of the reasons behind why they may be unable to work’* (p.18).

Narratives from this study show significant contrast between this aim and how employment support is delivered and experienced. The appropriateness of the employment support available, which was often mandatory for claimants, was a key theme. The standardised nature of training often failed to account for an individual’s previous experience, education, preferences and skills.

> *‘they give a one size fits all training, so I’ve got people who’ve got a degree and post-graduate qualifications have been oh ‘Do you know what a CV is?’* (Team Leader).

Policy approaches also emphasise the importance of positive relationships between staff delivering employment support and claimants receiving support. The DWP (2017b) states:

> *'We want customers to experience a positive relationship with well-trained work coaches, who have access to additional and specialised knowledge'* (p.16).

Conversely, this study found that work coaches and DWP staff did not have the training and specialised knowledge to support claimants move back into employment.

> *'In the end the man at [WP Provider] actually said to me that he trusted me to look for work erm and that he didn't think he could help me anymore and that he would just leave me to it'* (Tracy).
>
> *'Well I stopped going after the last time I was there, the employment adviser said that I probably know more about disability employment advice than they did'* (Steve).

Further policy rhetoric suggests that support should be available for those claimants deemed as furthest away from the labour market, including people placed in the ESA SG.

> *'We want everyone in the Support Group to have the opportunity to access personalised, tailored and practical employment support on a voluntary basis - when they want or need it'* (DWP, 2017b, p.22).

This study, however, found examples of very minimal support available to people who were eligible for the ESA SG. As discussed in chapter five, the support group was often experienced as being unsupportive.

> *'[on being placed in the SG] it might as well have said, don't worry, we are not going to bother you anymore, you're a lost cause in so many words. Sorry, like, but yeah you're right, you are incapable and we are not going to bother you anymore and there is nothing more we can do for you and this is how much you are going to get, so bye bye, we'll not bother you for another 100 years – that's what it felt like anyway'*(Julia).

Finally, welfare reform was justified within policy rhetoric as a way of making the social security system fairer, whilst maintaining support for those perceived as the most vulnerable in society.

> *'The Government is committed to reforming the welfare system to make it fairer, more affordable and to tackle poverty and welfare dependency, whilst continuing to support the most vulnerable in society'* (DWP, 2010, p.6).

Claimant narratives from this study show a clear distrust in the Government's commitment to creating a fairer system and instead often see it as a mechanism of punishment. This is particularly noted when people experience the process of the WCA and sanctioning regime:

> *'It's an interrogation now. It's not an assessment because the agenda is to fail you the minute…They just attack, attack, attack, attack. And on one assessment they said to me, I couldn't be feeling suicidal 'cause I didn't action it''* (Ruth).
>
> *'…for people who are a victim of a sanction, it's horrendous because how are you gunna sustain that? How are you gunna feed yourself? How are you gunna pay for your bills?'* (Specialist Welfare Officer).

Despite the Governments commitment to supporting the 'most vulnerable', the system currently fails to achieve this commitment. Instead, narratives from disabled claimants highlight how the welfare system limits people's ability to exercise self-determination, participation and contribution, therefore, eroding their citizenship. Furthermore, the system can be experienced as violent rather than supportive, with appropriate support being replaced with punishment for non-compliance.

The stark contrast between articulated policy goals and the lived experiences described show the need for an overhaul of how social security is developed and delivered. There is a need for a rights-based approach to both work and welfare to enable disabled people equal access to the labour market and access to social security that reflects the temporal, cyclical and permanent nature of disability.

Social Security policy, therefore, needs to be based on and fully rooted in disabled people's lived experiences.

### 8.3.7 The Importance of a 'Lived Experience' Lens

As discussed in chapter four, understanding disabled people's lived experiences was a key consideration of this study. The importance of understanding not simply what claimants experienced, but also how they experienced engaging with the punitive welfare system was of central importance to this research. The adoption of this approach ensured peoples voices and subjective experiences of engaging with the system were central to the findings of this thesis.

Wright and Patrick (2019) argue that the adoption of lived experience led approaches to social research can be a mechanism of elevating the significance of lived experiences and creating a 'shared typical' (McIntosh and Wright, 2018). They argue that this is particularly pertinent when policy-makers are reluctant to learn from the increasing evidence base which illustrates the lived experiences of welfare policies.

In this thesis, the adoption of lived experience conceptually helps to demonstrate the devasting and emotive human impacts that disabled welfare claimants experience when interacting with the welfare system. Furthermore, it adds to the 'shared typical' evidence base that demonstrates the detrimental impact claimants experience at the hands of the UK welfare system.

### 8.3.8 Reflections on the Findings

This study aimed to understand disabled people's experiences of engaging with the conditional welfare system. The narratives weaved throughout this thesis often make for uncomfortable reading. Although interviewees reinforced the need for support to conditional on fulfilling certain requirements, in practice, these experiences of the welfare system demonstrated no positive outcomes. This is paired with claimants' feeling a deterioration of their citizenship status and feelings of significant avoidance with the 'claimant identity' due to the perceived stigma.

When considering [RQ2], it is clear from the narratives that claimants regularly experienced a deterioration in their physical and mental wellbeing and through engaging with the system. For those who were in the ESA SG, several people reinforced the potential for harm that conditionality could bring when describing themselves as ‘one of the lucky ones’ (see chapter five). The detrimental impact on claimants’ identities was also evident, especially as interviewees negotiated their identities to ‘act out’ and resist certain roles (see chapter seven).

This study has developed over a number of years (2013-2019), thus policy has considerably changed during this period. Within this time, there have been two governments, under three leaderships, with each successive cabinet shuffles and reshuffles each reformulating the welfare problem. Consequently, analysing a continually evolving policy is difficult to address. However, what has continued to be a similarity within policy and governments over this period is their approach to welfare, disabled people and the increased use of conditionality. This is despite evidence against the effectiveness and ethicality of welfare conditionality (Dwyer *et al.*, 2018) and the increased prevalence of suicide amongst disabled people associated with austerity measures (Barr *et al.,* 2015; Mills, 2018).

Although primarily focusing on disabled people claiming ESA, the key arguments this thesis makes cannot be isolated to one particular policy or type of benefit but allude to a much greater issue around the ethos underpinning conditional welfare policies, which is consequently enacting a level of institutional violence against disabled people. The DWP's *‘Improving Lives: The Future of Work, Health and Disability’* (2017b) paper outlined, ‘the government’s commitment to see one million more disabled people in work over the next 10 years’. Based on this commitment, policies continue to be focused on work as the best route out of poverty. Welfare policy, and how it is enacted, is just one element of how disabled people experienced *being* an ESA claimant. The societal context which is overwhelmingly laced with rhetoric surrounding ‘dependency’ and polarises those who are perceived as economically contributing or not, justifies a climate of punishing those deemed as ‘undeserving’. Government and populist media communications reinforce this view, with disastrous impacts on those it identifies as the ‘undeserving’ ‘other’. The implementation of UC is a further increase in conditional welfare policy with an even higher prevalence of sanctioning. In fact, the Scottish Government's Review of Welfare Reform (2018a) stated that:

> *'Claimants of UC were more than six times as likely as claimants of either Jobseeker's Allowance, Employment and Support Allowance (ESA) or Income Support to be sanctioned'* (Scottish Government, 2018a, p.49).

Overall, the issues interviewees identified through their experiences rest on the flawed policy assumptions underpinning welfare conditionality. Processes and policies built upon these assumptions are therefore intrinsically destined to not achieve the goal of 'activating' people, as I that activation is not the problem. However, as this notion has been articulated in large scale studies (Dwyer *et al.*, 2018) and the government approach remains fixed[12], I argue that welfare conditionality has a veiled goal, which centres on scapegoating those perceived as the least powerful, with the intention to reinforce social divisions and reduce financial outgoings at any cost. Critics (Mills, 2018; Grover, 2018, Cooper and Whyte, 2017; 2018) have discussed this process in terms of 'social murder', 'structural violence' and 'institutional violence'. This study advances this theoretical perspective by providing empirical evidence to substantiate this argument rooted in the experiences of disabled people.

## 8.4 Limitations and Areas for Further Investigation

This study provided an insight into the lived experiences of a group of disabled people claiming ESA. As this was only a small-scale study, there were relatively low numbers of interviewees who had experienced the most conditional aspects of the reforms, particularly those who had been placed in the WRAG or had experienced sanctions. The main recruitment methods -through gatekeeper organisations -meant that often those who participated were engaged in services and had either received support to access ESA or were placed in the SG. Attempts to engage participants who were placed in the WRAG or declared as FfW were often met with fear and caution by claimants who were anxious about their involvement impacting on their benefits. It was also clear that many

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[12] As discussed in chapter two, it is important to note that the devolved Scottish Government have made changes to challenge and end such policies.

people were experiencing stress and emotional distress in relation to interacting with the welfare system and unsurprisingly chose not to discuss this in-depth for this research. However, other recruitment methods adopted, such as engaging with disabled people's organisations and contacting people through social media, meant that the sample was potentially biased towards more politically active people. It is also fair to say that limited capacity meant that recruitment strategies may have not reached the most isolated people experiencing the reforms.

Future research would benefit from increased engagement with people most isolated and potentially detached from community support. The people I spoke to had often been engaged with support services within their local community. Several interviewees discussed struggling to navigate the system and experienced significant detrimental impacts; therefore, it would be reasonable to hypothesise that those who were further detached from support services would experience further disadvantage.

On reflection, minimal demographic information was collected about participants during the data collection period; collecting specific information about age, ethnicity and locality would have allowed for an investigation of how such demographics influence claimants experiences. From the demographic information collected; the majority of interviewees were based in the North East of England, a region within England that has the lowest rate of employment at 71% (ONS, 2019). A minority of interviewees were from across other areas of England and Scotland. Within this, people were mainly located in urban areas. The differences in experiences based on location was not a key consideration of this study, however, this may be a useful consideration for future research to understand how such policy is enacted locally and how this impacts people's experiences.

This study presented a new typology of the relationship between identities and political engagement. As political engagement was not a key consideration from the offset and emerged during the data analysis process it would be useful to examine this further and more systematically. A pilot of the typology would serve to understand how it can be best utilised to understand disabled welfare claimants' identities and additionally if the typology could be further adapted to understand other identity characteristics. Similarly, further research which considers this in relation to other factors such as claimants' class and education may develop a clearer understanding of the relationship between the acceptance of identities and levels of political engagement.

This study has identified significant issues for disabled people accessing the current welfare system. However, interviewees had a limited indication of what alternative policies and processes would look like. It is imperative that future research considers what an effective system would look like. This research should be co-produced by and for disabled people. Limited work has provided an insight into what this would look like, with a specific exception to Baumberg-Geiger's (2018) report and findings from the large-scale welfare conditionality project (Dwyer *et al.,* 2018).

## 8.5 Implications for UK Welfare Policy

Reflecting on both Drake (1999) and Oliver's (2003) approaches to disability policies outlined in chapter two; neither feel fully able to relate to the recent policies, experienced by interviewees in this study. There are clear parallels to Drake's notion of 'control'. Interestingly, policy rhetoric has adopted the terminology of 'citizenship' approaches, albeit just in the lexicon as approaches have simultaneously denied the human and citizen rights of disabled people (UN, 2017). Therefore, understandings of policy approaches must account for the use of policy as a mechanism of punishment to ensure compliance. Such approaches are often paired with inappropriate tasks to comply with based on flawed assessments of work-readiness.

The section below outlines three key recommendations for redeveloping welfare policies for disabled people in the UK. It is noted that the devolved Scottish Government have made strides towards challenging the UK welfare regime – therefore, recommendations predominantly relate to the current policies in place for the rest of the UK. The impact of the Scottish Government's approaches to social security offers an insight into how different approaches can be operationalised and the consequent impact of such approaches.

### 1) The WCA

It is important to note that since the time this research was carried out, the DWP ‘stopped re-assessments for those with the most severe conditions in ESA and UC’ from September 2017 (DWP, 2017b). This study suggests that reform of the WCA needs to be on a much greater scale to address the significant failings of the current assessment process.

The DWP should recognise that disabled people are experts on their own impairment and experiences. A new way of accessing entitlement should be developed that takes into account the fluid and unique experiences disabled people face within the context of a disabling society. This should be developed by disabled people, for disabled people.

This should challenge the current focus on work-readiness and follow a needs-based approach. It should have consideration of the structural determinants of unemployment, utilising a barriers focused approach to shift notions of culpability from individuals. Lessons can be learnt from the Scottish Government’s approach, whereby, they aim to reduce the number of face-to-face assessments required and no longer outsource the responsibility of carrying out assessments to the private sector (Scottish Government, 2018b).

### 2) Valuing Contribution

Morris’ (2005) citizenship approach provides an inclusive understanding of contribution. Disabled people should have the right to contribute in a self-determined way. Where paid employment is not possible, they should maintain the right to full citizenship. Policy should, therefore, aim ‘to secure rights and citizenship, and, where necessary, reconfigure the social and built environment’ (Drake, 1999, p.45). ONS (2017b) highlighted that unpaid carers provide social care worth £57 billion. Forms of contribution such as unpaid caring roles and volunteering should be deemed with the same level of importance as paid employment.

### 3) The Role of Sanctioning

Sanctioning is situated within the context of punishment (see chapter five), it does little to promote employment (Dwyer *et al.*, 2018) and more concerningly, often exacerbates existing physical and mental health conditions. This thesis demonstrates that the limited experiences of sanctioning had in fact moved people further away from the labour market, therefore showing a clear contradiction between the stated policy goals and outcomes. The use of sanctioning for disabled people should be stopped.

## 8.6 Conclusion

This chapter has reflected the key findings of this study. It has considered the contribution it makes to existing academic literature and identified policy recommendations which are underpinned by the lived experiences of disabled welfare claimants. It has also identified the limitations of this study and areas of future research that should be explored. I argue that this research has made three main contributions to the existing academic literature on disabled peoples experiences of welfare support. Firstly, it has presented robust empirical evidence that substantiates recent conceptualisations of 'Institutional violence' (Cooper and Whyte, 2017;2018). Secondly, it drew upon Morris' (2005) tenants of citizenship to demonstrate how the welfare system erodes disabled claimants' citizenship through limiting their self-determination, participation and contribution. Finally, it has developed a typology which is based on the relationship that emerged within these findings between political engagement and how people negotiate their 'claimant' and 'disabled' identities.

Every week throughout the duration of this study, new stories of disabled people being 'failed' by the Government were in the media. However, this coverage was paired simultaneously with stories of 'fraudulent' claimants who were claiming benefits 'undeservingly'. Even in the last week of finalising this thesis, the media covered the death of another disabled person who fought the welfare state to secure benefits. Stephen Smith weighed only six and a half stone when he was declared fit for work. He was required to actively apply for jobs and had to discharge himself from hospital to attend an appeal for his benefit entitlement. He eventually managed to appeal the decision and was back-paid his entitlement 12 months later, shortly after he passed away (Ryan, 2019a).

Stephen’s story is not an anomaly. It is imperative that the experiences of disabled people continue to be heard. The current punitive welfare system should continue to be challenged to ensure that the violence against disabled people ends.

# Appendix I: Interview Schema

## a) For Disabled Benefit Recipients

*Questions should only be used as prompts; Interviewees will lead the conversation.*

### Opening Questions

- General experiences of work/welfare engagement.
- What benefits people are currently/previously claiming.
- Experiences of claiming process and WCA.
- Experiences of Sanctions and Support.

### Choice and Control within the claimant process

- How much control over the job search process do you feel you have?
- How do you use your time, and do you think this is a worthwhile use of your time? or simply meeting targets?
- What is your experience (if any) of the back to work programme?
- Do you feel like you have choice and control within the work programme?
- Do you feel like you have a say? Listened to or mattered?
- Have you had a positive/ negative relationship with the advisor?
- Have they been supportive?

### Choice and Control generally

- Tell me a bit about a typical day?
- Do you think the recent changes will have any impact on this in the future?
- Do you want changes? (I.e. do you want to enter employment?)
- Do you see employment as positive or constraining?
- How do you feel about the changes to welfare provision?

Citizenship/Rights and Responsibilities

- Do you feel welfare provision is a basic human right?
- Do you think it’s a state obligation to provide an adequate standard of living?
- Is the welfare available enough to support you to achieve a standard of living?
- Do you think you have equal rights as others?
- Do you feel like you have the right to work or receive welfare?
- What do you feel are your responsibilities?
- Do you think these should/do affect your rights?
- Have you faced any sanctions?
- Do you think these sanctions are/have been fair or proportional?
- To what extent do you think you are responsible for your current situation?
- To what extent do you think the government are responsible?

Identities/Self

- How do you personally feel about claiming benefits?
- Do you identify as a disabled person/Claimant?
- How do you think disabled benefit recipients are perceived?
- Have you engaged in any activism surrounding the reforms? I.e. blogged, protested, social media.

### b) Key Informants

*Discuss overall experience and gain an understanding of their job role. Utilise relevant prompts based on an individual basis.*

Choice and Control within the process

- How do you use your time, and do you think this is a worthwhile use of your time or simply meeting targets?
- What is your experience of implementing the back to work programme?

- Do you feel like benefit recipients have choice and control within the work programme?
- Do you (and recipients) feel like you have a say? Listened to or mattered?
- Have you had a positive/ negative relationship with the benefit recipient?

Choice and Control generally

- Tell me a bit about a typical day?
- Do you think the recent changes will have any impact on benefit recipients the future?
- Do you think these changes are necessary? Do you think they are positive?
- Are there any tensions between your role and policy?
- Do you see employment as positive or constraining?
- How do you feel about the changes to welfare provision?

Rights and Responsibilities

- Do you feel welfare provision is a basic human right?
- Do you think it's a state obligation to provide an adequate standard of living?
- Is the welfare available enough to support people to achieve a standard of living?
- Do you think benefit recipients have equal rights as others?
- What do you think are benefit recipients' responsibilities?
- Do you think these should/do affect their rights?
- Have you experienced the use of any sanctions?
- Do you think these sanctions are/have been fair or proportional?
- To what extent do you think benefit recipients are responsible for their situation?
- To what extent do you think the government are responsible?
- How do you think disabled benefit recipients are perceived?

# Appendix II: Participant Information Sheet

**Project Title: Welfare Conditionality for Disabled Benefit Recipients.**

**Joanne Michelle Brown**

PhD Candidate in Urban Studies, School of Social and Political Sciences, College of Social Sciences, University of Glasgow.

**Email:** j.brown.6@research.ac.uk

**Supervisors:** Dr Sharon Wright (sharon.wright@glasgow.ac.uk)
Dr Charlotte Pearson (Charlotte.Pearson@glasgow.ac.uk)

You are invited to participate in a research study. This statement hopes to provide you with the necessary information needed to decide whether you wish to participate. Any further information can be made available on request. Please take time to carefully read the information and to decide whether or not you would like to take part.
**Thank you for taking the time to read this statement.**

## Purpose

The purpose of this research is to gather views and experiences on welfare conditionality, specifically with regards to disability and health-related welfare support. Welfare conditionality refers to the idea that people who receive benefits from the state must, therefore, behave in a certain way. This study hopes to find out about the roles of both welfare advisors and recipients.

## Participation

You have been chosen as someone with experience of accessing or working within a welfare setting. It is up to you to decide whether or not to take part. If you decide to take part, you are still free to withdraw at any time and without giving a reason.

**Involvement**

You will be asked a series of questions through a face-to-face interview. Interviews will last around 30 minutes at a location convenient to you. Interviews will be recorded for transcription (recordings will be disposed of after transcription). Questions will consider experiences of welfare conditionality.

**Confidentiality**

All information, which is collected about you during the course of the research, will be kept strictly confidential. You will be identified by an ID number and any information about you will have your name and address removed so that you cannot be recognised from it. Personal data will be destroyed on completion of PhD.

**Results**

The findings gathered will be discussed as part of a PhD thesis and possibly within future publications arising on the submission of the thesis. This PhD is attached to the ESRC 'Welfare Conditionality: Sanctions, Support and Behaviour Change' Project.

This study has been reviewed by the University of Glasgow, College of Social Sciences Research Ethics Committee.

**Further Information**

Any further information can be requested through the researcher, Joanne Brown via email.

If you have concerns regarding the conduct of the research contact, these can be addressed through the College of Social Sciences Ethics Officer:

Dr Muir Houston: muir.houston@glasgow.ac.uk

**Useful Contacts**

As this study may address sensitive issues a list of useful contacts has been given below. If you are experiencing any distress following taking part in this study:

**Samaritans:** 08457 90 90 90

**Newcastle-upon-Tyne Citizens Advice Bureau:** 0844 245 1288

**Mental Health Matters:** 0191 516 3500

**The Clearing: The Place for Counselling, Psychotherapy and Emotional Support**: 0191 285 9309

# Appendix III: Consent Form

University of Glasgow | College of Social Sciences

**Welfare Conditionality for Disabled Benefit Recipients.**

**Joanne Brown**

1. I confirm that I have read and understand the Information Sheet for the study attached and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

3. I consent to interviews being audio-taped for transcription.

4. I consent to being referred to by pseudonym in any publications arising from the research.

I agree/do not agree (delete as applicable) to take part in the study.

| | | |
|---|---|---|
| Name of Participant | Date | Signature |
| Name of Researcher | Date | Signature |

# Appendix IV: ESRC Safety Protocol

## Introduction

This protocol sets out the requirements and procedures that apply for all team members when undertaking fieldwork on the *Welfare Conditionality* Project. Day to day management and mentoring of researchers engaged on the project will routinely be organised on an institutional basis. On occasions (e.g. whilst undertaking the focus groups in phase 2) researchers will be working in pairs and will be able to support each other in the field. However, for the majority of the time in phase 3 researchers will be working alone and it is important all researchers read and understand this document prior to entering the field. All team members are also required to read and familiarise themselves with the Social Research Association's *Code of Practice for the Safety of Social Researchers*, available at: *http://the-sra.org.uk/wp-content/uploads/safety_code_of_practice.pdf*

The following table sets out the named PI/Co-I contact who will be responsible for ensuring that the procedures set out below are followed and also indicates the named fieldwork contact person for each specified researcher. The PI and the Co-Is are also bound by this protocol and must nominate one of the Project Management Group (PMG) as their named fieldwork contact before undertaking fieldwork. If the nominated PI/Co-I is away on holiday, or otherwise unavailable, it is the responsibility of the researcher to ensure, before they undertake fieldwork, that they have a named contact within the project team or their institution that can be contacted at any time.

| **Named Fieldwork Contact** | **Named Researcher(s)** |
|---|---|
| Dwyer | Scullion (Salford)<br>McNeill |
| Fletcher | Batty (Sheffield Hallam) |

| | |
|---|---|
| Fitzpatrick | Johnsen (Heriot-Watt)<br>Watts |
| Flint | McNeill |
| Wright | Stewart |

**Researcher safety**

- Gatekeeper organisations will be asked to filter out any individuals whom they are aware may pose a safety risk when recommending participants. Researchers must also endeavour to obtain any prior information that is available (e.g. from support workers etc.) about potential safety-related issues associated with particular respondents which may, for example, influence where they should be interviewed. If, following such enquiries, the researcher feels their safety and well being is in any doubt then they should not interview the relevant respondent.

- Researchers will carry personal identification and a project specific mobile phone with them when conducting fieldwork.

- If possible/appropriate, interviews should take place in a prearranged location (pre-assessed for safety) where other members of the public or staff are present nearby.

- Interviews conducted by a lone interviewer in the respondent's home, or another private place, should be avoided wherever possible. In exceptional circumstances, where such an interview is the only or most feasible option, one or more of the additional following steps should be taken so that both interviewer and participant are aware that the whereabouts of the researcher is known to a responsible third party:

    a. The researcher should telephone their contact on arrival at the home, and at regular agreed intervals thereafter

    b. Involve project/support workers to pick up/drop off the researcher at the respondent's home

    c. Researchers may work as a team in an area, arriving at a house as a pair and arranging a time for the second team member to return to collect them

- Details of their itinerary and appointment times (including names, addresses and telephone numbers of people being interviewed or called and overnight accommodation details) must be forwarded by each researcher to their named contact person prior to undertaking any fieldwork.

- It is the responsibility of the researcher to inform their named contact of any changes to their daily itinerary that may occur and also to report in at the end of each day once all interviews have been safely completed. The named contact will keep telephone numbers for the researcher and their next of kin in case they do not report in at the end of the day. If by the agreed time the researcher has not called in, it is the responsibility of the named contact to take action by calling the researcher and, if necessary, the next of kin.

- Any incident during an interview that gives concern to the researcher that the respondent is likely to cause serious harm to themselves or others will be logged and reported to the named fieldwork contact as soon as possible (see Disclosure Protocol).

- If a researcher is made to feel threatened or uncomfortable by the behaviour of a respondent, or feels that the respondent is unable to respond effectively within the interview, then they should terminate the interview at an appropriate point, exit the location and contact their named fieldwork contact at the first opportunity.

- All incidents that occur relating to researcher safety in the field must be reported by the appropriate fieldwork contact, as soon as possible, to the project manager Ms Fleur Hughes. She will record details in a central project register and bring them to the attention of the PI (Dwyer) who will, in consultation with the researcher and named fieldwork contact involved, decide on the next steps to be taken (see debriefing below).

- **In cases of emergency:** If a researcher feels that their safety or well-being is in any doubt they must remove themselves from the interview as soon as possible. If they cannot exit then they should call a colleague as soon as possible (where practicable this should be their named fieldwork contact in the first instance) and use the code word **red file** e.g. '*Can you have a look in the red file please?*'. The member of staff receiving this call should ask for the following information and respond appropriately.

    - Check the location of the person 'Are you at …?'

    - Do you need assistance e.g. another team member, the police?

    - Do you want me to arrange someone to come and collect you?

**De-briefing arrangements for researchers involved in safety incidents in the field**

- If /when incidents occur in the field, initial debriefing will be carried out by the researcher's named fieldwork contact.

- It will be the named fieldwork contact's responsibility to work with the researcher to ascertain if any further actions (beyond reporting the incident to the project manager as set out above) and/or support may be required by the researcher.

- Any serious incidents should be discussed with both the project's PI (Dwyer), and the safety officer at the researcher's employing university.

- If violent incidents have occurred which may have some impact on the well-being of the researcher, these should be reported to the appropriate university's health and safety officer and to the local police force.

- Where the trauma of violence or the threat of violence may require structured support (such as counselling) this should be made available to the researcher via their employing university.

# Appendix V: Ethical Approval

University of Glasgow | College of Social Sciences

## Ethics Committee for Non-Clinical Research Involving Human Subjects

***Staff Research Ethics Application*** ☐ ***Postgraduate Student Research Ethics Application*** ☒

**Application Details**

Application Number: 400140064

Applicant's Name Joanne Brown

Project Title Welfare Conditionality for Disabled Benefit Recipients

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**Application Status** **Approved**

Start Date of Approval *(d.m.yr)* 18.01.15

*(blank if Changes Required/ Rejected)*

End Date of Approval of Research Project *(d.m.yr)* 17.12.15

**Only** if the applicant has been given **approval** can they proceed with their data collection with effect from the date of approval.

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**Recommendations (where Changes are Required)**

- ***Where changes are required all applicants must respond*** in the relevant boxes to the recommendations of the Committee and upload this as the **Resubmission Document** online to explain the changes you have made to the application. All resubmitted application documents should then be uploaded.

- ***If application is Rejected*** *a full new application must be submitted via the online system. Where recommendations are provided, they should be responded to and this document uploaded as part of the new application. A new reference number will be generated.*

*(Shaded areas will expand as text is added)*

| **MAJOR RECOMMENDATION OF THE COMMITTEE** | **APPLICANT RESPONSE TO MAJOR RECOMMENDATIONS** |
|---|---|
| | |

| **MINOR RECOMMENDATION OF THE COMMITTEE** | **APPLICANT RESPONSE TO MINOR RECOMMENDATIONS** |
|---|---|
| | |

| **REVIEWER COMMENTS** ***(OTHER THAN SPECIFIC RECOMMENDATIONS)*** | **APPLICANT RESPONSE TO REVIEWER COMMENTS** |
|---|---|
| **All the issues have been adequately addressed in the revised forms.** | |

Please retain this notification for future reference. If you have any queries please do not hesitate to contact the College Ethics Administration, email address: socsci-ethics@glasgow.ac.uk

# Appendix VI: NVivo Coding Framework

**List of Nodes and Child Nodes**

Citizenship

- Rights
- Responsibilities
- Perceptions of Government

Identity and Self

- Being Lucky
- Deservingness
- Identifying as disabled
- Media representation and public perception
- Othering
- Stigma and shame

Life on Benefits

- Desire to work
- Barriers to work
- Impairment effects
- Money and the benefits trap
- Standard of living

The Jobcentre

- Accessibility issues
- Appropriate help
- JCP staff
- Sanctions

The WCA

- Assessors
- Dehumanisation
- Emotions
- Paper assessment
- The appeals process

The Work Program

- Effectiveness
- Suitability

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